

DÁIL ÉIREANN

AN COMHCHOISTE UM SHLÁINTE

JOINT COMMITTEE ON HEALTH

Dé Céadaoin, 28 Samhain 2018

Wednesday, 28 November 2018

The Joint Committee met at 9 a.m.

MEMBERS PRESENT:

Deputy Stephen S. Donnelly,	Senator Colm Burke.
Deputy Bernard J. Durkan,	
Deputy Margaret Murphy O'Mahony,	
Deputy Louise O'Reilly,	

In attendance: Deputies Marc MacSharry, Mattie McGrath and Eamon Scanlon and Senator Rose Conway-Walsh.

DEPUTY MICHAEL HARTY IN THE CHAIR.

Lyme Disease: Discussion

Chairman: The purpose of this morning's meeting is to consider the subject of Lyme disease. We will hold two sessions on this topic. The first session will be with Tick Talk Ireland, the support group set up to encourage awareness, prevention and treatment of Lyme disease. They will be joined by Dr. Jack Lambert, a consultant in infectious diseases at the Mater Hospital. In the second session we will meet officials from the Department of Health.

I draw the attention of witnesses to the fact that by virtue of section 17(2)(l) of the Defamation Act 2009, witnesses are protected by absolute privilege in respect of their evidence to the committee. However, if they are directed by the committee to cease giving evidence on a particular matter and they continue to do so, they are entitled thereafter only to a qualified privilege in respect of their evidence. They are directed that only evidence connected with the subject matter of these proceedings is to be given and they are asked to respect the parliamentary practice to the effect that, where possible, they should not criticise or make charges against any person, persons or entity by name or in such a way as to make him, her or it identifiable. I advise witnesses that any opening statement made to the committee may be published on the committee website after the meeting.

Members are reminded of the long-standing parliamentary practice to the effect that they should not comment on, criticise or make charges against a person outside of the Houses or an official either by name or in such a way as to make him or her identifiable. I invite Dr. Jack Lambert to make his opening statement.

Dr. John Lambert: Farmers pick ticks off animals every day and pet owners pick ticks off their dogs every day. Every farmer and forestry worker in Ireland knows their animals are bitten by ticks and become sick with a variety of bacteria. The sick animals suffer from tick-borne diseases such as Lyme disease, Borrelia, Anaplasma, Rickettsial infections and Babesia, which causes red water disease in cattle. Do committee members think these ticks might be biting humans as well? The HSE's Health Protection Surveillance Centre, HPSC, website describes Lyme disease, a tick-borne infection, as a rare disease in humans in Ireland, with ten cases reported annually, and it estimates there are 100 cases nationally. However, a study from the blood bank in 1991 showed 9.75% of blood donors were positive for the Lyme disease antibody. This is not ten cases a year. An antibody means exposure or active infection. This means almost 10% of over 4 million people, which is 400,000, have had a tick bite. It is not a rare disease.

How does the HSE's estimate of ten to 20 cases a year compare to 400,000 exposures or active infections? In addition to Lyme disease, people also become ill from other infections, such as Anaplasma and Babesia. There is no recognition of these diseases or the co-infections on the HPSC website. Several years ago, I did a study of people with sudden illness who were then diagnosed with chronic fatigue. A total of 25% of the patients, mostly from rural communities, were Anaplasma positive. I treated them with antibiotics and they got better. I would rather have a longer course of antibiotics and be cured of chronic fatigue than have a lifelong diagnosis of chronic fatigue. Many believe there are huge underestimations of the true burden of tick-borne diseases in Ireland. Thousands of annual cases are more likely than ten or 100.

Let us consider these scenarios, which I deal with every day. A person goes for a hike in Wicklow and gets bitten by a tick but he or she does not see the tick bite. Three days later the person develops a fever, numbness and tingling all over. Another hiker gets a summer flu and aches and pains all over. A farmer develops migratory arthritis and strange neurological symptoms. These people see a rheumatologist and are diagnosed with rheumatoid arthritis but nobody thinks of Lyme disease. I had an example from Letterkenny last week. Lyme disease should be higher on our list. Some people have a rash and some do not. They may or may not remember a tick bite. The HPSC website states people should remember a tick or a rash but 80% of people do not.

Where do people sick from tick bites go? They go to their GPs. I hear all the time that those who remember the tick bite are told by their GPs that there are no ticks in Ireland, ticks do not spread Lyme disease in Ireland and people only get Lyme disease in Connecticut as that is where it was first diagnosed. They are asked whether they have travelled to America. They are also told they have ringworm or cellulitis.

Even though tick borne infections are common in Ireland, many GPs and specialists are missing the diagnosis. They do not consider Lyme disease as a possible diagnosis and when they do consider it they wait for a positive test. The trouble is the antibody test for Lyme disease only picks up 50% of cases. It should be a clinical diagnosis. Somebody with a tick bite and a rash who is unwell should be treated. The doctor should not wait for the antibody test. However, doctors do wait for the antibody test, which is only 50% sensitive. If it is negative they tell people they do not require treatment because it is not Lyme disease. Lyme disease requires a clinical diagnosis supported by testing. None of the consultants or GPs seems to understand this. Other strains of Lyme disease are missed as are co-infections. Often, the test does not come back positive in patients with active Lyme disease.

Without a positive test result, people cannot get treatment. Persons who can afford it go to Germany to get special tests and special treatment. The reality is we need treatment and diagnostic tests in Ireland for everyone and not just for those who can travel abroad. People state the German laboratories are not accredited but this is wrong. This is a rumour that is spreading in Ireland. Sadly, many patients who get a tick bite and a rash get the German test and bring it back but are told by their consultants and GPs that they will not accept it.

The recommended treatment on the HPSC website for Lyme disease is two weeks of antibiotics but many people do not get better after two weeks of antibiotics. They are still sick. They are then told it is post-infectious and to live with it. Many studies have shown that people get better with longer courses of treatment. What is the harm of a longer course of antibiotics? We treat every infectious disease in the world based on our clinical response but not Lyme disease. Treatment is stopped after two weeks and if the person is still unwell he or she is told it is post-infectious. It is a challenge for patients, let alone for clinicians to prescribe when there are guidelines and one is criticised if one does not adhere to them rigorously.

What happens if Lyme disease is not treated? Multiple peer reviewed publications by the Infectious Diseases Society of America, which has 15,000 specialists, state the infection is over after two weeks but many other studies show longer courses of treatment benefit patients. These studies are ignored. A draft of the HPSC Lyme disease guidelines that I reviewed recently stated that even without treatment the infection spontaneously goes away. It does not. In a study by Dr. Stricker, an infectious disease specialist, 75% of Lyme disease sufferers had arthritis, 15% had neurological diseases and 2% to 10% had cardiac disease, as it affects the heart, two years after being left untreated. None of these studies is included in the HPSC Irish

guidance. During the revision of the international classifications of diseases, ICD-11, the World Health Organization, WHO, developed new categories of Lyme disease that identified five life-threatening complications, including many late stage and chronic conditions; severe complications related to the brain, that is, neurological Lyme disease; and congenital Lyme disease, that is, Lyme disease that spreads from mother to child. The guidelines have been released in the past six months. None is included in the HSE's document or that of the Health Protection Surveillance Centre, HPSC.

In contrast, the status of Lyme disease policy, opinions and the stakeholder process in Ireland is very outdated. The Government has been fully engaged in the ICD-11 revision process with the WHO, the results of which were released in July. However, the Infectious Diseases Society of Ireland, the HSE and the HPSC continue to present outdated views on Lyme disease. They claim it is a rare disease, one that is easy to diagnose, treat and cure, and do not recognise persistent chronic Lyme disease. Most of the patients I see have persistent chronic Lyme disease. They respond to antibiotics and can be cured.

The HPSC is rewriting its Lyme disease guidelines. However, its process only includes the opinions of consultant doctors who do not believe in persistent infection, advocate maintaining the unreliable testing strategy and repudiate the longer courses of treatment on which patients are getting better. These are internationally accepted guidelines, but they are planning on adopting the guidelines of the National Institute for Health and Care Excellence, NICE, of which the United Kingdom has carried out a review. The Irish bodies are rubber-stamping everything that has been done. They are maintaining that Lyme disease is easy to diagnose, that there is no such thing as chronic Lyme disease and that a short course of antibiotics will make people better. They have excluded most of the international peer-reviewed publications and do not accept the WHO guidelines. Why are we copying inaccurate guidelines, rather than independently reviewing all of the evidence?

I recently announced the opening of a Lyme disease resource centre supported by private donor funding. I work at the Mater hospital and Lyme disease patient groups have helped to determine the services of the centre, the two main objectives of which are education and research. Its activities will include public education, for example, signage, to inform people that they should be aware of ticks, as most people are not, and how to prevent bites. The centre will also train GPs, the first practitioners to see patients and they are missing it all the time. We intend to train GPs to better consider Lyme disease in their differential diagnosis when they see a bull's eye rash, rather than calling it as shingles, ringworm or cellulitis. These diagnoses have been made in cases I have seen in the last couple of weeks. The centre will also raise funds for research into these infections. We need to better understand the animals, humans and ticks in Ireland. A complex interaction takes place once a person has these infections. It is a debilitating inflammatory condition which people call an autoimmune phenomenon. However, it is an infectious disease that triggers inflammation and autoimmunity. It is not a post-infectious condition but an ongoing one.

The Centers for Disease Control and Prevention, CDC, and the European Union have announced increasing rates of Lyme disease infections. They are now stating there are 850,000 cases in the European Union and 400,000 in America. They have upgraded their previous estimates by between 10% and 100%. We need education, prevention, better diagnosis and treatment for patients. Our mission is better health for those whom we serve.

What does Ireland need to do to address tick-borne diseases? The cost of undiagnosed, untreated and undertreated tick-borne diseases is not known. The costs incurred in America

are estimated to be huge. The cost of diagnoses of chronic fatigue, fibromyalgia and lifelong disability is huge compared to that of catching Lyme disease early and providing treatment upfront. Patient groups and politicians have taken the lead in identifying the lack of diagnosis and care experienced by Lyme disease sufferers in Ireland. Those persons who have resources can travel abroad and access the more sensitive tests and treatment options offered by private care providers. What about people in County Donegal who cannot afford to take the bus to Dublin for treatment, let alone pay €5,000 for treatment in Germany? There are huge social inequalities.

There is a clear disconnect between what doctors and the Health Service Executive are doing in Ireland and the advances proposed by the Irish in EU forums in Belgium and WHO forums. We need to come on board with them. The HSE and the Minister of Health need to disband the current committees that appear to be rubber-stamping current opinions which are outdated. They appear to be unaware of new developments announced worldwide in the treatment of tick-borne infections. Clinicians must treat those who suffer from tick-borne diseases with dignity and support their right to care. Chronic Lyme disease infection, with all of its complications, is devastating millions of lives across the globe, including thousands in Ireland. It is unprofessional for a doctor who cannot find the cause of an illness to resort to telling the patient that he or she is depressed or suffers from a psychosomatic illness. However, this is an experience common to patients of whom I take care before I see them. There is huge stigma and ignorance about Lyme disease. Kind and compassionate medical care requires clinicians who understand the limitations of their knowledge and testing strategies and believe their patients when they say they are indeed ill but the healthcare provider cannot identify a source. Rather than dismiss the patient's experience, it is better to acknowledge that he or she is sick, even if the reasons are not well understood. Clinicians need to work with the patient to find the cause of the illness and work with him or her to make him or her better. Better tick-borne diseases education and support for GPs on the front line are required in order that the cost of debilitation and disability can be reduced. The immediate investment of moneys in the public hospital system to establish a public clinic for those who cannot afford private care is required. All patients in Ireland with these conditions deserve reliable testing and individualised treatment. A funded campaign to educate patients on prevention and early identification is recommended.

We are a nation of compassionate people who enjoy many recreational activities provided by this beautiful island, but watch out for ticks. Many of us love to hike, garden, play football or rugby and simply enjoy the natural beauty of this land. Many depend on the land for their livelihood. Many members of the population travel frequently to tick-endemic areas and bring these illnesses back with them. These factors put most of us at risk of contracting tick-borne diseases, but they are also incentives for Ireland to become a leader in the science and medicine of tick-borne diseases.

Chairman: I thank Dr. Lambert. I call Ms Lawless to make her opening statement on behalf of Tick Talk Ireland.

Ms Kerry Lawless: Tick Talk Ireland will be ten years old in 2019. We have 2,700 members, North and South, in urban and rural areas. The membership has grown by something like ten people a day in the past few months. In the 24-hour period after the documentary "Living With Lyme Disease" was aired, 150 people contacted us. That was the level of demand for the three voluntary administration workers and on the Tick Talk Ireland Facebook page. Other individual patients and local patient groups were contacted. One particularly active volunteer in the north west left her house on the following day to go to Penneys. It took her four hours to

get there because people were stopping her to say their children or neighbours were sick or that they knew someone with the condition. They asked her if the sickness could be Lyme disease and, if so, what they could do. They described receiving negative test results and trying various approaches. Some said their doctors would not believe them, or that they did believe them but did not think they could actually care for them because of the guidelines. In some cases, passers-by described consultants laughing at them. They wanted to know what they should do and where they should go. That is what a voluntary group dealt with in one 24-hour period and patients who are sick are dealing with in trying to help other patients.

We will have a lot of reasons to be proud next year when the organisation will be ten years old. We are going to have a big celebration. We will look back at the individuals who have made it possible, the work that has been done, the level of awareness created and the people who have been helped. Then we will reflect on other things that have happened in that ten-year period. I refer to the huge advances made in science and the amount of peer-reviewed, validated research available. We do not know everything there is to know about Lyme disease and other tick-borne illnesses, but we know a lot more than we did ten years ago. There is so much new knowledge available, while there have been many advances in clinical practice. What have the Department of Health, the HSE and the Health Protection Surveillance Centre done? The answer is nothing. They have stuck rigidly to guidelines which are contested and have been removed from the CDC website because they do not meet the strict scientific criteria applied, yet we are clinging blindly and rigidly to them, insisting that the Earth is flat and that if we keep saying it is, it will somehow become flat. What happens when these bodies are blind to the science and new developments? The answer is that people suffer. People have lost their livelihood. They have had to sell farms and wind up businesses. They have gone bankrupt. Marriages have broken up. Children have missed school or never been able to go back. Mothers have been threatened by social services that their children will be taken away because they insist that they are ill, that it is not a psychological but a physical illness that can be cured. All that has happened in the past ten years. Luckily, other people have managed to access treatment here in Ireland, through Dr. Lambert. I am one, I am a public patient, there are very few of us left and we have managed to get better. Other people, like my colleague, Mr. Symes, travelled abroad and got treatment for himself and his son and is back to farming. Ms Nicci St. George Smith, who is present, also got treatment. She went the herbal route because there is no one way to deal with this and she is in recovery. We are trying to make our voices heard for the people who have not been able to access treatment.

Apart from those 2,700 members of Tick Talk, how many people do not use social media, did not see the documentary, do not know how to contact us or reach out and believe what they were told by the general practitioner, GP, or the consultant? How many believe the diagnosis of fibromyalgia or chronic fatigue, that they “have to learn to live with it”, are on symptom-modifying drugs and painkillers, and lead small lives when there is absolutely no need for it because antibiotic or herbal treatment can make them better? Maybe not everyone makes a full recovery depending how sick they were, which co-infections they got, how much damage it has done to their nervous systems and so on. We meet resistance, as Dr. Lambert has said. People insist it is rare when they do not know because they have not done studies. They insist it is easy to treat when there are countless studies that say that is not the case. They tell us they cannot give antibiotic treatment because it is dangerous. They give antibiotic treatment for tuberculosis. If one’s spleen is removed, one remains on antibiotic treatment for the rest of one’s life and the sky does not fall in. I have been on long-term antibiotic treatment and I have got better, week on week, month on month. I am not quite there but I am here today and two years ago I was in bed. I am monitored closely, my bloods are taken, my liver is doing fine, I am tolerating the

antibiotics, I have made the lifestyle changes I need. I am taking the supplements and protecting my gut health because I am getting proper care. I am doing it right and I am getting better. Why cannot everybody have this opportunity? Why is it just because I was lucky enough to live in Dublin and was able to access the public system or others were lucky enough that their communities rowed in behind them and fundraised €25,000 or €30,000 for them to travel to the US, to Germany, to other places to get the treatment they should have here?

We are still met with the refusal by the Department of Health, the Health Service Executive, HSE, and the Health Protection Surveillance Centre, HPSC. A new report is coming out. One of the last times Tick Talk appeared before this committee the committee recommended the setting up of a sub-committee on Lyme borreliosis. The sub-committee was set up. The so-called experts were all gathered in the room, Tick Talk nominated a patient representative, and in three years it has done very little. I have seen the draft report – I do not know if other people in the room have – it is completely lacking in vision and ambition. It has kept as narrowly as possible to the terms of reference. It has not even satisfied those terms. For three years, every time one of our members has gone to their local Deputy and asked for a parliamentary question to be submitted we are told there can be no comment on this because the report is coming. The report exists in draft form now. I wonder why we waited three years and how many people have got sick in the past three years who could have got an early diagnosis and treatment and got their lives back by now but instead have been allowed to develop a chronic, lifelong debilitating illness. We are talking about clinging to contested guidelines that we do not support, that came out of the Infectious Diseases Society of America, IDSA, which is even beginning to say the test is not accurate and that perhaps relying on it is sub-optimal. Have we shifted? Are we looking at doing that? We claim we follow these guidelines and best practice. We claim everything we do here is based on the evidence yet when the very people who designed the guidelines are beginning to question them, we still say what we are doing is right.

Since the cross-party action group was set up last year there have been significant developments. The political support we get is heartening and has allowed us make some progress. We had meetings with the HSE and the Department of Health. We were received very politely, we were listened to, we were not quite patted on the head but it was close because this is quite a gendered issue too. As with many autoimmune issues, more women than men are affected. That all comes into play as well. We presented our analysis, which I believe has been circulated to the committee and we have hard copies for everyone in the audience of what they say, how the research refutes them and what we would like them to do. We were told more or less that there might be common ground on prevention, maybe we could get a few posters up in the national park but when it comes to matters such as testing, the proper diagnosis, the treatment of chronic Lyme, we have to listen to the experts.

We asked the Department and HSE at the meeting and we are asking the committee today, to help us make people step back from these fixed positions and read all of the science, not just the science that confirms what they already believe but all of the science that is available and that has been accepted by the World Health Organization and come up with fresh guidelines based on that. Let us not follow the UK blindly and replicate the guidelines it has come up with. There are improvements in them in respect of prevention and the acute cases when people have been recently bitten. All it did, however, was tinker round the edges and did not grasp how serious this is, how much has to be done and it certainly did nothing for people with chronic Lyme. The reason I had chronic Lyme for ten years was that I was undiagnosed, misdiagnosed and denied adequate treatment. There was no reason for me to lose ten years of my life. There is no reason for thousands of other people across Ireland to lose years off their lives. We are

talking about treatment protocols that work and about antibiotics. For us to follow the National Institute for Health and Care Excellence, NICE, guidelines blindly and for someone from Tick Talk to be back here in another ten years telling the committee that more and more people have been bitten, got sick, lost their farms and become bankrupt would be a scandal because there is something we can do about this.

Another suggestion in the draft HPSC report is that one of the recommendations is that a new sub-committee will be set up to develop new guidelines. Will the very people who misdiagnosed me and other patients and who denied us treatment be the ones sitting around the room devising these new guidelines? Is the committee going to say that it suddenly trusts the people who for the past ten or 15 years have ignored the science, refused to read the new research, refused to keep up with evolving clinical practice to come with effective guidelines for the Irish health system? No. The reason we are in this mess is that these people would not read the science or keep up with evolving medical practice and have stuck to the idea that science never changes, medical practice never evolves, there is no new knowledge. There has to be a fresh group of people in the room, people who have a background in treating patients with Lyme disease and making them well if we are to have meaningful guidelines and a meaningful change of practice. This is where we need the committee's help. We need to bring political pressure to bear because the medical community at consultant level has shown itself to be incapable of change. Maybe as a patient and lay person I am being unfair. There are lots of good GPs who want to help their patients but they are scared to because they do not have the backing of a consultant. Will they be in trouble if they prescribe antibiotics for more than two or three weeks? I will ask Mr. Symes to read a text he received yesterday which backs this up.

Chairman: I thank Ms Lawless for her opening statement. I will move on to the committee members. Mr. Symes will have an opportunity to come in. Lyme disease is a recognised infectious disease. There is a difference between an acute illness and a chronic one. I will give Ms Lawless and Dr. Lambert an opportunity to answer the question. The issue concerns not diagnosing the acute phase and allowing the chronic phase to develop to the extent that it becomes difficult to diagnose because it has so many different facets. It has neurological, rheumatological and fatigue aspects. It has so many aspects. There is a recognition that Lyme disease exists as an infectious disease. The difficulty is how to deal with the chronic phase if the acute phase has not been properly diagnosed. Is the issue the Department of Health's resistance to recognising the chronicity of Lyme disease? Is that the fundamental issue?

Ms Kerry Lawless: From what patients tell us, there are three sets of issues. I am not exaggerating. We have had patients present at their GP with the tick still present in their arm, the rash and symptoms to be told that there is no Lyme disease in Ireland and that it is a foreign illness. Yes, Lyme disease is in the medical textbooks and everybody accepts it is a disease but there seems to be a belief that it is something that happens outside Ireland, is very rare and could not possibly be Lyme disease, so there is that fundamental issue. Even people who are lucky enough to get a positive test such as a member in Kildare, a young mother who tested positive on the ELISA test - there is a one in two chance of testing positive and she hit the jackpot - and who also tested positive with a lumbar puncture, was not given sufficient treatment-----

Chairman: I apologise for interrupting Ms Lawless but is the difficulty in the acceptance of chronic Lyme disease the difficulty in diagnostics? Perhaps Dr. Lambert might come in.

Dr. John Lambert: I would say that 80% of acute Lyme disease has been missed. We explained some of those scenarios to the committee. That is number one. It should be a clinical diagnosis and we educate GPs, but for the 80% who go on to develop chronic disease, the

opinion of many people until recently was that there is no such thing as chronic Lyme disease. The belief was that it just spontaneously goes away or, if it is treated for a couple of weeks and the patient is still sick, it is post infectious because the patient was given antibiotics. The new WHO guidelines have changed all of that, but at present, the National Institute for Health and Care Excellence, NICE, guidelines in the UK have not acknowledged this new acknowledgement that there is such a thing as chronic persistent Lyme disease that needs longer treatment with antibiotics. The challenges are that early diagnosis is missed and those who go on to develop chronic disease are told it is post infectious and that there is no such thing as chronic Lyme disease. That was the opinion until now, including in the Irish guidelines, and in its new guidelines, Ireland is saying the same thing. We are suggesting that this is bad medicine and that those guidelines should be changed.

Chairman: I will now bring in members.

Deputy Stephen S. Donnelly: I thank the witnesses for appearing before us this morning and for their preparation. I know they have put together a lot of documentation. I thank Dr. Lambert for his work and Ms Lawless for her testimony and work with the association. Obviously, it has affected her in a very serious way over many years. It is hoped her work has been very helpful. It sounds like it has been very useful to many people in the country, so I thank her for that. After this session, we will hear from the State. The deputy chief medical officer and various professors of medicine will appear before us to talk about this.

It is a peculiar issue. Most of time when we are dealing with chronic conditions in this committee, the conversation is around treatment and support - medical and social treatment and so forth. It is rare that we have a debate about whether something actually exists. My understanding from the testimony and documentation is that it is accepted that acute or, in lay terms, short-term problems exist. It is accepted here that a person can get an infection from Lyme disease. We will get the statements later that fully accept that. They say about 300 cases present each year. They skip over the chronic, or long-term, bit. They do not differentiate, and I think we will get into that in the second session, but my understanding is that the medical community and the State recognise Lyme disease. It is a reportable incidence. About 300 such incidences are reported each year. It is recognised and treated as a short-term infection but it is not recognised and treated as a longer-term infection. Is that about right?

Dr. John Lambert: That is correct.

Deputy Stephen S. Donnelly: Great.

Ms Kerry Lawless: The notifiable form of Lyme disease is one extreme form of the disease. There are only about 18 such cases reported each year because the criteria are so narrow. They have extrapolated that figure to come up with what used to be 100, it is now 200 and the Deputy has just told me it is 300. That is new.

Dr. John Lambert: The only thing that is reportable is if somebody ends up in hospital and gets a spinal tap. Those cases are then reported but they report any other cases. If they wanted to, they could say there are really 400 or 500.

Ms Kerry Lawless: They do not know.

Dr. John Lambert: I know a GP practice in Galway that had 25 cases one summer. There are probably 3,000 practices in Ireland so I could come up with another number. We do not know.

Deputy Stephen S. Donnelly: What they are saying is that nervous system involvement arises in approximately 10% to 15% of cases. Therefore, they estimate there could be about 300 cases in a year of Lyme disease that they would describe as the serious form.

Ms Kerry Lawless: The point is that it is incredibly under-reported. If one keeps saying-----

Deputy Stephen S. Donnelly: In the interests of time, I just want to get into the question. We are not medical experts. We have one doctor here. Therefore, we rely on medical experts and the institutions. We have a pretty sophisticated medical community. I know Ms Lawless is frustrated with its lack of willingness to change on this issue, although, in fairness, it changes on other issues all the time. It incorporates new technology, learning and research all the time.

Ms Kerry Lawless: So why is Lyme disease different?

Deputy Stephen S. Donnelly: We have a pretty good medical and scientific community in this country that brings new treatments on line all the time. In a while, we will be told that the guidelines produced by the Infectious Diseases Society of America, IDSA, are those upon which the vast majority of clinicians in Ireland base their treatment. The IDSA comes up with the guidelines. The witnesses in session two will go on to tell us that there is a consensus statement on clinical management by the scientific advisory committee of the Health Protection Surveillance Centre in Ireland, the Infectious Diseases Society of Ireland, the Irish Society of Clinical Microbiologists, the Irish Institute of Clinical Neuroscience and the Irish College of General Practitioners. Let us assume they are very smart, switched-on people and they have this consensus view and let us assume Dr. Lambert is right. What is it about this issue that such decent and clever people who dedicate themselves to this stuff are just not listening or are not seeing something? Why are they unable to see something in this case? Indeed, NICE in the UK has just concluded the same thing as the bodies I mentioned. How are so many eminent scientific and medical bodies saying it does not exist when Dr. Lambert is treating people who have it and Ms Lawless has it? What is going on?

Dr. John Lambert: All I can tell Deputy Donnelly is that all the evidence that went to the WHO to review these chronic conditions and treatments for chronic infection have given rise to new ICD-11 codes. They were reviewed by worldwide experts. Why does IDSA state there is no such thing as chronic Lyme disease? The last guidelines are from 2006 and they were reviewed by what was then the Institute of Medicine in 2011 in Washington DC. They were seen as not fit for purpose as they were not evidence-based. Those guidelines were removed from the website as a result. I do not know why many of my colleagues continue to say we use the 2006 guidelines as they are evidence-based and it is the current recommended treatment. There are new guidelines used by many clinicians treating these patients. This is a smaller group of 1,000 people in the International Lyme and Associated Diseases Society, ILADS, who are treating the disease. These 2014 guidelines are also evidence-based and it indicates longer courses of treatment. There are publications to support that.

There is a large polarity between IDSA and ILADS. I am a member of ILADS, IDSA and the Infectious Diseases Society of Ireland. Has any of my colleagues in Ireland ever spoken to me about this matter? It is like Chinese whispers. It is a bit of a puzzle to me as well. There are strong opinions in the medical community and held by specialists. Those can be written down but has there ever been an open forum discussing the science and looking at the new World Health Organization guidelines? Is any of the people coming today aware of the new WHO guidelines and the ICD-11 codes? I do not think they are.

Deputy Stephen S. Donnelly: The medical and scientific communities deal with matters like this every day and, please God, most of the time they get them right. There is evidence on this and it is not just anecdotal. The evidence is from around the world. Is there something about this chronic condition that is different and makes it harder for the standard analytical approach taken by these bodies to recognise it?

Dr. John Lambert: There is. If a neurologist diagnoses people with multiple sclerosis before somebody comes along and says it is Lyme disease, there would be a major reluctance to change the approach. I have a few patients with misdiagnosed amyotrophic lateral sclerosis, or Lou Gehrig's disease, as it was actually Lyme disease and they got better with antibiotics. It is hard for people to change. Many rheumatologists have studied fibromyalgia or atypical rheumatoid arthritis for ten years and change is difficult for clinicians. I love all my colleagues in Ireland and they are very good consultants but there is a huge barrier and resistance to this. I am puzzled but people are fixed in their thinking. When people mention Lyme disease, the reaction is that it is a rare disease and patients are crazy. There is such a prejudice against it.

I am puzzled. I treat patients with HIV and I am a lead person treating hepatitis in Ireland and I do not face this with other diseases. It is funny as I ask the same questions about Lyme disease every day. We must address some of those issues as well to face the barriers. My colleagues are willing to look with an open mind at other areas, thinking outside the box and looking for new ideas and answers to apparently unsolvable dilemmas in Ireland, but it is a bit different with Lyme disease.

Deputy Stephen S. Donnelly: It is very puzzling.

Dr. John Lambert: Yes.

Deputy Stephen S. Donnelly: We also deal with orphan drugs quite a bit and orphan drugs, by definition, are for rare diseases. The system has no issue in dealing with the concept of rare diseases. With other diseases and infections, I have never heard the State say that as it is rare, the people who have it actually do not have it and the condition does not exist. Being rare is not cited in any other case so it is not the issue. There must be something specific about how this unfolds as the system is more than capable of dealing with rare diseases. I just do not understand it.

Ms Kerry Lawless: I do not understand it either and I am not a clinician. From what I have learned through having Lyme disease and getting treatment, there does not seem to be anything in the disease itself that would lead to this. It seems to be an institutional barrier. I was not joking when I said people are insisting the world is flat as that is what it feels like as a patient reading research and looking at evidence, with fellow patients getting better after treatment while still being told they were never sick in the first place. Our Taoiseach has spoken about this and described us as vulnerable people being taken advantage of by this foreign testing. The idea is we are being psychologically geared up to believe we have this mystery disease rather than just accepting there are mental health issues or chronic fatigue. I have never heard another group of patients described like this. It has happened in the history of science as multiple sclerosis patients were called hysterics before the CT scanner was invented. We are not the only group of patients this has happened to but I am thankful it is a rare occurrence. I am not thankful for the fact that clinicians do not argue about the science but rather they talk about overseas labs being uncredited and that these poor, vulnerable patients are being taken advantage of. They argue it is a mental health issue.

Deputy Stephen S. Donnelly: I have a question on testing and treatment. There are four clinicians for this in Ireland so does the State fund the best testing that is currently available? If a clinician decides a patient has chronic Lyme disease and he or she should be treated with whatever the right course of longer-term antibiotics is, would testing and ongoing treatment be currently funded by the State?

Dr. John Lambert: No, as the current testing is only the antibody test. That is 50% sensitive. People argue that the other tests done abroad are not valid etc. and there is major controversy in that respect. We need better testing in Ireland and we do not have all possible tests available. A clinical diagnosis can be made but people are not allowed or afraid to make those clinical diagnoses. People should be treated based on history and suspicion, and if patients respond to therapy with antibiotics, as occurs with other infections, we would be on the right track. We do not have optimal testing and not everybody can access those tests. People are restricted in how long they can be treated with antibiotics. A prostate infection can be treated for two or three months with doxycycline but if a person has a devastating Lyme infection he or she can only be treated for three weeks. After that a person is “cured” and treatment should be stopped or there would be consequences. It is a bit of a paradox.

Chairman: I will bring in other witnesses in a moment but I want to give the opportunity to our members to contribute.

Deputy Louise O'Reilly: I thank the witnesses for coming in. I had experience in my previous role as a union official representing a woman suffering from Lyme disease. We had a big uphill battle to get the disease recognised. It struck me at the time, and it rings out in agreement with Ms Lawless's comments, as she was fobbed off, told it was a mental health issue and it was not recognised by anybody but the woman was clearly extremely sick. She could not go to work, which is why she had involvement with a union official rather than a clinician. It is only three and a half years ago and we struggled to get clinicians in the State to support us in making that claim. It was easier to get them outside the State. I am happy to say the claim was successful in the end but it took much out of her to fight for that recognition.

We read this morning that there is a level of overdiagnosis. I have questions similar to those already asked, I suppose. I am struggling to understand the resistance if the evidence exists. As I said, I have experience of dealing with people suffering with the condition but the biggest battle seems not to be with the illness but in getting it recognised. It is very worrying. Dr. Lambert has stated that the medical community is sometimes afraid to make a clinical diagnosis. Will he expand on that and give us some insight? We are going to have representatives of the HSE before us and we will need to get a full picture. It is the purpose of this hearing.

On international best practice, where can we model and learn from? I know that people travel to Germany, the United States, etc.

It might be helpful if I asked all of my questions together and they were then banked.

Turning to travelling abroad for a diagnosis and treatment, can the delegates give us an estimate of the cost involved for an individual? I know that there are things that cannot be quantified such as time off work, etc., but I am just asking for an estimate. Is the cost reimbursed? Is treatment available under the treatment abroad scheme? How is the matter dealt with?

On the report, I share the frustration felt. I also tabled parliamentary questions and it does seem that the report has been delayed, but we will be in a position in the next session to ask

some questions about that matter.

My last question which is related to my previous one is for Dr. Lambert. He referenced reliable and individualised treatment. Where is it accessible? Is there the skill set in Ireland to provide it? Would we be ready to go to provide it in the morning? What level of training would be required and what would the numbers involved be if it was to be rolled out?

Chairman: I thank the Deputy. I call Mr. Symes whom I interrupted.

Mr. Edwin Symes: I received a text message this morning from a friend of mine whose wife is very ill. She is from Ireland and was bitten by a tick one year ago. She had a bullseye rash, entered into the Irish system and had a two-tier test. Both test results were negative. She has gone to every consultant in the country to try to figure out what is wrong. She ended up sending a blood sample to Germany to be tested. The text message stated she had gone to her GP who acknowledged that she needed help. The doctor did not want to use the word “Lyme”, but she did trust the results from ArminLabs in Germany. She said that if it was her, she would travel abroad for treatment. That is how a GP in Dublin feels.

Ms Kerry Lawless: That is the level of fear about which we are talking among GPs.

Chairman: The first of Deputy O'Reilly's questions was about over-diagnosis. What is the response of the delegates?

Dr. John Lambert: On over-diagnosis, an antibody test shows that a person has the infection or had it in the past. If somebody such as a farmer from Malin Head is sick with a multi-system disease and the test result is positive, it is probably Lyme disease. What is needed is not an antibody test but a clinical diagnosis. Antibody tests are poor. It does not matter whether it is a German or an Irish test and the result is positive or negative, it could mean an infection or a prior infection. We need to educate people in how to take a good history, examine a patient and interpret test results. That is really important and the first issue.

There are more than ten or 100 patients with Lyme disease. We are underestimating the number of tick-borne infections. Vets treat thousands of animals with these infections all over Ireland and the world. It is clear that humans are being bitten by the same ticks and contracting the same diseases.

The next question was about following international best practice in guidelines. In France there is a pioneer by the name of Dr. Christian Perronne. He is one doctor who went against the Infectious Diseases Society of America, IDSA, and all of its clinicians. He has fought for five years and, against the wishes of many of his clinician friends, he has got the Irish Government to agree to the French plan. I refer to establishing treatment centres, using a clinical diagnosis and treating patients based on the response to therapy. We have a national outpatient antibiotic programme. We treat people with antibiotics, sometimes for two weeks, sometimes for four weeks, eight weeks and, in some cases, six months. The people who are probably coming here after this do this all of the time. We do not treat different infectious diseases for one time-set. Being prescriptive is not good for patients. The French guidelines recommend that we treat patients for as long as it takes to make them better. That is probably the best standard. There is a French national website which was put together by Dr. Perronne.

On how much people have to pay if they travel outside the country, sometimes the cost is €1,000 or €2,000 just for testing. If a person then travels to Germany or America, he or she will pay between €5,000 and €10,000 for short-term therapy. People will actually spend €30,000.

I know people who have spent between €80,000 and €100,000. I refer to the former Kerry football player Anthony Morris who went to the Jemsek Speciality Clinic in Washington D.C. where, apparently, he paid \$90,000. People are paying huge amounts of money for treatments, some of which are unnecessary. There is not always good science behind some of treatments available internationally. However, people are getting better-----

Deputy Louise O'Reilly: They are desperate.

Dr. John Lambert: They are, but many of them are getting better. They are paying between €10,000 and €100,000 in leaving the country for diagnostics and receive treatment. It is a lot of money.

Ms Kerry Lawless: Let me come in here. There was another question about the delay in dealing with the HPSC. The three-year delay is a big factor. I refer also to the number of people who have become ill unnecessarily in that time. However, for us the bigger factor is the lack of ambition and vision in the report. It will not move things on. To be honest, if it was a good report, the three-year wait would have been worth it, but the fact is that there is no ambition or vision.

The other question the Deputy asked was would we be in a position to roll out GP training tomorrow. Dr. Lambert already provides training for GPs. My own GP was trained by him. There is also a system in place in the United Kingdom. It is not perfect, but the Deputy asked if we could start something tomorrow. There is a model and a champion in the United Kingdom in the treatment of Lyme disease. There is an ongoing project, with online resources. There are also workshops provided. There is to be open access. In taking the best of that system and the best of what Dr. Lambert is doing, we could start to roll something out. The response to the plan in the United Kingdom, if it is anything to go by, was overwhelming demand. GPs want to make their patients better, but in order to do so they need support and training.

Deputy Louise O'Reilly: That is fine.

Dr. John Lambert: I am not sure a training programme will work if there is still a polarisation of views on whether patients can be treated longer. There has to be consensus among consultants. I refer to the debate between the IDSA and the ILADS on patient-centred treatment and not being prescriptive. Many barriers have to be broken down before an education programme would work and GPs would feel comfortable in prescribing properly for their patients.

Mr. Edwin Symes: On the cost element, my son travelled to Germany where he underwent eight months of treatment at a cost of €10,000, but he has made a full recovery.

Deputy Louise O'Reilly: That is good news.

Mr. Edwin Symes: He could not receive treatment in Ireland.

Chairman: Have people with chronic Lyme disease been able to source treatment under the treatment abroad scheme?

Ms Kerry Lawless: It has been very hit and miss. Some people have not been able to find the right code, while some have. For others, it depends on when they make the application. There are many people from Poland and Latvia living in Ireland who have got sick here. They use the scheme very successfully to travel back to their home countries to access treatment. Others have been unsuccessful. In our longer strategy document it is one of the issues on which

we have asked for a review.

Chairman: Under the treatment abroad scheme, a consultant is required to certify that the treatment is not available in Ireland.

Ms Kerry Lawless: That is correct.

Chairman: That is the critical point in seeking treatment abroad.

Ms Kerry Lawless: It is a block for some. There was also a major issue with the codes used. Without the right codes, the form could not be filled in and the scheme could not be availed of. Some members have been successful, while some have not. Some have been able to claim the consultant's fee, but the cost of travel has to be borne by them. It has been hit and miss.

Chairman: I thank Ms Lawless.

Senator Colm Burke: I thank the delegates for their presentations. The disadvantage we have is that, other than the Chairman, none of us is a qualified medical practitioner. We have to rely on the advice given to us by medical practitioners. One of the documents I have is from the Infectious Diseases Society of Ireland which was signed by 28 consultants. It has made a presentation to us. I will quote one or two issues the Infectious Diseases Society of Ireland, IDSI, raised on which the witnesses might comment. I reiterate that we, as members, are at a disadvantage because the document has been signed by 28 different people. It states that in 2016, The Swiss Infectious Disease Society and the Swiss Society for Neurology combined to produce evidence-based guidelines for the management of post-treatment Lyme disease syndrome. That report states "Growing and unequivocal evidence confirms that prolonged or repeated antibiotic therapy for PTLDS is not beneficial, but potentially harmful". That is one of the issues.

The document continued:

Chronic Lyme disease is usually a diagnosis that a patient with chronic symptoms of pain, fatigue, and difficulty in thinking, acquires in the absence of another explanation for their symptoms. There are many patients with a variety of real and troubling chronic symptoms including fatigue, weakness, myalgias, arthralgias and neurocognitive symptoms who believe they have a 'chronic' form of Lyme disease. Although these patients are truly unwell, and some significantly disabled, symptoms are non-specific and overlap significantly with those of other medically unexplained symptom complexes such as chronic fatigue syndrome or fibromyalgia. There is no evidence to support occult Lyme infection as the cause of these symptoms. Most will have multiple serial negative Lyme antibody tests in the setting of very long-term symptoms. There is no convincing evidence to suggest that Lyme disease represents either a marker of immunodeficiency or leads to impaired immunity.

Basically, there is an acceptance that patients have symptoms but not all of these symptoms could be categorised as Lyme disease.

The Infectious Diseases Society of Ireland has given us a report that has been approved by 28 consultants. The report seems to differ from the presentations that have been made here this morning. We, as members of the committee, are not medical experts and it is very difficult for us to reach a conclusion when we receive contradictory evidence. I ask the witnesses to comment on the matter.

Dr. John Lambert: I am a member of IDSI but I have never seen this report. Part of the challenge, as I have said, is that a huge polarity exists. Let us go back to the International Classification of Diseases or ICD-11 codes that talk about chronic persistent Lyme, and have been approved by the World Health Organization.

(Interruptions).

Dr. John Lambert: Hundreds of articles have been submitted that show Lyme persists and the IDSI call it post-treatment Lyme disease. It is not post-treatment but ongoing infection. Hundreds of articles have been submitted to the WHO, and reviewed for them, that show Lyme persists even after people get two or four weeks of antibiotic treatment. There are animal studies and rhesus monkey studies where one treats them intravenously with antibiotics for two months and then sacrifices them at the end but one can still grow Lyme. This is not post-treatment but ongoing infection. Unfortunately, none of those studies have been included in the IDSI documents.

I agree with the Senator that the IDSI has come up with an opinion that has been signed off by 28 clinicians in Ireland. Why does one have an opposing international organisation, like the WHO, that has had all of this science put together and presented to it and which came up with a different conclusion? The Senator is right that it is very confusing for the committee when one group says one thing and another group saying something else. We are not saying that every case of fibromyalgia is caused by Lyme disease. I would think that a person in Donegal who has fibromyalgia but was previously well yet now suffers flu and fever should entertain the diagnosis of Lyme. I am just telling members that we are missing lots of cases of Lyme disease.

I have never seen the report cited by the Senator. I would love to read and review the report. I would love an opportunity to be in a public forum where these things are discussed. New science has come along. In terms of the IDSI publications, I saw something coming along there back in December but I never received a chance to review or discuss it. I have never had the chance to present the WHO data to the IDSI. Obviously the IDSI has excluded the WHO data. Therefore, the IDSI document is outdated and does not reflect current science.

Senator Colm Burke: It is something that was made up for this committee this morning.

Dr. John Lambert: I am not disagreeing. I am saying we should ask the people who compiled the document whether they are aware of the ICD-11 codes and the WHO document. I am sure that they are not.

Senator Colm Burke: The IDSI quoted a 2016 detailed analysis by the Swiss Infectious Disease Society. Is Dr. Lambert saying the report produced by the Swiss authorities is incorrect?

Dr. John Lambert: I have not seen the report. In terms of the evidence base, we go back to the 2006 IDSI document on the treatment of Lyme guidelines. As far as I am concerned, we keep on going back to the same poor science. The WHO has produced new recommendations and as many as 800 articles show there is a persistence of chronic Lyme disease. I would want to make sure that all of those scientific articles are included in the publication.

Ms Kerry Lawless: The 28 consultants have come together and have come up with an agreement. As the Senator has said, it must be very difficult for people from a non-medical background because the consultants are seen as the experts and they have said there is no con-

vincing evidence. I contend that there is convincing evidence. They have either not read the evidence or refuse to do so. Are the 28 consultants who signed the document saying that the World Health Organization is wrong?

Senator Colm Burke: The IDSI has quoted quite a number of reports. The IDSI relied on quite a number of research documents when they preparing its report because it referred to the documents in the report. The committee has received a report signed by 28 people. They are concerned that prolonged treatment, which is an issue that repeatedly arose in the submission, can lead to other medical difficulties.

Dr. John Lambert: These are the same doctors who give prolonged treatment for bone infections by prescribing outpatient antibiotics for six weeks, 12 weeks or six months. In one situation for chronic Lyme disease, it is dangerous to administer antibiotics but for other infections, it is not dangerous.

The best way to resolve this matter is if I responded to these documents in an open forum. I can provide the committee with data that updates the IDSI document, which I have never seen.

Senator Colm Burke: Yes.

Dr. John Lambert: The best way forward is to not have people meeting in a room and signing off a document that declares their way is right or my way is right. We need to have transparency and not a Chinese whispers approach to science, which is the current situation for Lyme and, indeed, for other diseases.

Senator Colm Burke: I am the only member of the committee who was here three years ago when this issue was dealt with. The same issues that were raised at that meeting have arisen this morning. We do not seem to have made any advances in the past three years.

Ms Kerry Lawless: We have.

Dr. John Lambert: We have.

Ms Kerry Lawless: The World Health Organization-----

Dr. John Lambert: The WHO and almost all of the countries are now coming on board to change their view and consider the new science.

Senator Colm Burke: Is it not then a matter for Dr. Lambert, as the professional here, to deal with the Infectious Diseases Society of Ireland? I mean in the sense that its view seems to differ in some respects with the view of Dr. Lambert.

Dr. John Lambert: The view should support the science not the opinion. I would like to review the report. People often cherry-pick findings to suit themselves. I have done my homework and carried out a comprehensive review. There is a lot more than meets the eye when one considers these documents. There has to be greater transparency, better science and some dialogue with the groups involved to come up with a fair and scientific consensus that actually represents the new understanding of the disease, something we did not have a couple of years ago. I am not sure if the documents actually contain that knowledge.

Ms Nicci St. George Smith: With the greatest of respect, I would love to address what Senator Colm Burke said. I am a patient who is in remission. I was bitten in 2000 and had a bullseye rash. I was tested and diagnosed with Lyme disease and given doxycycline for ten

days. I took the antibiotics and never thought about it again, but I continued to have low grade pain and health issues until I developed Parkinson's disease like symptoms and, in my late 20s and early 30s, Alzheimer's disease like symptoms. I was unable to read, found speaking very difficult, found it very difficult to walk, had no energy and was in constant pain all over my spine and body. I was an aid worker and made documentaries, but I could no longer work. It was then brought to my attention that I might still have an infection. I was the biggest sceptic and cynic and thought it was crazy talk and ridiculous, that the infection did not exist and could not remain in my system. It was the last idea on the list of possibilities, but I went to be retested and tested positive. After 15 years the infection was still in my body. I went for treatment and made a full recovery. I have gone back to work and I am currently making a documentary on Lyme disease in a global context. We are talking to people involved in the latest research on Lyme disease, Borrelia, tick borne co-infections and vector borne infections. The people who signed off on what members have in front of them should be listening to those to whom we are talking. We are with science which does not deny this. It would deny what the people mentioned have signed off on. Change is coming and will trickle down, but we have a choice. We can do what Deputy MacSharry suggested and become pioneers, be ahead of the curve and contain the disease or we can be late to the party and watch as the world changes and we are still dinosaurs. As Dr. Lambert said, I ask that there be open discussion here and that we bring in some of the experts to address the people mentioned because they do not have this information or they are choosing not to-----

Senator Colm Burke: In fairness, they were brought in three years ago.

Ms Nicci St. George Smith: I am talking about Dr. Eva Sapi, the world's leading expert on biofilms and Borrelia. This is the kind of thing about which we will be talking. We are talking about why the testing is not accurate. These are the issues about which we need to talk. Why are we not being listened to and why the situation is being treated as though it is not happening? This is really important and we need to get them in here.

Senator Colm Burke: We are lay people and being given the document in the same way as we were given it three years ago. It seems to be coming with a conflicting view. We have to deal with that issue. That is from where we are coming.

Ms Nicci St. George Smith: We can rectify the conflict if we get the experts and the people with the questions in the one room.

Deputy Bernard J. Durkan: Who are the internationally known and recognised experts in this area, apart from the WHO which has been mentioned? Some of the universities must have led in this research. What have they come up with?

Are there similar conditions from which people suffer with similar characteristics? For instance, one that comes to mind is the human form of brucellosis which has similar characteristics, including a rash and continuous flu symptoms. I might have the flu, but I do not think I have that condition. However, I wonder about it because if we are determining who the experts are, we need to get the information first in order that at least we can all have access to the best information which should be made available as soon as possible.

Dr. John Lambert: On who are the experts, in America there are groups of centres of excellence in Baltimore and Stanford, California. A number of groups are conducting research into Lyme disease. In Europe there are no centres of excellence in academic centres, but I have mentioned Dr. Christian Peronne, a clinician in France who is recognised as a treating physician

and an international expert on Lyme disease. There are a limited number of experts worldwide because there has not been a huge investment of resources to understand these diseases.

Deputy Bernard J. Durkan: Is there not ongoing research into rare diseases internationally?

Dr. John Lambert: If members look at the percentage of money put into researching hepatitis or HIV, they will see that internationally research into Lyme disease is under-resourced. That is my observation.

Deputy Bernard J. Durkan: The pharma companies are also involved and must be showing an interest.

Dr. John Lambert: Not in Lyme disease because the antibiotics used to treat Lyme disease are generic. Therefore, there would not huge investment by pharma companies in the treatment of these infections. There would be in new developing technologies but not in the treatment of Lyme disease.

Deputy Bernard J. Durkan: On a regular basis we meet people who are interested in rare diseases. They do not differentiate between one rare disease and another. The treatment may be different or the same, but I cannot understand why we do not have more information available to us that would lead us to the areas where the experts are who have the information readily available.

Ms Kerry Lawless: We have the research that has been submitted to and accepted by the World Health Organization. There are 800 journal articles which are significant pieces of research that have been assessed and accepted by the World Health Organization. Therefore, there is the science and the research and the new codes were based on this overall look at the research. It is contested, but through its process the World Health Organization stepped back and looked back at all of the research, decided what would be accepted and what new codes would be designated such that the complications in late stage chronic Lyme disease are accepted and there are codes for same.

In May 2019 at the World Health Organization there will be a *pro forma* decision and work will begin on the guidelines. Therefore, it is coming and countries have until 1 January 2022 to start implementation. At it is on its way, the question is whether we should step back, open our eyes, look at all of the research and move from the contested and fixed positions. Do we stop mimicking America where everything is so politicised and extreme and say we are a small nation, that we have an issue, that we have experts, most of whom are in this room, and that we need to sit together to engage in proper dialogue and look at all of the research, including that which does not support our opinions because it is still valid and has been peer reviewed?

We also have to look at the experience of people who ask not to be told that they have chronic Lyme disease because they were treated for it and recovered, the fibromyalgia and their chronic fatigue went. Not everyone who has had a diagnosis of fibromyalgia suffers from chronic Lyme disease. The issue is complex because so many of the symptoms overlap, but with the right care and treatment patients recover. Nobody goes into medicine to make patients worse. Everyone in this room went into and stayed in medicine-----

Chairman: Please address the committee, rather than the other way around.

Ms Kerry Lawless: I truly believe they went into medicine to help and make people better,

but the current stance and polarisation are hurting patients. We need to sit in the same room and look at all of the research and science and what is working for patients. We have to come up with new sets of guidelines, rather than blindly follow contested guidelines from other countries.

Deputy Margaret Murphy O'Mahony: I welcome all of the witnesses this morning. Dr. Lambert stated some patients remain ill but are denied further treatment because their condition is post-infectious. I ask him to expand on what is meant by that statement.

Dr. John Lambert: If after being treated with three weeks' antibiotics for Lyme disease someone is still unwell, my experience and the guidelines I follow are to treat for three more weeks because many patients who do not get better in the first three weeks will get better with an additional three weeks of treatment. This applies to Lyme disease and other infections. I manage other infections this way as well. However, what commonly happens with the current guidelines is people will treat a patient for three weeks and if the patient does not get better, the medical professional will tell him or her the infection is cured and the disease is post-infectious. One cannot know it is post-infectious because it is impossible to grow these bacteria. For this reason, one has to use one's clinical judgment. That is what I mean when I say people are denied further treatment. More people respond to longer courses of treatment and they should be offered further treatment.

Deputy Margaret Murphy O'Mahony: It is like any other condition.

Dr. John Lambert: Yes. We do it for other infectious diseases.

Deputy Margaret Murphy O'Mahony: In that case, why is not done with Lyme disease?

Dr. John Lambert: One should not be prescriptive. Some people with cellulitis get better in seven days, while with others it sometimes takes between 14 and 21 days. There are different infections.

Deputy Margaret Murphy O'Mahony: Lyme disease seems to be treated differently from other infections and is not taken seriously, or else there is not enough information available on it. The public is not even aware that it exists. I ask Dr. Lambert to comment on how this could be changed and if he agrees with that view. The lack of prevention is obviously a serious problem. I presume it could be easily overcome with a little education for the general public and medics. I would like to wish Tick Talk Ireland well as we approach the tenth anniversary of its foundation. I thank witnesses for the work they have done.

Chairman: Did the Deputy ask a specific question?

Deputy Margaret Murphy O'Mahony: Yes, I asked for comments on prevention and education. I also asked Dr. Lambert why he thinks Lyme disease may not be taken seriously by the general public and why people may not even know about it.

Dr. John Lambert: I secured private funding recently to establish a Lyme disease research centre, working with the patient groups here to increase awareness and education about the fact that Lyme disease is common. There are ticks in Killarney and there should be signage to that effect. We should educate people who are going to walk in the Wicklow Mountains to cover up, use insect repellent and check themselves afterwards for ticks. There are ticks and some of them carry Lyme disease. We have done some studies on that. Signs have been erected in Cape Cod and education is provided. I agree with the Deputy that the first thing we need is preven-

tion through education of the public. Signage in forestry would be a good way to do that.

Deputy Margaret Murphy O'Mahony: That could be cheaply and easily done.

Dr. John Lambert: I see so many cases of under-diagnosis and misdiagnosis in all specialties, including general practitioners. People with a bullseye rash are told it is cellulitis, so getting to the GPs and training them early on in making the right diagnosis would make a significant difference in ensuring we do not have downstream these people with chronic Lyme disease who have been misdiagnosed. That would be a very important step. We do not want it simply said that those patients have been missed. They are post-infectious. We need to look at all the data rather than position papers which state opinions. There is a large number of data out there, some of which are contradictory but much of this information is very good and raises some of these issues. The best way forward would be to have an open forum looking carefully at all the science available rather than at position papers.

Deputy Margaret Murphy O'Mahony: I agree.

Dr. John Lambert: The World Health Organization has done that and we should do the same.

Senator Rose Conway-Walsh: I thank all of the witnesses for their presentations. I am particularly interested in Dr. Lambert and his expertise. I thank him very much for all of the information he has given.

My most recent contact with Lyme disease was when I saw a woman packing bags in Super-Valu a couple of weeks ago in Castlebar. She explained she was doing it to raise money for her daughter who was chronically ill with Lyme disease to get the treatment she needed and which she was obviously being denied. I have since had further correspondence from somebody else with Lyme disease and I find it extremely disturbing that people are being dismissed and laughed at by well paid clinicians in hospitals and told, more or less, that they have a mental illness and to go home because they are suffering from depression or whatever, without any blood tests or research being done to identify what their condition is. That is absolutely appalling. I am not a permanent member of this committee, but I have taken time to attend today's meeting for this reason.

Was there a research centre in Limerick that did some work on Lyme disease?

Dr. John Lambert: There are some scientists down there doing some testing of the ticks. I have worked with some of those groups and the ticks in Ireland have Lyme disease.

Senator Rose Conway-Walsh: Is that centre closed now?

Dr. John Lambert: I do not think it is open.

Senator Rose Conway-Walsh: My information is that there is no doctor there now, although I stand to be corrected on that. If a person watching proceedings today is experiencing symptoms that point to Lyme disease, what should he or she do? Say this person is living in the west of Ireland without the means to go anywhere privately. What does that person do?

Ms Kerry Lawless: At the moment, Tick Talk Ireland advises persons in that position to go back to their GP. As a patient group in Ireland and the UK, we are not happy with the National Institute for Health and Care Excellence, NICE, guidelines. We think those guidelines are a missed opportunity but there are some improvements at an acute stage when people have just

been bitten. The first port of call we recommend is to go back to their GP, possibly to bring the extracts from the NICE guidelines with them, to talk again about their patient history and whether they remember being bitten or had some form of rash, and to try to get a clinical diagnosis. We advise them that it might not work but that is the first port of call.

Senator Rose Conway-Walsh: Can the GP do a clinical diagnosis to tell people if they have Lyme disease?

Ms Kerry Lawless: Based on tick exposure, patient history and obvious clinical symptoms, the guidelines in the UK are saying the GP should go with a clinical diagnosis. They also say the presentation of the bullseye rash is sufficient to make a diagnosis. The Irish guidelines say the presentation of a bullseye rash is sufficient but GPs do not seem to be aware of that in our experience of speaking to patients.

Senator Rose Conway-Walsh: Can patients be treated by their general practitioner if the GP makes that clinical diagnosis?

Ms Kerry Lawless: One of the reasons we are here is that patients come to us after their GP has either recognised the rash but did not have the confidence to diagnose or was worried about treating and relied on the enzyme-linked immunosorbent assay, ELISA, test or forms of the two-tiered testing. It seems to be very hit and miss. We advise people that they will have to go through a number of steps and overcome a number of obstacles. I do not know any other illness for which people have to do this.

Senator Rose Conway-Walsh: I want to get back to the GPs and the GP training. At this stage, how many GPs in Ireland are trained on Lyme disease? How long does the training take? What form does it take?

Dr. John Lambert: There is no current training for GPs. I have run a couple of workshops that have been attended by 15 to 20 GPs. There are 3,000 GPs in Ireland. There is no current programme.

In London, the Royal College of General Practitioners has now assigned a GP to train GPs. She has gone out around the country teaching GPs how to get the early diagnosis to catch it early. That is an important strategy. It is something we should replicate in Ireland.

Senator Rose Conway-Walsh: Dr. Lambert states there is one in London. If a GP decides today that this might be something that is affecting a number of his or patients and wants to get trained in it, where does the GP go to get the training?

Dr. John Lambert: There is nowhere.

Senator Rose Conway-Walsh: If they go abroad, for instance, if they go to London, can they get the training?

Dr. John Lambert: Not necessarily. There are no training programmes. They can attend a conference so that they can learn about Lyme disease. There are international conferences all over the world but there are no current GP training programmes in Europe. There is only this pilot programme that it is being conducted by the Royal College of General Practitioners for the English GPs in endemic areas.

Senator Rose Conway-Walsh: When will that pilot programme finish?

Dr. John Lambert: It is a one-year programme. The first one-day course was two weeks ago in Birmingham attended by 70 GPs.

Ms Kerry Lawless: The materials will be available online in open access. The issue is one of staff who will deliver the training. That sort of training, to the best of my knowledge, is on an opt-in basis. There is no compulsion. One is talking about GPs following their individual interest in how they get training rather than the State deciding that this is a critical area in which people need basic skills.

Senator Rose Conway-Walsh: If the State were to decide tomorrow to get its GPs trained in respect of Lyme disease, what would it need to do? What expertise does it need to bring in?

Ms Kerry Lawless: It goes back to the fundamental question of whether we can train GPs in early diagnosis.

Senator Rose Conway-Walsh: Who trains them?

Ms Kerry Lawless: That is probably contested by the people in this room. In terms of patient support groups, we would say to look at the GP champion in the UK who has an expertise there, to look at people through the French system who are setting up the centres of excellence and to look at people, such as Dr. Lambert, who have that sort of experience. The more fundamental point is, if one trains up GPs and gives this new skill set and if they still come up against this set of guidelines which restrict care and deny the existence of late-stage complications in chronic Lyme disease and still fly in the face of what the World Health Organization is now doing, we are stymied again.

Senator Rose Conway-Walsh: I understand what Ms Lawless is saying there. We have limited time to ask questions. If we had a critical mass of GPs who had enough awareness and enough training on the subject of Lyme disease, perhaps we would get somewhere because there would be the pressure from the GPs as well, in terms of the new information.

Ms Kerry Lawless: In terms of prevention in acute stages.

Dr. John Lambert: That would be a great idea, especially in areas in Ireland where Lyme disease is endemic.

Senator Rose Conway-Walsh: We discussed treatment abroad to an extent. In a case where somebody must go abroad to get this treatment, can Ms Lawless take me through in a simple way what he or she would need to do?

Ms Kerry Lawless: Often, if people come to Tick Talk Ireland and have not got the treatment they require from their GP and are being told the two-tier testing indicates they do not have Lyme disease, we suggest to them there are other tests that people can do abroad. We are quite careful with people. We say that these tests may not, and most likely will not, be accepted in Ireland and even though one can get confirmation of a diagnosis, which is quite satisfying because one finally has answers to why one is ill, it may not help progress the person in terms of accessing treatment.

Senator Rose Conway-Walsh: I am trying to get at the funding of it, particularly for those who cannot afford it.

Ms Kerry Lawless: People tend to fundraise.

Senator Rose Conway-Walsh: If they do not have a clinician to sign off on it here for them to get whatever treatment or diagnosis abroad, they cannot get funded for it because they will not have a code.

Ms Kerry Lawless: That is why they do bag-packing, as the Senator saw with her constituent, and they do GoFundMe campaigns and run pub quizzes. This is not the way for people to access treatment. They also go to clinics in Poland, in Germany and in the United States. They follow quite conventional medicine of intravenous, IV, antibiotics and infusions and they come back. The vast majority of our members and fellow patients who come through the system, like Mr. Symes, recover, come back and go back to farming or whatever, and to their lives, because they were able to access treatment abroad that was denied to them here.

Senator Rose Conway-Walsh: This is what makes it scandalous because the treatment is obviously so simple and effective.

Mr. Edwin Symes: I was fortunate I had the money to do it. Many people do not. Then one is stuck in limbo.

Senator Rose Conway-Walsh: Once again, it is the case that those who do not have the money sit and be sick.

I want to ask about the link with arthritis that Dr. Lambert mentioned. Is that proven because those figures are quite alarming? Did Dr. Lambert give a figure of 75%?

Dr. John Lambert: I specifically quoted an article from Stricker *et al.* They studied patients two years down the way who had proven Lyme disease that was not treated and 70% of them had what was called “migratory arthritis”, that is, arthritis that moved from one place to another. If one did not take the right history and did not think about a tick bite, one might diagnosis it as rheumatoid arthritis or other diseases. In fact, the first patient I saw in Ireland five years ago was from Connemara and he was diagnosed as having atypical rheumatoid arthritis. He was given methotrexate - nobody thought Lyme disease. The infection was disseminated. A year later, when he was critically unwell, they did an antibody test for Lyme disease and it was positive. That was my first patient. Some cases of arthritis are being misdiagnosed and Lyme disease is being missed.

Senator Rose Conway-Walsh: I thank the witnesses.

Deputy Marc MacSharry: As a former member of the committee but a gatecrasher, I thank the Chairman and the members for allowing me speak. It is mainly in the next session where I would like to ask questions but I will make a couple of points.

Dr. Lambert trained in Michigan and was involved in Rochester in New York. He was an assistant professor at Johns Hopkins and then went to St. Mary’s and Kings College Hospital in the UK, and now he is in the Mater. As an infectious disease consultant, is Dr. Lambert seen as in any way underqualified or a black sheep within the health system in Ireland?

Dr. John Lambert: No. I manage HIV, tuberculosis, hepatitis and other infections, including Lyme disease.

Deputy Marc MacSharry: Reading Dr. Lambert’s biography for the Mater, that makes sense. Dr. Lambert’s biography does not mention Lyme disease anywhere, either for the Mater Private Hospital or the Mater public hospital. Is there any political reason for that?

Dr. John Lambert: Lyme is a very contentious disease. People have huge opinions, as I said, of it.

Deputy Marc MacSharry: Would the clinical director, for instance, of the Mater or the Ireland East hospital group, say that he cannot include Lyme disease, that he or she sees Dr. Lambert as a specialist in HIV and other infectious diseases but the hospital does not want him saying anything about Lyme disease? I was only reading Dr. Lambert's biography online and there is no mention of Lyme disease. Is there any reason?

Dr. John Lambert: No. I get referrals for Lyme disease from many years ago. I get referrals for HIV, hepatitis and tuberculosis to the Mater Hospital. I have seen patients for all infectious diseases, including Lyme disease.

Deputy Marc MacSharry: It is just that Dr. Lambert's biography does not say it and I was just wondering was it a matter of his own choice to exclude that.

Dr. John Lambert: I was not aware of that. I am quite happy to change that and announce that I have been seeing patients with Lyme disease and I have tried to learn a lot about Lyme disease as part of my ongoing medical education.

Deputy Marc MacSharry: What is Dr. Lambert's view on the reason for such push-back from the medical establishment here, apart from himself, in terms of embracing what seems, from the patient's perspective, to work?

Dr. John Lambert: I have brought up the issue many times that testing is not perfect. It does not matter if it is an Irish test or a German test; the testing is imperfect. We do not have perfect diagnostic tests and we should be treating people clinically. That really is my opinion.

There is significant polarisation. If one looks at the guidelines, many of the standard guidelines state that the antibody test is close to 100%. In my opinion, it is 50%. We need better diagnostic tests. In the meantime, we do not have better diagnostic tests and we are stuck with patients who are sick. In terms of evaluating patients, I use my clinical judgment but my opinion may differ from the guidelines. As I said, I have done my homework on Lyme disease. I have applied for grants to better understand Lyme disease in terms of better diagnostic testing but I am also seeing, managing and treating patients clinically and seeing them get better so I have engaged with Lyme disease as nobody else was doing so. My goal is to bring more GPs, specialists and colleagues on board to tackle Lyme disease in a more collaborative and co-operative way because there are a lot of unknowns about it.

Deputy Marc MacSharry: Up to this week, when the Lyme disease resource centre was launched, we were depending on word of mouth and GPs who were up to speed and involved with this area for people to be referred to Dr. Lambert.

Dr. John Lambert: The Lyme disease resource centre has nothing to do with clinical care. I was given a private grant by a donor to raise awareness and establish an educational centre.

Deputy Marc MacSharry: I know that. The point I am making is there is no public support for that centre. It is privately funded.

Dr. John Lambert: It is privately funded.

Deputy Marc MacSharry: Has there been any push-back on the establishment of that?

Dr. John Lambert: As it was misrepresented as a treatment centre, there has been significant push-back. It has been clarified that it is not a treatment centre but I believe there should be one. People should not be obliged to leave the country. More resources should be put into better understanding this disease and making sure everybody can access new diagnostics and better treatments for Lyme disease. There is a need for the HSE and the Department to prioritise this as a disease of significance because it is affecting lots of people.

Deputy Marc MacSharry: From where Dr. Lambert sits, and we seem to have established this from listening to the answers to other people's questions this morning, this is an area that is not funded, where no official GP training is provided by the State and where, in the absence of an absolute agreed gold standard in testing and clinical diagnosis, it is the luck of the draw based on the level of knowledge of the GP or whether the patient is lucky enough to have been led to Dr. Lambert. Is that a fair assessment of the situation surrounding Lyme disease in Ireland at the moment?

Dr. John Lambert: There is no good pathway for care in Ireland and many patients are getting lost in the system.

Deputy Marc MacSharry: There is a suggestion that in Ireland, we tend to follow what we see as best practice. On some issues, that might be the National Institute for Health and Care Excellence, NICE, in the UK while on others, it might be the Infectious Diseases Society of America, ISDA, or the guidelines of the Centers for Disease Control and Prevention, CDC, on others. Is that how Ireland tends to do its business?

Dr. John Lambert: Sometimes we rubber-stamp and copy other people's guidelines.

Deputy Marc MacSharry: Copy and paste. They are probably good enough with regard to a lot of things. I read recently that officials from both the CDC and ISDA own or have shares in the ownership of patents relevant to some Lyme disease tests?

Dr. John Lambert: I do not get involved in the politics-----

Deputy Marc MacSharry: Based on his medical knowledge, is that a-----

Dr. John Lambert: Yes, I have read reports-----

Deputy Marc MacSharry: Dr. Lambert has read reports that this is the case.

Dr. John Lambert: There are licensed antibody tests that I think are imperfect and there are issues with patents and who has ownership of those patents.

Deputy Marc MacSharry: I am a member of the Committee of Public Accounts. Would Dr. Lambert agree that from a governance perspective, it would not be appropriate to have people who own the test setting the guidelines that others throughout the world may choose to mimic?

Dr. John Lambert: I am a medical doctor so I cannot really comment on that but it does not sound that great.

Deputy Marc MacSharry: What is the view of Tick Talk Ireland on this?

Ms Kerry Lawless: We have looked at the work of Jenna Luche-Thayer and her submission to the United Nations. She has looked at this conflict of interest, the conflict of interest

that existed before 2006 when these guidelines were drawn up and the fact that not all of these patents were declared publicly by the people who were involved in drawing up the guidelines. The UN has noted this and is looking at it as a form of corruption so we are very concerned about that and the fact that these 2006 guidelines are still being held up as some sort of standard across the world when the transparency that should have been there did not exist and when there have been notable conflicts of interest. Deputy MacSharry mentioned that he is a member of the Committee of Public Accounts. We have talked a bit about the human cost today and the committee will have seen three patients who have undergone treatment and are in the process of reclaiming their lives after an average of nearly 18 years - 12 years in my case and four years in another case - but we must also look at the cost to the Exchequer. If it is said that there are 45,000 cases of Lyme disease in the UK, I am presuming that Lyme disease is under-reported, which is fairly well established, that costs the UK between £3 million and £3.5 million per year. That is the economic and societal cost.

Deputy Marc MacSharry: Is that for the whole country or X number of patients?

Ms Kerry Lawless: That is in terms of the annual incidence of Lyme disease basing it on 45,000 cases, which would be a gross underestimation. I am just giving the Deputy an idea-----

Deputy Marc MacSharry: And it would cost between £3 million and £3.5 million.

Ms Kerry Lawless: Yes.

Deputy Marc MacSharry: That sounds low compared with what Dr. Lambert said, which was that it was somewhere between \$25 billion and \$75 billion in the US. Applying a crude population ratio, the figure here would be between €375 million and €1.1 billion per year. I know that is a crude ratio. The UK figure sounds very low but I take Ms Lawless's point.

I will finish with a question for the Chairman. Senator Colm Burke quoted earlier from a document from the Infectious Diseases Society of Ireland that Dr. Lambert said he had not seen. He seemed to allude to the fact that this was a paper done for the committee. Did the committee secretariat seek a document from the Infectious Diseases Society of Ireland?

Chairman: It was documentation submitted by the Department.

Deputy Marc MacSharry: By the Department. In support of its own-----

Chairman: As part of its submission.

Deputy Marc MacSharry: So will the Department be presenting what Senator Colm Burke referred to?

Chairman: I am not sure what it will present.

Deputy Marc MacSharry: Senator Colm Burke seemed to be referring to a document that nobody has. I am interested in finding out whether that document was generated specifically for the committee.

Chairman: It was circulated to the committee.

Deputy Marc MacSharry: Will I have an opportunity to ask the authors of that document about it?

Chairman: Yes.

Deputy Marc MacSharry: That is great.

Chairman: On behalf of the committee, I thank Dr. Lambert. I know that perhaps he had not intended to stay so long but I thank him for his contribution. I also thank Ms Lawless, Mr. Symes and Ms St. George Smith from Tick Talk Ireland. We will suspend for a few minutes to allow our other witnesses to take their seats.

Sitting suspended at 11.28 a.m. and resumed at 11.34 a.m.

Chairman: I thank everyone for attending this morning. The purpose of our second session is to resume our discussion on the topic of Lyme disease with officials from the Department of Health. On behalf of the committee I welcome Dr. Ronan Glynn, deputy chief medical officer, who is accompanied by Dr. Paul McKeown, specialist in public health medicine in the Health Protection Surveillance Centre; Dr. Cillian de Gascun, consultant medical virologist and director of the National Virus Reference Laboratory; Professor Karina Butler, president of the Infectious Diseases Society of Ireland and consultant in infectious diseases in Crumlin and Temple Street children's hospitals; and Dr. Gerard Sheehan. I am not sure of Dr. Sheehan's title.

Dr. Gerard Sheehan: I work with the Mater Hospital and University College Dublin.

Chairman: I thank Dr. Sheehan. I draw the attention of witnesses to the fact that by virtue of section 17(2)(l) of the Defamation Act 2009, they are protected by absolute privilege in respect of their evidence to the committee. However, if they are directed by the committee to cease giving evidence on a particular matter and they continue to so do, they are entitled thereafter only to a qualified privilege in respect of their evidence. They are directed that only evidence connected with the subject matter of these proceedings is to be given and they are asked to respect the parliamentary practice to the effect that, where possible, they should not criticise or make charges against any person, persons or entity by name or in such a way as to make him, her or it identifiable. I advise them that any opening statements made to the committee may be published on the committee website after the meeting.

Members are reminded of the long-standing parliamentary practice to the effect that they should not comment on, criticise or make charges against a person outside the House or an official either by name or in such a way as to make him or her identifiable. I invite Dr. Glynn to make his opening statement.

Dr. Ronan Glynn: I am deputy chief medical officer and recently appointed lead in health protection at the Department of Health. First, my colleagues and I wish to acknowledge that Lyme disease has been the subject of significant attention in recent years. The matter has been regularly highlighted in the Oireachtas by means of Leaders' Questions, parliamentary questions and Topical Issue debates and has previously been discussed by this committee. I thank the committee for inviting us to discuss the issue. I am joined by my colleagues: Dr. Paul McKeown, Dr. Cillian De Gascun, Professor Karina Butler, and Dr. Gerard Sheehan.

Lyme disease, also known as Lyme borreliosis, is an infection caused by a bacteria called *Borrelia burgdorferi*. It is transmitted to humans by bites from ticks infected with the bacteria and is the most common tick-borne infection in the US, Canada, and Europe. Lyme disease infection is generally mild, affecting only the skin. The most common noticeable evidence of infection is a rash called erythema migrans. This is seen in up to 90% of patients. Occasionally, there may be more serious symptoms involving the nervous system, the joints, the heart or other tissues.

Lyme disease was made statutorily notifiable in Ireland by the Infectious Diseases (Amendment) Regulations 2011. The notifiable entity is the more severe neurological form of Lyme disease, Lyme neuroborreliosis. The choice of Lyme neuroborreliosis as the notifiable entity was based on scientific advice from the European Centre for Disease Control and followed wide consultation with experts across EU member states. Since first becoming notifiable, between eight and 21 cases of Lyme neuroborreliosis have been notified each year in Ireland. One of the major advantages of using Lyme neuroborreliosis as the notifiable entity is that the relationship of the proportion of neuroborreliosis cases to other cases of Lyme disease is well described and relatively stable; nervous system involvement arises in between 10% and 15% of Lyme infections. We can estimate, therefore, that there could be up to 300 total cases of Lyme disease in Ireland each year.

One of the reasons for making a disease notifiable is that it helps to raise awareness of that disease, and awareness of Lyme disease has been steadily increasing since it was made notifiable. For example, a recent scientific paper reported that, over the five years from 2011, the number of requests for Lyme testing in the west of Ireland increased by almost 80%. However, despite this increase in testing, no significant increase in the number of positive tests was detected.

Lyme disease is diagnosed by medical history and physical examination. The infection is confirmed by a standard two-stage set of blood tests. A 2016 survey reported that all laboratories offering this testing in Ireland are appropriately accredited and are testing in accordance with best international practice. Lyme disease is normally treated using common antibiotics. My colleague, Professor Butler, will make a more in-depth statement regarding the diagnosis and treatment of Lyme disease but the vast majority of clinicians in Ireland base their treatment approach on the guidelines produced by the Infectious Diseases Society of America, IDSA. In addition, a consensus statement on the clinical management of Lyme disease, which endorses the IDSA guidance, has been issued jointly from the scientific advisory committee of the Health Protection Surveillance Centre, the Infectious Diseases Society of Ireland, the Irish Society of Clinical Microbiologists, the Irish Institute of Clinical Neuroscience, and the Irish College of General Practitioners.

The best protection against Lyme disease is to prevent tick bites when walking in grassy, bushy or woodland areas, particularly between May and October. Both the Health Protection Surveillance Centre, HPSC, and Tick Talk Ireland provide guidance on protection against the contraction of Lyme disease and the HPSC runs a Lyme disease awareness campaign each year. A Lyme disease subcommittee established at the HPSC aims to examine best practice in prevention and surveillance of Lyme disease and to produce a report to identify the best strategies for the prevention of the disease in Ireland. The HPSC delayed the publication of its report to incorporate the findings of an extensive systematic review of the evidence on Lyme disease published earlier this year by the National Institute for Health and Care Excellence in the UK. The HPSC report is now due to be published early in the new year.

I am happy to hand over to my colleague, Professor Butler, who will address the committee in more detail about Lyme disease. The panel of witnesses will then answer any queries members may have.

Professor Karina Butler: I am a consultant paediatrician and infectious disease specialist and have been diagnosing and treating patients with infectious diseases for more than 30 years. I speak on behalf of the Infectious Diseases Society of Ireland, IDSI, and am joined on the panel by Dr. Gerard Sheehan. In the Public Gallery are Dr. Catherine Fleming from Galway and

Professor Colm Bergin, Professor Patrick Mallon and Dr. Ceppi Merry from Dublin. The IDSI submission has been co-authored and approved by 22 infectious disease specialists representing each of the Dublin and regional centres, affiliated universities and the RCSI. An overwhelming consensus of expert opinion supports the written submission. As doctors, we care for patients of all ages who have or are suspected to have an infectious disease. We seek to ensure that all patients under our care, including those who have or believe they may have Lyme disease, receive the highest quality of evidence-based medical care. We have no other agenda.

Lyme disease is a significant infection which, if untreated, may progress to cause serious illness. However, early Lyme disease is a clinical diagnosis which does not require laboratory testing and can be cured by a relatively short course of antibiotics. Early Lyme infection does not always return a positive result in laboratory testing. However, the reliability of testing increases over time such that one would expect those who have had symptoms for months or years due to Lyme disease to test positive. In Ireland, samples are tested according to best international standards and the absence of a positive test is not a barrier to treatment. If clinical suspicion is high, physicians can and do prescribe an appropriate three or four-week duration antibiotic treatment either orally or intravenously depending on the clinical symptoms. Treatment in Ireland is based on international evidence-based guidelines drawn from several sources, including European guidelines and those of the IDSI. None of those guidelines recommend prolonged courses of antibiotics to treat Lyme disease.

A small minority of patients experience persistent symptoms following appropriate and adequate treatment for Lyme infection. However, prolonged courses of antibiotics have not been shown to benefit these patients. There is no evidence of benefit, but there is evidence of potential harm. Some patients have chronic disabling symptoms that are not readily explained medically although the symptoms are undeniable and can have a profound effect on quality of life. Chronic Lyme infection may be proposed as the cause of such symptoms in spite of negative Lyme antibody tests and the patient having been afforded appropriate treatment. However, there is no evidence to support the concept of chronic or persisting Lyme infection that is resistant to standard courses of antibiotic therapy. Such diagnoses are frequently based on tests that are not accredited for clinical diagnosis and are carried out in overseas laboratories. One of the major problems with such testing is that in an effort to achieve better sensitivity, that is, that a test will detect all possible cases, there is a profound loss of specificity. That means that the tests may produce false positives indicating that persons without Lyme disease have been infected with the disease.

We sympathise with patients and families who are affected by chronic symptoms that significantly impact on their quality of life. Our sincere goal is that all patients can have the best possible treatment outcome. Prolonged antibiotic therapy does not benefit these patients. Conversely, as I stated, it is associated with increased risk of serious unintentional harm. We take very seriously the tenet of our profession: *primum non nocere*; first, do no harm. It is a potent reminder that every medical and pharmacological decision carries the potential for harm. Decisions regarding patient care should be based on validated scientific evidence. Modern medicine is an evidence-based science and best outcomes are achieved when that underpins medical practice.

The IDSI is concerned that the use of tests not accredited as clinical diagnostic tests for Lyme disease may result in overdiagnosis of the disease and, often, other infections. Additionally, in the worst cases the misleading results are associated with the potential for misdirected referral and inappropriate treatment. Opportunities may be missed for thorough medical as-

assessment to detect or exclude significant alternative pathology as the cause of the symptoms. We recognise that there are research gaps in terms of the epidemiology, diagnostics and treatment of vector-borne diseases.

We appreciate that all present today and those involved in this issue undoubtedly seek the best outcomes for those affected. However, we must acknowledge the real problem of the overdiagnosis of Lyme disease based on unaccredited tests carried out overseas. Diagnosis and treatment of Lyme disease must be evidence-based. Deployment of limited resources towards unvalidated treatments will necessarily deprive or curtail resources spent in other areas. As doctors, my specialist colleagues and I are concerned to learn of patients travelling overseas for prolonged courses of intravenous antibiotics, often coupled with an array of nutritional supplements and treatments at significant cost and personal hazard but with no proven benefit. There is no evidence of benefit to such treatments but there is potential for harm. In our submission, we have sought to present accurately the current situation with regard to Lyme disease, its diagnosis and treatment. We have no agenda other than to provide evidence-based, high-quality care for our patients.

Chairman: I am unsure whether the witness heard the evidence presented to the committee earlier this morning. The committee is aware of and understands the well-known entity of acute Lyme disease resulting from a person being bitten by a tick. The issue with which we must deal is chronic Lyme disease and its post-infection phase. That involves the acute phase being missed, possibly because the person had minimal or no symptoms or the symptoms being misdiagnosed or undertreated. The issue of treatment and access to and accuracy of diagnostics arises in regard to the chronic phase of Lyme disease. Do the witnesses, as clinicians, accept that there is chronic Lyme disease which is, perhaps, not treated or not recognised?

Professor Karina Butler: If early Lyme disease is not treated, there is a definite risk of the development of late complications. In general, such complications manifest as arthritis, cardiac involvement or a variety of neurological and other symptoms. There is no doubt that that exists. The likelihood of antibody tests being positive increases significantly over time such that, for example, 97% of persons with arthritis as a result of Lyme disease will strongly test positive for Lyme disease. My colleague, Dr. De Gascun of the National Virus Reference Laboratory, may wish to contribute on that point. A US task force submission indicates that patients whose early Lyme disease was not diagnosed and who had very significant resultant chronic symptoms such as cardiac or other problems tested strongly positive in the standard two-step testing.

There is no doubt that a minority of persons diagnosed with and treated for Lyme disease will experience persistence of symptoms, but there is no evidence that that represents persistent infection. In fact, randomised control studies have examined whether re-treatment with prolonged antibiotic therapies or adopting a holistic approach with other treatments would make any difference for such patients. Although some patients got better, the proportion to do so was the same among those who received the treatment strategy as among those who did not. In other studies, patients with Lyme disease were shown not to have benefited from prolonged courses of antibiotics.

Chairman: If a clinician is unable to prove a patient has a particular illness but, based on intuition, puts the patient on a course of treatment and the patient gets better, is the logical conclusion that the treatment brought about the improvement?

Professor Karina Butler: Anecdotally, if I were to treat someone like that, I would not necessarily know whether there was a temporal association with the antibiotic or a causal as-

sociation. My knowledge that the antibiotic has had an effect is based on the studies that have shown people treated with it improve and those who are not treated with it do not. Where there is an intervention and something happens, the question always arises as to whether there is a temporal association or a causal association. To know that difference, we have to examine the science and trials that compare similar groups of people, one of which receives the intervention and one of which does not. This is to determine whether the benefit is evident only among those who receive the intervention.

Chairman: Where one can prove there are antibodies to Lyme borreliosis, is Professor Butler saying the presence of the antibodies does not indicate active infection?

Professor Karina Butler: I am saying with all serological testing, there are problems to a certain degree with both underdiagnosis and overdiagnosis. Sometimes we get false positive tests, and we can get false negative tests. Therefore, we must use the testings, together with the clinical scenario, that give us the greatest probability that the testing we see and the result support the clinical entity and confirms our diagnostic suspicion.

Chairman: Professor Butler estimates those who have the neurological symptoms of borreliosis infection or Lyme infection comprise 15% of the total number of people who could be infected. If they are treated with antibiotics, do they improve?

Professor Karina Butler: If one treats those people with antibiotics, one will cure the infection. The majority of those people will improve but there will be persistent symptoms among a minority of the patients.

Chairman: How long after?

Professor Karina Butler: The symptoms do not always resolve.

Chairman: If one is bitten by a tick and presents two years later with neurological symptoms and is treated with antibiotics, is the assumption that the infection is still active?

Professor Karina Butler: If the patients have been untreated, there is a likelihood that the infection might still be active, which is why they are treated with the antibiotics. After a course of antibiotics where it is neurological, which involves a period of at least four weeks, the assumption is that the infection will be cured. Not all symptoms will resolve and there can be some permanent damage that will not be reversed.

Chairman: Does any other member of the panel wish to make a comment?

Dr. Paul McKeown: I am from the Health Protection Surveillance Centre. I am a consultant in public health medicine. In addition to concurring with Professor Butler, I would like to add some background information that might be useful. In the United Kingdom and Ireland, serosurveys have been undertaken over the years. In other words, blood has been taken from large groups of people and tested for the presence of past exposure to the borrelia bug, which we will call Lyme borreliosis. The testers have generally done this by using blood donor blood. There is a pool of blood taken from thousands of people that is tested for the presence or absence of Lyme disease. The first of the tests was undertaken in the New Forest in Hampshire. The New Forest is a well-known area that generates a lot of Lyme cases each year. It was found that the background positivity rate - in other words, the proportion of people in the New Forest area - was approximately 22%. The blood of approximately 600 subjects was tested. Therefore, something shy of one person in four had a positive blood test. I actually worked in

the hospital that undertook the study. The consultant there was very used to harking back to us. We, a group of doctors, came in together and we were immediately enrolled in a study. I had a blood sample taken and I was positive for Lyme disease. The consultant said I had got it from the New Forest but since I had started work in the hospital only on the previous Monday, I believe I did not get it there. I was almost certainly bitten by a tick on one of many happy holidays as a child in Achill.

During Professor Butler's introduction, she made the very important point that the diagnosis will be based upon clinical features and the presence of a positive blood test. Irish figures suggest that, around Portumna, 8% to 10% of the background population have a positive Lyme test. In other parts of the west, the proportion is much lower. This shows it is a very localised phenomenon. We know the area where one is most likely to come into contact with and be infected by ticks is publicly accessible parkland. Around the west and south of Ireland, there are a number of areas that have concentrations of ticks that are infected. When somebody goes for a Lyme blood test or any other type of test, it is important to ensure the results are taken in conjunction with the clinical picture of what he or she is exhibiting. A positive test on its own can be misleading.

Senator Marc MacSharry: Had Dr. McKeown symptoms?

Dr. Paul McKeown: If I was bitten as a youngster in Keem I do not remember, but I know my mother used to bathe us and rub the ticks off.

Deputy Marc MacSharry: It is reasonable to assume that Dr. McKeown was not symptomatic.

Dr. Paul McKeown: I probably was not. It is almost certain.

Chairman: Unfortunately I have to vacate the Chair for a period. Deputy O'Reilly will assume the Chair. The first contributor will be Deputy Donnelly. If Deputy O'Reilly wishes to contribute, Deputy Durkan will assume the Chair.

Deputy O'Reilly took the Chair.

Deputy Stephen S. Donnelly: I thank all the delegates for attending and for their time. I would like to walk through the process from the patient's perspective and try to understand where the disagreements are between the testimony we heard earlier today and the one we are hearing now and the difference between the various studies the delegates are citing and those cited earlier today. It has been suggested that general practitioner training on identification might not be great and that there is a great opportunity to train general practitioners to recognise a tick bite and the potential for short-term treatment. Is it true that there is a lot of work to be done on awareness-raising in the general practitioner community?

Dr. Gerard Sheehan: I am from the Mater. I am an adult consultant. There is a variable level of awareness among general practitioners but the experience with Lyme disease in this country is relatively focal. Certainly in particular parts of the country, general practitioners are becoming increasingly aware of the early features of Lyme disease. If a general practitioner sees something that would raise the question of Lyme disease, the patient can readily be referred to a specialist centre within each hospital group where he or she may be seen by an infectious disease consultant. Alternatively, the general practitioner could telephone the hospital and talk to the registrar or consultant to get immediate advice.

Deputy Stephen S. Donnelly: So it would not surprise Dr. Sheehan. It was put to us that in some cases, the lack of awareness among general practitioners is leading to misdiagnosis, which I understand can lead to a longer-term infection because the infection is not being treated straight away.

Dr. Gerard Sheehan: This is the dilemma in general practice.

Deputy Stephen S. Donnelly: Is the point on awareness-raising reasonable?

Dr. Gerard Sheehan: It is occurring to some extent but it holds true throughout the whole gamut of medicine. The difficulty for the general practitioner is that he or she is required to have knowledge of so many areas of medicine. It is part of a general issue. In their training phase GPs act as senior house officers in hospitals. We have a GP trainee attached to our service in the Mater Hospital and he or she comes for three or four months. At the end of the rotation the trainee is quite knowledgeable on a range of infectious diseases, including Lyme disease.

Deputy Stephen S. Donnelly: If, for example, a GP sees a patient and has received the requisite training and experience to be aware of the condition, the first course of action is to make a clinical diagnosis and do a two-stage blood test. Is that correct?

Professor Karina Butler: No. With such a disease there is no need for a blood test. It could be done, but there is no need to do one. If the doctor sees the patient and thinks the issue is Lyme disease, he or she will treat it as such. Very often GPs ask about it and we recommend treatment.

Deputy Stephen S. Donnelly: The standard treatment is a course of antibiotics for three to four weeks.

Professor Karina Butler: The treatment is generally a course of antibiotics for three weeks.

Deputy Stephen S. Donnelly: There does not seem to be much disagreement on short-term or acute episodes if we consider what the delegates say and what we heard earlier. It sounds like there is an opportunity in creating a better awareness among GPs, particularly in place like Portumna where the condition is more prevalent. Moving to the longer term, it is my understanding the delegates recognise that the infection can last, regardless of whether it is treated. Is that true? If we assume a patient takes antibiotics for three weeks, is it the case that two months or two years later the infection can still be present?

Dr. Gerard Sheehan: In general, if somebody has *erythema migrans*, the rash, whether antibody positive or antibody negative, and takes the correct course of antibiotics, it will be said the bug is gone and he or she has been cured. If somebody presents two years later with a facial palsy, for example, arthritis or a heart block, clearly one will re-examine the possibility that one was wrong. One will examine the possibility that there has been a second infection along the way. In general, the starting point is that the facial palsy, arthritis or heart block might have another cause. One should be open to a variety of possibilities, including that somehow the antibiotics failed. One will, of course, err on the side of giving treatment directed at that complication of Lyme disease if the possibility is countenanced.

Deputy Stephen S. Donnelly: It could be a year or however long after the initial episode; therefore, the view is there could still be an infection and it might still be appropriate to treat the infection with antibiotics.

Dr. Gerard Sheehan: My view is that in general it would not be, but one should be open to the idea that this opinion was wrong. It would be covered.

Deputy Stephen S. Donnelly: Great.

Professor Karina Butler: Some of the studies indicate that there is always the possibility of reinfection and it has been looked at in some of the later presentations that it may have been missed. The possibility would not be dismissed just because a person happened to have been treated at a different stage earlier.

Deputy Stephen S. Donnelly: Okay. There seems to be agreement that the disease exists and that short-term antibiotics work in most cases. There is an opportunity to improve the level of awareness, including through GP training and raising patient awareness. In the longer term an infection could still be present or re-emerged, but it may be treated with antibiotics. It might be the right case, as we are talking about quite small numbers.

Dr. Gerard Sheehan: The dilemma is more the patient who presents with non-specific symptoms where he or she is suffering from tiredness and fatigue and has aches and pains. In that circumstance there is a large variety of possible explanations that must be considered, not just Lyme disease. Patients might be ill-served in focusing on Lyme disease when it might not be relevant to the cause of their illness.

Deputy Stephen S. Donnelly: Absolutely. It could come from a wide range of explanations. I want to understand whether one such explanation could still be Lyme disease. The doctor or consultant may make a clinical diagnosis, with many tests to narrow the cause. Do the delegates accept that one of the possibilities could be long-term Lyme disease infection?

Dr. Gerard Sheehan: Yes, of course. It would be worked out by reliable testing. That is where the big difference is between our view, or what is essentially the conventional medical view throughout the world, and unconventional views. At this stage it is based on testing. Essentially, the two-tier test we have described is considered to be almost 100% effective in making a diagnosis. From case to case, if somebody has something that points to the possibility that he or she is suffering from an active infection, irrespective of the result of the test, it will be considered and treated accordingly.

Deputy Stephen S. Donnelly: Sure. I have heard very little so far that contradicts previous statements. There might be a different emphasis, but we are accepting short and long-term possibilities, the potential for long-term infection and that treatment with antibiotics can work on long-term infections. We are also accepting that the cause might be something else entirely. What about long-term treatment with antibiotics, as opposed to the course of treatment of three to four weeks that has been mentioned? It was presented to the committee as one of the approaches used when it was believed there was a long-term infection.

Dr. Gerard Sheehan: To treat specific infections, we are not afraid to use long-term antibiotics. We have people on intravenous antibiotics for six weeks commonly and for three or even six months. They are for very specific and well defined entities where the benefits of such a somewhat risky course of treatment are justified. The obvious example is an infection of a prosthetic joint such as when somebody has an artificial hip and is unlucky enough to witness a complication. For Lyme disease, we find no evidence of benefit and this issue has been examined in at least four random control trials. This is where a large number of people are randomly assigned to be treated for three months with antibiotics, while others are assigned to not being

on antibiotics. Essentially, no benefit was recorded. but patients would be exposed to a hazard.

Deputy Stephen S. Donnelly: When Dr. Sheehan states there is no benefit, is it a case of zero benefit or a low percentage?

Dr. Gerard Sheehan: In studying the issue rigorously, one must study one population versus another. In both populations there may be elements of improvement, but there is no statistical difference between intervention and not having it.

Acting Chairman (Deputy Louise O'Reilly): I am conscious that other members also wish to comment.

Deputy Stephen S. Donnelly: When the regression analysis is made, there is zero benefit in using long-term antibiotics.

Dr. Gerard Sheehan: Essentially, yes.

Senator Colm Burke: I thank the delegates for their presentation and the work they do. During the earlier presentation I referred to the report given to us by the delegates. It is very comprehensive and provides references to previous research. The delegates heard the earlier submissions. It was said medical personnel were not taking this matter seriously and that there had been a lot of criticism of the way it was approached by established medical practitioners. I referred to the report signed by 28 people, but what has been the reaction to such criticism?

Towards the end of her presentation Professor Butler indicated "as doctors, my specialist colleagues and I cannot but be concerned when we learn of patients travelling overseas for prolonged courses of intravenous antibiotics, often coupled with an array of nutritional supplements at a significant cost, personal hazard and no proven benefit." This morning we heard that one person's treatment had cost over €10,000. What numbers of people are travelling abroad, of which we are aware?

Professor Karina Butler: I am afraid I have no figures or specific collated numbers. All I know is that I have seen several patients who have been encouraged to seek tests overseas. From patient reports, it seems it costs €800 to €1,200 to have the testing panel done and it covers a wide array of pathogens. Many of the tests are standard and universally accepted and there is no controversy about them here. There is no reason to seek them overseas. They test for Lyme disease, CMV, microplasma and a range of pathogens.

Senator Colm Burke: Are they tests available in Ireland?

Professor Karina Butler: Some of them are such as the ones that test for the EBV virus. They are carried out in our reference laboratory and people are charged for them.

Senator Colm Burke: Does the hospital deal with people who have been abroad for treatment?

Professor Karina Butler: Yes. We have experience of patients coming back to us who have gone abroad. We do not want to be specific because we do not want patients to be identifiable. Some undergo coagulation tests on a daily basis and in certain centres receive type IV antibiotics, all at huge cost and with no proven benefit. They often come home with an array of nutritional and other supplements and receive other therapies for which there is no evidence base.

Senator Colm Burke: I also asked this morning about the criticism of the profession. I have been contacted by a number of people who believe the medical profession is not responding appropriately.

Professor Karina Butler: I cannot speak for every practitioner, but I can speak for my own practice and that of colleagues. Anyone who is referred with a query related to Lyme disease, whether they have it or want an interpretation of test results, receive an appointment. We do not have waiting lists and generally see people promptly. The average consultation time I spend with such a family is between 60 and 90 minutes, during which time I go through things with them. We do take the issue seriously because there are reasons patients come to us. They have symptoms, but we do not believe they are necessarily of Lyme disease. There is a lack of clinical pathways for conditions of chronic fatigue or non-specific symptoms. We have to work to improve in that regard.

Senator Colm Burke: It has been said there are recent studies from the WHO which the profession here has not taken on board. What is Professor Butler's view?

Professor Karina Butler: We are not in agreement with the WHO's classification.

Dr. Ronan Glynn: It is important to put the WHO's international classification of diseases, ICD, language in context. The WHO did not produce guidance but a list of categories of Lyme disease. It is essentially a dictionary. It is very important to distinguish between it and clinical guidance which is used in clinical practice. The WHO has stated that, just because a particular entity is included in or excluded from the dictionary, it is not a judgment on whether a condition is valid or that a particular treatment works. It should not be seen as an indication of efficacy or a validation of a particular condition.

Senator Colm Burke: One of the things said this morning was that the medical profession in Ireland was ignoring the advances of science in this area. It is a very serious allegation.

Professor Karina Butler: Why would we, given that our entire practice is based on trying to drive forward medical practice and embrace science, ignore science that is real and has been validated? If there was evidence that prolonged courses of treatment helped to alleviate symptoms such as these, it would be the easiest thing in the world to write a prescription for antibiotics for six months. It is much harder to explain to patients why one does not do this. Long courses of antibiotics are associated with the potential for harm and, as Dr. Gerard Sheehan said, even with courses to treat a bone infection, for which we have to do prescribe them, there is the hazard of secondary infections such as clostridium difficile and colitis. There are hazards associated with antibiotics resistance and related to allergic reactions to antibiotics. On a wider scale, in this era when there is a real drive to husband the resource of antibiotics and not to use them inappropriately, we could be frittering away the chance to preserve the antibiotics that are active against pathogens.

Senator Colm Burke: Misinformation can be very dangerous in medicine. Do the delegates believe there is a need for more information on Lyme disease and a clear message to ensure people can accept the advice they receive here, rather than believing they have to travel abroad?

Dr. Paul McKeown: I will answer the first part of the question about raising awareness. Doctors want to ensure the patients who come to see them will receive the correct diagnosis. As for counting cases of Lyme disease and treating them, it is the same as everything else - one has

to start with the correct diagnosis. I agree that raising awareness is crucial in the context of the treatment of Lyme disease. In 2011 the disease was made notifiable, but since about 2009 my organisation has had material on the website, designed to make Lyme disease comprehensible and tell people how to prevent it - by preventing tick bites and removing ticks after spending days in tick infested areas or areas where there are likely to be ticks. This is information that should be available and we have been pressing to get it out, but getting information out to entire populations can sometimes be difficult. In Ireland tick bites occur at a particular time of year and it is much more likely that one will be bitten by a tick between the end of March and November. This information needs to be made available to people. We hold a Lyme disease awareness week, which has become a Lyme disease awareness day, for that purpose. At the beginning of the tick-biting season in March, April or early May we raise issues and point to posters and flyers. We refer people to the frequently asked questions section on our website. The information is supplemented by media interviews which I conduct every year. Our Lyme disease sub-committee recommends that we make much greater use of social media and has suggested that, during the summer and after Lyme disease awareness day, we send alerts fortnightly to our large Twitter following. Raising awareness at this level is crucial and a major part of the work of the sub-committee which is involved in determining how much information is being given and how much more is needed.

Deputy Margaret Murphy O'Mahony: When one has a blood test done, the sample is sent off and a lot of things are tested for. Why is Lyme disease not included in this process? I know some of the doctors on the Beara Peninsula in Cork South West, which I represent, and there is a fairly high rate of Lyme disease there. Some of the GPs add it to the list of requirements for blood tests. Why is that not done in areas where the disease is common? It would maybe catch things earlier.

How often is the western blot test used? I researched it online and found that the result is 99% dependable. Do the witnesses agree with that? Will they comment on prevention of, and education about, Lyme disease?

Dr. Cillian De Gascun: I will speak about the testing component. Generally speaking, for any test that is provided a doctor has to have a pre-test suspicion. Certainly from the perspective of the National Virus Reference Laboratory, NVRL, our testing numbers date from the start of 2015 and we have performed over 21,000 tests for Lyme disease. That figure increased by approximately 50% between 2015 and 2017. We would infer that there is an increased awareness of Lyme disease and more testing for it. Despite the increased testing being performed, the number of positive test results has not increased significantly. In fact, it has probably decreased slightly which might suggest that more people who are not infected are being tested.

At the NVRL, we perform an enzyme-linked immunosorbent assay, ELISA, an antibody test that looks for immunoglobulin G, IgG. Generally speaking, as we heard earlier, in the early stages of infection with erythema migrans the sensitivity of that assay is low. That is well established and it is the reason we do not rely on it for the treatment of erythema migrans or early disease. However, we also know that in the late stage of the disease it is almost universally positive in patients who have had infection for more than, say, three to six months. The chances of patients presenting with a long-term illness of a year or two years or maybe more being falsely negative on the ELISA that we use are very slim.

We have referred approximately 1,200 of the 21,000 tests done since 2015 to the rare and imported pathogens laboratory in Public Health England in Porton Down, which is our reference laboratory. It engages in a two-stage process, performing a second enzyme immune assay

and the western blot or the current equivalent, the immunoblot to which the Deputy alluded.

There is access to testing in Ireland. I operate a laboratory which receives more than 300,000 samples a year and we perform over 900,000 tests a year. If there were a better test available, I would want to perform it. I went into medicine to provide care for patients. We review our testing repertoire across all pathogens for which we test. We look for emerging pathogens and developments in the area in which we should be testing.

To touch on the previous point, there is no indication that there are better tests out there that we are not using. Our concern in the context of testing is that people are travelling overseas to use unaccredited tests which have not made it to market. Research to develop diagnostic testing for Lyme borreliosis has been taking place probably since the 1980s. The US Centers for Disease Control, CDC, made recommendations in the mid-1990s regarding the two-tiered approach and that has not been surpassed. If there were a better approach out there, pharma would be in like a shot. Equally, if there were better tests I would introduce them. The concern for us is that people are using tests that are not validated. I am not suggesting any testing approach is perfect, which is why we work with our clinical colleagues. If they have a high index of suspicion and my test is negative, we would refer it on and perform additional testing. There is no barrier to testing in our laboratory and I can certainly speak for the other laboratories around the country.

Deputy Bernard J. Durkan: It was suggested in the discussion this morning that the medical profession in general is sceptical of the results achieved overseas in terms of treatment and diagnosis.

Dr. Cillian De Gascun: In terms of diagnosis we are sceptical because they are unaccredited tests and the data from those tests have not been published in the literature. We try to provide an evidence-based approach to diagnosis and treatment in Ireland and that is what we are doing. If this laboratory wants to make its findings public, it should publish them in the literature so that they can be reviewed and evaluated. At present, however, they are unaccredited tests which have not been clinically validated. For example, if I want to develop a test for Lyme borreliosis or anything else, I can start off locally in my laboratory and if I think it works in my population, I can share it with colleagues and publish my findings and methods in the literature. They can then be evaluated by other groups, internationally and nationally, to see if they are plausible. If they are reproduced internationally, I would hopefully have patented it by that stage. If they are reproducible internationally and I have a working test, it will be in huge demand and marketed and distributed globally. That is not happening in this case. People are going overseas to use unaccredited tests that have not been clinically validated elsewhere and there is no suggestion in the literature of an evidence base behind them, unfortunately.

Deputy Bernard J. Durkan: What in Dr. De Gascun's opinion is the reason for the high costs of the tests overseas which apparently bring much more dramatic results?

Dr. Cillian De Gascun: This is another significant concern around conflict. This is a private laboratory operated by an individual who has developed these assays and they are only offered privately, to the best of my knowledge. There is a conflict of interests there. We see results coming back from that laboratory to this country and the patients are looking for treatment in the public sector. There is no evidence that those tests are any better than the tests that are available in Ireland.

Dr. Gerard Sheehan: I would say that it is commercially driven. It is to make money.

Deputy Bernard J. Durkan: Dr. Sheehan mentioned treatment in conjunction with supplements. What are the supplements and what effect do they have on the treatment of a patient? For instance, I read somewhere recently that the majority of supplements are a waste of time and are used to convince patients that they can feel better or whatever the case may be. What is the doctors' response to that?

Dr. Gerard Sheehan: I agree with what Deputy Durkan read recently. They are a waste of time.

Dr. Cillian De Gascun: There is no evidence base for them.

Deputy Bernard J. Durkan: Why do patients go abroad to get a service that they believe will cure their particular condition and for which, they believe, there is evidence proving effectiveness? Why would they do that and spend more money than is necessary? What is the average cost of treating a patient here and abroad? A figure of €10,000 was mentioned in the earlier session. I would regard that as an extraordinary cost. What does it cost to treat a patient here, on average?

Dr. Gerard Sheehan: It depends on the circumstances, on whether they are being treated as an inpatient or an outpatient and whether they have a serious complication. Most patients are treated as outpatients so the cost is very small. It is the cost of the prescription and the antibiotic in the public service. For those practising entirely in the public service, there are no private fees or anything like that. It is different if somebody approaches someone in their private rooms.

Deputy Bernard J. Durkan: Would it be true to say that every child and every adult has been bitten by a tick at some stage in their life?

Dr. Paul McKeown: Taking the New Forest example, that testing regime showed that approximately one in four people was positive. The New Forest is in an area with a lot of ticks, deer and small mammals. As well as feeding on human blood, ticks have a varied diet and also feed on other blood. If in the New Forest roughly one in four people has a positive Lyme test, I do not know if it is possible to say everyone has been bitten but in areas like that a significant minority of people will be positive. In Dublin, where there would be lower tick populations, the figure would be 0.5% or 1%. Only a minority of people in Dublin would have been bitten. In the high endemicity areas it is a significant minority.

Dr. Cillian De Gascun: As a group, we would support the approach of additional tick surveys in the country. To the best of my knowledge there has not been one in a number of years.

Deputy Bernard J. Durkan: As someone who was born and raised in the countryside, I assure the witnesses that I was bitten several times in my teens. This could be the reason for my present condition, but the jury is still out on that. Ongoing research is presumably carried out to identify the incidence of Lyme disease, which is as it should be. Furthermore, and this is definitely my last question, I presume the overseas places that specialise in treatment draw patients from all over Europe or all over the world. Is that the case?

Dr. Gerard Sheehan: We presume so but we do not know.

Deputy Bernard J. Durkan: It would be very interesting to find that out.

Vice Chairman: I will pick up on one very brief point that was made. Dr. McKeown said a survey has not been conducted for a number of years. Could he give us an indication of the last

time one was carried out? I think there was a prevalence survey the other day-----

Dr. Paul McKeown: Is the Vice Chairman referring to a survey on ticks?

Vice Chairman: Yes.

Dr. Paul McKeown: I know that a study group in UCD has been undertaking work in this regard. I have inquired about it but the person involved is on holiday. The previous survey was two to three years ago. Tick surveys are useful whenever the concentration of ticks in a given habitat can be determined. It is also useful to know the proportion of those ticks that are positive. Generally, it is anything from 5% to 25%. The important point is that there is a danger that this would make us complacent and we would believe ourselves to be safe in a given area because only 2% of the ticks there are infected and there are not that many of them. A basic universal precautions approach should apply. We know that the kinds of areas where ticks are to be found are very well described. They are woodland or parkland. Ticks clamber up fronds of grass and hang on to them with their back legs ready to jump at any passing mammal, including humans. We know from surveys across Europe that 90% of adults bitten by ticks are bitten on their hands, arms, legs or feet and that approximately 40% to 50% of children bitten are bitten around their hairlines and in their necks, particularly the soft tissues there. We would therefore much prefer universal advice to the effect that these are the kinds of areas where one can expect there to be more ticks and that these basic precautions should be taken when examining oneself. One is most likely to find a tick on one's arms or legs, but everywhere should be examined. Therefore, while such surveys are useful, I would not base any strong policy on them. I would want to ensure that everyone had the necessary information to minimise the chances of being bitten by a tick.

Professor Karina Butler: To answer the Vice Chairman's question, the most recent publication was in 2017 and was based on tick surveys in 2016. They were not comprehensive, however. They were just-----

Vice Chairman: In isolated areas.

Professor Karina Butler: -----isolated checks. We have compiled a brochure of evidence that we are happy to leave for the committee if members wish to have a copy.

Vice Chairman: Yes. I thank Professor Butler.

Deputy Marc MacSharry: I am not a permanent member of the committee. Was the invitation to today's meeting sent just to the chief medical officer's office or to everyone present?

Vice Chairman: The Deputy is not a permanent member and I am not a permanent Chairman.

Deputy Marc MacSharry: I know that. I was just-----

Vice Chairman: That is why I had to check. The invitation was sent to the Department, and my understanding is that the lead person here present requested additional personnel be present.

Deputy Marc MacSharry: That is great. It is a very impressive line-up. Outside of this room, I co-chair the cross-party action group on Lyme. When we requested a meeting with the chief medical officer, neither he nor his deputy was available. This array of wonderful people was certainly not available. There is one person-----

Senator Colm Burke: This is the official committee dealing with healthcare and the Deputy should stop undermining it.

Deputy Marc MacSharry: Excuse me.

Senator Colm Burke: The Deputy is undermining the committee.

Vice Chairman: Excuse me, Senator.

Deputy Marc MacSharry: Would the Senator like-----

Vice Chairman: Deputy MacSharry has the floor. Gentlemen, if you can for one moment, please.

Deputy Marc MacSharry: It is a wonderful-----

Vice Chairman: Will speakers ensure that their questions are focused? I have explained to Deputy MacSharry exactly how the invitations were issued, so if he could proceed with his questions, we-----

Deputy Marc MacSharry: Presumably, having spent 16 years around this place, I know what I am entitled to say when I have the floor.

Vice Chairman: Absolutely.

Deputy Marc MacSharry: It is a very impressive array of people, and it is difficult not to take the view that they wanted to be on message on this and to kill this discourse about Lyme disease and the mythology of there being issues surrounding this. Is Dr. Lambert a member of the Infectious Diseases Society of Ireland, IDSI?

Professor Karina Butler: Yes. He was sent the consensus statement and was not a signatory to it, nor did he respond. At the IDSI annual meeting last year, Lyme disease was a focus. There was an invitation to all to attend for open discussion on the matter and Dr. Lambert did not attend.

Deputy Marc MacSharry: Was he invited to be a party to the document the witnesses sent to the committee?

Professor Karina Butler: This is an expansion of the consensus document that was sent to him and to which he did not respond.

Deputy Marc MacSharry: The document was sent to Dr. Lambert.

Professor Karina Butler: The beginning of it was. This particular document has not been sent to him.

Deputy Marc MacSharry: As I am not from a medical background, all I can say is that the document seems to have included consenting voices as opposed to seeking out the dissenting ones.

Professor Karina Butler: It reflects the overwhelming consensus, with one exception.

Deputy Marc MacSharry: I have not had an opportunity to ask Dr. Lambert about this but he certainly did not know of its existence earlier, judging by the responses to Senator Colm Burke's questioning. Given the discourse whereby we have constituents contacting us to say

the opposite of what the witnesses are saying about the evidence of international treatment, perhaps this is a case of the placebo effect among those who have spent €10,000 on treatment and have returned to Ireland feeling well.

Regarding the International Classification of Diseases, ICD, codes, Dr. Glynn said the ICD is just a dictionary. How does one get an entry into the dictionary? Can I write to the World Health Organization telling it I have a new symptom and would like to call it something and asking it to add the definition to the ICD codes the next time it reviews them? How does one get an entry into the ICD if it is just a dictionary?

Dr. Ronan Glynn: Obviously, I am not involved in the drawing up of the ICD codes so I cannot-----

Deputy Marc MacSharry: No, but as the deputy chief medical officer of the State, I would hope Dr. Glynn would have some input into the matter. He pointed out that the ICD is just a dictionary and is not a set of clinical guidelines or anything else. How does one get an entry into the WHO dictionary for what are chronic conditions?

Dr. Ronan Glynn: The WHO looks at-----

Deputy Marc MacSharry: What does it look at?

Dr. Ronan Glynn: -----the evidence.

Deputy Marc MacSharry: Is that scientific evidence?

Dr. Ronan Glynn: Yes.

Deputy Marc MacSharry: Is it validated scientific evidence?

Dr. Ronan Glynn: It depends on the condition.

Deputy Marc MacSharry: In that case, it is not validated evidence. Sometimes the WHO uses validated scientific evidence and other times it does not.

Dr. Ronan Glynn: To be very clear, and as I have pointed out, the WHO has said that the inclusion of a certain condition or treatment within its code should not be taken as a validation of that condition. We can only-----

Deputy Marc MacSharry: The condition might not exist then, so the WHO has a list of things people just dream up. Mr. Glynn said a minute ago that the WHO bases the ICD on validated science but now he is saying this is not the case, that it is just an *ad hoc* list into which people can throw the names of anything.

Dr. Ronan Glynn: I will come back to the Deputy with the precise detail.

Deputy Marc MacSharry: It is very worrying that Dr. Glynn, as the deputy chief medical officer of the State, is not an authority on this issue. I refer to the document I have seen which the witnesses have provided. Dr. Lambert is not associated with it but the witnesses prepared it specifically for this committee. It seems to be consistent with the view other than Dr. Lambert's. It mentions, and Dr. Glynn mentions, post-treatment Lyme disease syndrome. It is strange that there is no code in the WHO for that. I wonder why that is. How come that did not get into the dictionary? Does Mr. Glynn know the answer to that?

Dr. Ronan Glynn: That submission was on behalf of the IDSI, so-----

Deputy Marc MacSharry: It is something I have come across internationally as well. The document references some studies in the national health institutes of the United States and other areas. Post-treatment Lyme disease syndrome does not have an International Classification of Diseases code. I wonder why that is. I am just asking. That no one appears to be able to answer is a concern because I thought we were basing everything on validated science here.

Professor Karina Butler: That is a subdivision of the chronic symptoms that have been reported by people associated with Lyme disease. It is for clarification that this is divided into two subgroups, namely, those who have seropositive evidence, that is, those who have had confirmed Lyme infection, and those who have never tested positive for infection but have symptoms that they attribute to Lyme disease. The WHO in its classification has embraced these two groups. For the purpose of clarification, and to explain the matter to the committee, we have adopted the more clinical definitions, that is, this subdivision. I hope that is clear.

Deputy Marc MacSharry: That said, post-treatment Lyme disease syndrome is not an established or recognised code within the World Health Organization. Is that not correct?

Dr. Ronan Glynn: As things stand, yes.

Deputy Marc MacSharry: As things stand. Has Dr. Glynn sent in a submission to have that changed?

Dr. Ronan Glynn: The point is that the new codes have only just been released and they will not be adopted until 2022.

Deputy Marc MacSharry: They are already adopted but they will not be *pro forma* approved until next May. What happens then? Ireland fed into the process and I have seen this in parliamentary questions and answers from the Minister, most recently last week, where it says we are at the beginning of the process and it will not be agreed until next May. They will be rubber-stamped next May. All of the negotiations have gone on, with Ireland in the middle with all the other countries, and these codes have been agreed. They will not change and will be rubber-stamped next May. Dr. Glynn said they do not provide any guidelines, but I assume the WHO codes count for something and, on the back of those, organisations like the National Institute for Health and Care Excellence, or the Department, or the Infectious Disease Society of America and everybody else may then come up with new guidelines in line with the new codes. Those codes seem to have been pulled together based on validated science rather than members of the public sending in a view that a certain chronic disease or illness exists.

Dr. Ronan Glynn: It is very important to be clear about the timeline between the development of guidelines and what the WHO does in terms of codes. There are guidelines based on clinical evidence so the National Institute for Health and Care Excellence in the UK produces guidelines based on all of the evidence.

Deputy Marc MacSharry: That will come after.

Dr. Ronan Glynn: No, that comes first. As deputy chief medical officer, I am particularly interested in the reviews of the best available evidence and my job is to ensure the best evidence is used across the country for all conditions. I am particularly interested in that. It is on that published evidence that international statistical classification of diseases and related health problems, ICD, codes are formed so that we can then classify diseases. A patient is treated in

a clinic based on best available clinical evidence produced by the National Institute for Health and Care Excellence and international societies around the world. Ireland has its own community that has looked at the evidence and developed a consensus document based on what it believes to be the best approach.

Deputy Marc MacSharry: That is the 22, not including Dr. Lambert. Is that right?

Professor Karina Butler: I want to speak as a clinician to say that regardless of whether it is osteomyelitis, acute osteomyelitis, chronic osteomyelitis, early stage, late stage or post-Lyme disease symptoms, we do not diagnose or treat based on WHO ICD codes. They have no relevance.

Deputy Marc MacSharry: What relevance have they?

Professor Karina Butler: Not very much in clinical practice on a daily basis.

Deputy Marc MacSharry: Why do we bother sending people to participate in this?

Professor Karina Butler: They are useful on a descriptive basis to categorise different groups of things and to facilitate conversation.

Deputy Marc MacSharry: One can opt in or out if it suits. Is that it?

Professor Karina Butler: They are useful for their purpose. Diagnosing and treating patients is not their stated purpose.

Deputy Marc MacSharry: What is their purpose?

Vice Chairman: Dr. McKeown also wants to respond.

Deputy Marc MacSharry: We are in the middle of a response.

Vice Chairman: I am conscious that our witnesses are also-----

Dr. Paul McKeown: I was going to answer the Deputy's question. The first set of codes I recall were the ICD-7, followed by ICD-8, ICD-9 and ICD-10. This will sound like bean counting but they provide categories or boxes into which patients can be assigned. From those, diagnostic related codes can be developed. That is administrative. For example, lung cancer in Ireland can be categorised by how severe it is, what cell type it is and how advanced it is. This allows for greater description of the complexity of a case and particularly whenever it comes to assigning funds and resources to management of patients in a hospital and prioritisation of diseases this allows us to compare two completely separate diseases such as an infection in a bone compared to skin cancer. That allows the potential to compare the diseases and their costs. It is an administrative thing and it is quite-----

Deputy Marc MacSharry: In its practical delivery-----

Dr. Paul McKeown: -----removed from the daily clinical management of patients.

Deputy Marc MacSharry: The position of the office of the CMO, deputy CMO and the Infectious Diseases Society of Ireland is that the ICD codes have no tangible practical relationship to clinical guidance or treatment. Is that the case?

Dr. Paul McKeown: I would not say that.

Deputy Marc MacSharry: Dr. McKeown said it was administrative, so I am struggling to get this as a layperson.

Dr. Paul McKeown: It is largely administrative but, by the same token, it allows financial comparisons to be made and helps to describe the disease. Medical students learn diseases based on whichever edition of the ICD is available. It assists doctors in clinical identification but it is primarily clinical guidelines that assist in the treatment of patients and the correct diagnosis and how they would be categorised. It is then, based upon what the clinician determines is the diagnosis, that they are fitted into the ICD-10 boxes. That then allows the accurate determination of the complexity in the cost to the hospital. It is a way of bringing all of those disparate areas together.

Deputy Marc MacSharry: It has almost no relevance then.

Dr. Paul McKeown: No, it has quite a lot of relevance.

Deputy Marc MacSharry: To clinical treatment? I am confused. Dr. McKeown is telling me the ICD codes are administrative.

Dr. Paul McKeown: I am not confused. I am saying-----

Deputy Marc MacSharry: I am confused, not Dr. McKeown.

Vice Chairman: I do not think the Deputy is on his own in his confusion. The line of questioning seeks to ascertain exactly what status and weight is placed on ICD codes and I am struggling. I share the Deputy's surprise at the number of very high level people we have managed to assemble here this morning, and that is probably good news for people who want answers to questions, but is there one person who might be able to answer this definitively? There seems to be a degree of answer, then row back and a bit of slippage.

Dr. Gerard Sheehan: I would agree that the codes have little relevance to clinical practice. It is very much relevant to the administration of a hospital and keeping track of what is happening and how things are billed and counted.

Deputy Marc MacSharry: We should take a mental note to stop wasting money sending people to engage with the WHO on ICD codes because it seems an awful waste of money.

I would like to come back in if there is a second round of questioning.

Vice Chairman: There will be a second round of questioning.

Deputy Marc MacSharry: Dr. Sheehan said that there is no proof that long-term antibiotics-----

Dr. Gerard Sheehan: Make a difference.

Deputy Marc MacSharry: -----make a difference. There are over 100 publications in journals that say otherwise.

Dr. Gerard Sheehan: I disagree.

Deputy Marc MacSharry: That is just what I have read. It seems there is disagreement between specialists in infectious diseases. Has Dr. Sheehan read Dr. Daniel Cameron's paper on this?

Dr. Gerard Sheehan: No.

Deputy Marc MacSharry: Has he ever discussed the issue with Dr. John Lambert?

Dr. Gerard Sheehan: No.

Deputy Marc MacSharry: Is that not most unusual? Does Dr. Sheehan not work in the same hospital as him?

Dr. Gerard Sheehan: Yes.

Deputy Marc MacSharry: Dr. Lambert earlier mentioned the establishment of a Lyme disease resource centre. Would Dr. Sheehan be a supporter of that?

Dr. Gerard Sheehan: Dr. Lambert has done a solo run on this. I just double checked with the CEO of the Mater Hospital and the hospital has no strategic plans-----

Deputy Marc MacSharry: I did not mention the hospital at all. I am interested to know would Dr. Sheehan be supportive.

Dr. Gerard Sheehan: No.

Deputy Marc MacSharry: He would not,

Dr. Gerard Sheehan: No.

Deputy Marc MacSharry: Why is that?

Dr. Gerard Sheehan: The services that we have at present deal with the issue. The infectious disease clinics which are present at the Mater and other Dublin centres, and Galway, Limerick and Cork, see people with Lyme disease all the time.

Deputy Marc MacSharry: Would it be Dr. Sheehan's view that the view held by Dr. Lambert and others is a delusional or deluded view when it comes to Lyme disease?

Dr. Gerard Sheehan: I would never say that.

Deputy Marc MacSharry: What is it then? Is Dr. Lambert's view partially accurate, somewhat accurate or not accurate?

Dr. Gerard Sheehan: It is inaccurate in many ways.

Deputy Marc MacSharry: It is inaccurate in many ways. Would Dr. Sheehan not be concerned about the competence of such a physician practising in this country if he was that confident in the inaccuracies of Dr. Lambert's views?

Dr. Gerard Sheehan: The Deputy is asking me to get into something that is very personal to somebody.

Deputy Marc MacSharry: No, I am not.

Dr. Gerard Sheehan: He is.

Deputy Marc MacSharry: It is completely clinical. I am only interested in outcomes for patients. Dr. Sheehan said he thinks this particular view is inaccurate. Are patients at risk as a

result of such views being held in this country?

Dr. Gerard Sheehan: There is a risk of the over treatment or over diagnosis of patients and that antibiotics will be inappropriately used in a very prolonged fashion. The poor stewardship of antibiotics poses a broad risk to the general population. One must realise that antibiotics are one of the great miracles of medicine and date from the mid-20th century. They were initially very effective against most organisms but half of antibiotics, or possibly more, are now ineffective. There is a very high possibility that all antibiotics will become ineffective within a generation or two. It is very important to consider the stewardship of antibiotics, that is, not using them when there is no benefit from such use. The prolonged treatment with antibiotics of patients who have falsely positive Lyme disease tests and an incorrect diagnosis is the most extreme example of such poor stewardship in medicine. There are, of course, many other examples. We must address antibiotic stewardship.

Deputy Marc MacSharry: Okay. Is it acceptable to treat acne, bone infections, the removal of a spleen, tuberculosis and other conditions with long-term antibiotics?

Dr. Gerard Sheehan: The use of intravenous antibiotics to try to cure an extraordinarily serious problem-----

Deputy Marc MacSharry: Antibiotics are not just administered intravenously. One can take them in other ways.

Dr. Gerard Sheehan: A course of intravenous followed by oral antibiotics could be used to treat a difficult to cure bone infection. Antibiotic therapy along those lines can improve outcomes. There are very good examples of situations where it is the right thing to do. It is a precious resource and we must use it only when it is effective.

Deputy Marc MacSharry: Dr. Sheehan is of the opinion that Dr. Lambert is on a solo run which he does not support. Does Dr. Sheehan not support him in his personal quest or does he not support more education and training for GPs as Dr. Lambert suggested this morning?

Dr. Gerard Sheehan: I strongly support more education for GPs, medical students and other health professionals.

Deputy Marc MacSharry: Dr. Sheehan believes that Dr. Lambert is on a solo run and his view is inaccurate.

Dr. Gerard Sheehan: Yes.

Vice Chairman: Professor Butler indicated that she wishes to contribute on this issue. I ask her to be brief as other members are waiting to speak.

Professor Karina Butler: I have read the papers published by Dr. Daniel Cameron, who has been censured in his home state because of his practices. I have discussed the issue with Dr. Lambert, who has been a colleague of mine for many years, and I have looked at his research in this area. I have suggested to him that where questions are unanswered and it is reasonable to hypothesise, we should do so. If we do not have an answer to a question but suspect what it might be, we should design a study to test the hypothesis. That has not yet been done. What has been reported are anecdotal case series reports of patients whose symptoms have been improved with treatment. However, as I explained earlier, perhaps before Deputy MacSharry entered the room, one must consider whether something is causal or temporarily related. To

determine that, one needs well conducted and controlled scientifically and ethically reviewed research. We await the results of such studies. Studies meeting those parameters which have examined prolonged antibiotic therapy for patients with these symptoms who are seronegative have not indicated benefit for the patients.

The key fact is that there are patients who have a range of symptoms for which we, as doctors, do not have ready explanations. When I began my training, such symptoms were attributed to chronic brucellosis, which was mentioned and for which people received prolonged courses of antibiotics in the absence of diagnosis. They have also been attributed to chronic fatigue syndrome, glandular fever virus and vaccinations. There are still such patients and the only way we will get to the bottom of their illness is through well conducted and controlled research. When such research has been carried out to investigate whether Lyme is the explanation for such symptoms, it has not found any evidence that that is the case. The problem is that patients and their families who desperately want to get better are driven to seek solutions. They are being fed the misinformation that there is an answer to their problems and that if they take the antibiotics and many other treatments, they will have a better life. Some such patients will get better but that will not result from the course of treatment but, rather, come about because it is the time for that to happen.

Senator Rose Conway-Walsh: I thank the witnesses for their presentations. I had to attend the Order of Business in the Seanad but I was present for the earlier discussion. The committee is trying to match what the witnesses are saying with what what we were told in the previous session and the people who come to us to say that they have Lyme disease and nowhere to go and it will cost them a significant amount of money and so on. I am very glad to see that in the conclusions of the written statement submitted by the IDSI it is stated that the tools to tackle Lyme disease in Ireland are readily available, that it can be managed within our country and that there is no need for patients to go abroad for diagnosis or treatment. The submission also states that a very small number of people are affected.

Professor Karina Butler: A small number of patients have Lyme infection. There is probably quite a large number of patients who have symptoms which might need to be investigated.

Senator Rose Conway-Walsh: How many people are tested per year for Lyme disease?

Dr. Cillian De Gascun: I can only speak to the volume of testing carried out at the National Virus Reference Laboratory, NVRL. Testing is also carried out at other laboratories around the country.

Senator Rose Conway-Walsh: How many people go to their GP with suspected Lyme disease and are tested for the disease?

Dr. Cillian De Gascun: In our laboratory it varied between 4,000 to approximately 6,500 tests per annum over the past four years.

Senator Rose Conway-Walsh: How many of those were subsequently diagnosed with the disease?

Dr. Cillian De Gascun: Our positivity rate is between 6% and 7%. Those tests are referred to the United Kingdom for confirmatory testing at the rare and imported pathogens laboratory. Of those we refer to that lab, approximately one third are subsequently diagnosed. That leads us to believe that, notwithstanding the patients who are suffering, the numbers testing confirmed positive for Lyme disease in Ireland are small.

Senator Rose Conway-Walsh: That does not match up with the previous information we were given. The 1991 study of the blood bank in Dublin showed 9.75% of blood donors tested positive for the Lyme antibody. How does Dr. De Gascun explain that?

Dr. Cillian De Gascun: I do not know what test was used in 1991 or whether the positive samples were subsequently referred for confirmatory testing, which would have been carried out using the western blot at that time. The first-line assay would usually have a higher positivity rate than the confirmatory test. It would be slightly more sensitive.

Senator Rose Conway-Walsh: Dr. De Gascun would dismiss the findings of the 1991 study.

Dr. Cillian De Gascun: No, I would not. I do not know whether there is a significant difference. Our positivity rate in 2015 was 7.4%, which is not too far off 9%. As I stated, I do not know what the criteria were in the 1991 study or what assay was used.

Senator Rose Conway-Walsh: Might the number with Lyme disease be higher than suspected?

Dr. Paul McKeown: Perhaps I can be of assistance. I have read the 1991 study of blood donors. It looked at the background population. As I stated earlier, 25% of those tested in the New Forest study were positive. The 1991 study sampled blood donors, which is a reasonable proxy for the background population. As the results from the NVRL originate with people who attended a doctor because of suspected Lyme disease or because they had been bitten by a tick, one would expect the positive test results to be higher. That probably explains the difference between the figures.

Senator Rose Conway-Walsh: It does not explain it. I am unsure what the sample size was in the 1991 study but, considering that a rate of 9.75% was identified among a random sample of blood donors, could one extrapolate that, given a population of 4 million, many people may have Lyme disease and be unaware of it?

Dr. Paul McKeown: A positive blood test means that these people were exposed to the Lyme bacterium. In other words, they were bitten by a tick.

Senator Rose Conway-Walsh: Yes.

Dr. Paul McKeown: However, the majority of them will not have had symptoms of Lyme disease. I am not sure if the Senator has heard that I have a positive Lyme disease test. Maybe I had a rash as a child when I was bitten by a tick, but I have never had symptoms. I have certainly never had a big rash or other symptoms of Lyme disease. A majority of people who are bitten by a tick do not develop symptoms. It is only the minority who do.

Senator Rose Conway-Walsh: However, they can have Lyme disease.

Dr. Paul McKeown: Absolutely, yes.

Senator Rose Conway-Walsh: If someone has not had symptoms to date, can those symptoms appear at a later stage?

Dr. Paul McKeown: I will pass that question to a clinical colleague.

Professor Karina Butler: I have been looking at the numbers. The Senator asked about

numbers. In the paediatric area we have been looking at this over the last five-year period. I have just done some quick addition. There probably were between 2,000 and 3,000 tests across the country, as far as we could ascertain. These are retrospective data. Between 1.5% and 4% of those who were tested showed positive results. Certainly awareness is increasing and people are submitting blood samples for testing, but the positivity rate has not changed at all over the years. Although the numbers presenting with chronic symptoms are increasing, and those who might have previously attributed them to other conditions are now thinking of Lyme disease, the actual rates of infection in Ireland do not seem to be increasing greatly as of yet.

Senator Rose Conway-Walsh: Where are the tests done?

Professor Karina Butler: In Dublin, tests are done in the UCD National Virus Reference Laboratory. They are also done in other laboratories in Ireland, including in Galway, the University of Limerick and Cork. Different centres carry out testing.

Senator Rose Conway-Walsh: If somebody goes to his or her GP with symptoms and thinks it might be Lyme disease, can he or she ask for a test? Is that person entitled to a test?

Professor Karina Butler: As we were saying, if patients present with early symptoms they do not even need to have a test. If it is characteristic, they should get their antibiotic treatment at that time. If it is at a later stage and they think the symptoms are related to Lyme disease, yes, a test can be done. There is no problem with that.

Senator Rose Conway-Walsh: Is there a waiting list for the test?

Professor Karina Butler: No.

Senator Rose Conway-Walsh: The figures where-----

Professor Karina Butler: Nor are there waiting lists for people to be seen, certainly in my clinic. There might be a wait of a couple of weeks, but nothing particularly long. In fact we often prioritise those patients because we realise the stress and concern that surround this.

Senator Rose Conway-Walsh: It seems strange, then, that people are going out of the country to get a diagnosis. Do we know how many patients are diagnosed and treated by a GP?

Professor Karina Butler: Those figures are not captured.

Senator Rose Conway-Walsh: Does Professor Butler think it would be useful to capture those in order to get-----

Professor Karina Butler: In capturing data on disease, the only figures that are reliably captured outside of specific studies are on notifiable diseases. The notifiable disease, as we have discussed earlier, is neuroborreliosis. We can get an estimate of the numbers from that because that relationship has been pretty well characterised.

Senator Rose Conway-Walsh: Does Professor Butler not think it would be fairly simple to capture those numbers from the GPs?

Professor Karina Butler: No, it is actually very difficult. With the best will in the world it is extraordinarily difficult to capture figures on something like this when one is relying on GPs around the country reporting it. It seems simple and it would be good information. We can absolutely try to do it but it is extraordinarily difficult. Even when we have tried to find such

figures on very defined diseases, for example, the number of children with chicken pox outside of those who end up in hospital, it is almost impossible to get those numbers.

Senator Rose Conway-Walsh: Why is that? Is it down to the GPs' unwillingness to do it?

Professor Karina Butler: It is down to busyness and the fact that there is work involved. There is paperwork. I am not a GP so I cannot speak for them, but my understanding is that they might have five to ten minutes to see a patient. It simply gets lost in the mix.

Vice Chairman: If I could interject very briefly, has anyone asked the GPs to collect the data?

Professor Karina Butler: For this, no.

Vice Chairman: As such, nobody really knows that they have problems of busyness or otherwise.

Professor Karina Butler: There has not been any systematic effort of which I am aware to report on or collect the numbers of patients presenting. Perhaps there has been one within the Irish College of General Practitioners, ICGP.

Vice Chairman: Very well. I thank the witness.

Senator Rose Conway-Walsh: Can I suggest an attempt on the part of GPs to capture that information? If we want to allay concerns about this we must get to the bottom of it. We have many other issues to deal with within and without the Joint Committee on Health. We want to find out how many people in the country have Lyme disease and how many people are being treated. Unless we have the information it cannot be dismissed as just a few people. I would suggest that we need that information. A request to the GPs to do what needs to be done would be a useful outcome of today's meeting.

The witnesses say that women are being misdiagnosed with Lyme disease. Who is misdiagnosing them?

Professor Karina Butler: They are receiving a diagnosis based on EliSpot tests that are carried out overseas and are thus coming back with the impression that these test results indicate that they have Lyme disease.

Senator Rose Conway-Walsh: How many people have been diagnosed with Lyme disease overseas and have had that diagnosis overturned here?

Professor Karina Butler: I do not have those numbers.

Senator Rose Conway-Walsh: We need the numbers in order to be able to support what Professor Butler is saying. It is really important that we have them. People need to know. People are paying thousands of euro to go abroad to get tests. Professor Butler just said that people are being misdiagnosed. We need to know. As I said earlier, I met a woman who out of desperation is packing bags in SuperValu to get the funding to send her daughter for the treatment she needs. We cannot have that. There is an onus on us and certainly on the witnesses to make sure that this information is presented in a really accurate way in which people can have confidence and trust.

Dr. Cillian De Gascun: That is why we have come here today. We have concerns about

those tests. They are not accredited and they have never been clinically validated.

Senator Rose Conway-Walsh: However, the witnesses cannot tell me the number-----

Dr. Cillian De Gascun: We are telling the committee that patients are travelling overseas and being diagnosed with unaccredited tests. They are then returning to this country and being seen by some of my colleagues here and Dr. Lambert, who was here earlier on. That is one of the reasons we are here today.

Senator Rose Conway-Walsh: However, the witnesses do not have the numbers to back it up. They are asking us to trust them.

Dr. Cillian De Gascun: We know about the test that is being provided. I appreciate that we do not have the numbers but we are concerned about the nature of the test being provided. It is not accredited, has never been clinically validated and is not widely available on the market because it has never been proven as an effective test. If it were, I would introduce it in the morning.

Senator Rose Conway-Walsh: That is why it is serious-----

Dr. Cillian De Gascun: Absolutely.

Senator Rose Conway-Walsh: -----and it is really important that we have those figures. Can the witnesses submit them at a later date? Is there information from which figures can be extrapolated and presented to the committee?

Dr. Gerard Sheehan: The Senator may not appreciate the difficulties involved. When gathering data about diagnosis in general and infections especially, we get really good reliable data when a specific test goes to an Irish set of labs. That is relatively easy to do. It becomes impossible to get true accuracy if the test is happening elsewhere. We can say anecdotally that for the past few years, we have increasingly encountered patients with that story who have been sent on to us. It is impossible for me as an individual practitioner to know what national prevalence the eight or ten people I have encountered reflect. My best guess is that it is a few hundred people. I also am concerned that with the publicity attracted by this issue and the media attention it is receiving, we will see a lot more people who are falsely diagnosed with Lyme disease.

Senator Rose Conway-Walsh: That is why it is so important that we have the data; so that tomorrow I can tell somebody who is fundraising-----

Dr. Gerard Sheehan: However, the data source will be in Germany, not Ireland.

Senator Rose Conway-Walsh: It will be in Ireland once they come back having been told that they have a missed diagnosis. One can discredit the results from the foreign labs-----

Deputy Bernard J. Durkan: That is not accurate.

Senator Rose Conway-Walsh: What is not accurate?

Deputy Bernard J. Durkan: We are in dangerous territory.

Vice Chairman: Senator Conway-Walsh has the floor and has asked a legitimate question.

Deputy Bernard J. Durkan: I am sorry, we are now in the business of giving information having regard to the information we have already received. The information is not credited

information in any event but we are going to get into the area of diagnosis. I would strongly avoid that kind of thing.

Senator Rose Conway-Walsh: It is not about diagnosis. I just want to be able to advise people not to go abroad based on the numbers of diagnoses, which were proved incorrect last year and the previous year, in order that they would not waste their time fundraising and so on because the chances would be that they were wrong. I am not doing diagnoses or anything, I just want the information to support that.

We discussed GP training earlier. Is Dr. Sheehan confident that the GPs have sufficient training here? If there is a training gap for GPs, what is being done?

Dr. Gerard Sheehan: GPs have a great difficulty with the vast number of diseases that they must educate themselves up on. It is probably unrealistic to expect that a GP would have a deep level of knowledge about, say, 500 different entities. We have GPs who rotate to us working as junior doctors and at any one time, there is one GP trainee working on our team. During that three-month period, the trainees get a thorough knowledge of all the major infections that we deal with including tuberculosis, HIV, malaria and Lyme disease. The way that we get educated is to encounter a patient, analyse it and work it out.

Senator Rose Conway-Walsh: Therefore Dr. Sheehan is satisfied that the GPs throughout the State -----

Dr. Gerard Sheehan: I am satisfied that some GPs will end up with a good knowledge.

Senator Rose Conway-Walsh: What can we do for the ones who are not *au fait* with Lyme disease. What more can we do to fill the training gap?

Dr. Gerard Sheehan: The GP organisations will have to address that issue. The Senator will have to address her questions to them.

Senator Rose Conway-Walsh: Therefore none of the people here have any responsibility for furthering the training.

Dr. Gerard Sheehan: We have responsibility for GP education but not to organise it or see what is prioritised or not.

Senator Rose Conway-Walsh: Whose responsibility is it to organise such training, if training needs to be done?

Dr. Cillian De Gascun: The Irish College of General Practitioners, ICGP, oversees the training.

Vice Chairman: The committee will correspond with the ICGP and find out about that. As I am conscious of time and that two people are indicating to come in, I ask that Dr. De Gascun be brief.

Dr. Cillian De Gascun: It is important that members recognise that we are not saying that GPs are not trained or that they are incapable. I think we would all agree that those GPs who work in Lyme endemic areas are very familiar with the disease and very capable of diagnosing it and referring on to specialist care if necessary. There will be some individuals, perhaps a broad swathe, who will feel less comfortable but we are very confident in the abilities of those who are working in the appropriate areas nationally.

Senator Rose Conway-Walsh: Is Dr. De Gascun saying that there is sufficient expertise in the State to diagnose Lyme disease and to treat it, etc.?

Dr. Cillian De Gascun: Yes.

Vice Chairman: I believe that Professor Butler wishes to come in. I ask her to be very brief and then I will call Senator Colm Burke and Deputy MacSharry.

Professor Karina Butler: GPs have good awareness. Last year, the Infectious Diseases Society of Ireland's annual meeting focused on Lyme disease and we have ongoing infectious disease training of paediatricians through the Royal College of Physicians of Ireland. These topics are repeatedly covered but one cannot guarantee that every single person is up to date all the time.

Senator Colm Burke: It is important to clarify that no one here, and certainly not me, is trying to discredit the work being done by those present. The issue I raised at the opening session was the report on which 28 people signed off. It is a clear document that sets out the views of the Infectious Diseases Society of Ireland on the management of this matter. Will the witnesses clarify that they are satisfied that we have the expertise in this country to deal with Lyme disease, its diagnosis and treatment? Are they satisfied that we have all the most up-to-date information and tests and are dealing with the issue properly? There already has been an event where totally inaccurate information was put out in respect of the HPV vaccine. Similarly, we seem to have a lot of misinformation in relation to this. It is important that the witnesses clarify here and now that they are satisfied that were a GP to be concerned about the management of a patient, there is enough expertise in the country to deal with it.

Professor Karina Butler: I am fully satisfied that is the case. Furthermore, I can assure the committee that as infectious disease practitioners, we continue to watch the literature on the evolving science and whatever progress is made in the area. While we recognise there are gaps in knowledge and unanswered questions, when there are evidence-based improvements, they will be readily embraced into our practices.

Senator Colm Burke: Is the expenditure that people are incurring abroad unnecessary?

Professor Karina Butler: It is unnecessary, misplaced and is giving false hope to families.

Deputy Marc MacSharry: I thank the Vice Chairman for putting up with me for so long as a visitor on the committee. Dr. Butler said that overseas treatment does not work. I am paraphrasing but she said that people who are desperate travel and are being fed an answer and that when people get treatment abroad, they get better because they were supposed to, not because of the treatment. Is that an accurate summation?

Professor Karina Butler: I said that prolonged treatment for these people has not been shown to have benefit.

Deputy Marc MacSharry: That is what Professor Butler meant but what she said was that people were being fed an answer, I think her words were that people were "feeding people an answer", that patients go abroad, get expensive treatment, and get better when the infection was ready to right itself.

Professor Karina Butler: I think what I said was "feeding them hope".

Deputy Marc MacSharry: We will look at the transcript. I have a problem with that. I

am not a physician and nor do I claim to be but from a human perspective and as a representative, ignoring or dismissing the patient experience as a placebo or as him or her being fed an answer is not a message I expect the witnesses would like to send out, given that 12 physicians or officials from the Department and various other bodies are in the room. However that is very much the one that I have received.

I am concerned for patient safety. If a senior physician like Dr. Sheehan is calling the view and practice of another physician as inaccurate in its outcomes -----

Senator Colm Burke: I think this issue of trying to discredit medical practitioners here is wrong -----

Deputy Marc MacSharry: Have we another Chairman?

Senator Colm Burke: This committee is not the appropriate forum.

Vice Chairman: Nobody will be discredited at or by this committee.

Senator Colm Burke: That is what Deputy MacSharry is trying to do.

Vice Chairman: Deputy MacSharry is entitled to ask a question and he is well aware of the parameters that exist in these Houses.

Deputy Marc MacSharry: I have not questioned the competence of anybody but in the line of questioning and discourse this morning, others have. The implication is that some people are practicing what other physicians believe to be based on inaccurate medicine. Those present are saying that long-term antibiotic use could be damaging and others take a different view. I say there were 100 publications but the witnesses said this is not the case. Professor Butler stated that Dr. Cameron was censured, and he was, but it was not for that matter. It would be fair to point that out for the record and it would be misleading for us to leave the committee with the impression that it was based on his findings on long-term treatment with antibiotics. I am not querying anyone's competence and especially not that of Senator Colm Burke, and I know that he did not intend to question mine.

I have a concern regarding the division of discourse, particularly in the context of the 12 people from the Department versus Dr. Lambert. Numerous people have contacted the joint committee and we set up an *ad hoc* cross-party action group online because Members from all parties and none were being approached by individuals who stated that they had Lyme disease. There are two people in this room who have gone abroad for treatment and who recovered. Perhaps Professor Butler is correct in stating that it is all in their minds, but perhaps she is not.

This country has paid a heavy price for choosing to dismiss or not listen to dissenting voices. There are two tests, namely, the western blot test and the ELISA test. The Infectious Diseases Society of America has stated that the latter test is sub-optimal. The only thing that is agreed is that there is no definitive test. What is the problem with clinical diagnosis? If the symptoms fit, what is the problem with applying the range of treatments? Dr. Sheehan may favour one and Dr. Lambert may favour another but the proof of the pudding is that patients are being helped. I am not a physician but I have met people affected by this disease. One of them is present. He was previously in a wheelchair and now he is not. I am concerned regarding the number of physicians from various hospitals and bodies who have turned out today to rubbish the patient experience, on one hand, and Dr. Lambert's view, on the other. The fact that we are choosing, in the words of Professor Butler, to view the patient experience as something to be

taken with a pinch of salt is regrettable.

Vice Chairman: I thank Deputy MacSharry.

Dr. Ronan Glynn: I will address the point regarding representation. As Deputy MacSharry stated, I was not in my current post when the cross-party action group came to the Department. Since I took up the post, the Deputy submitted questions and these were answered within two weeks. We have tried to engage proactively on this. The idea of bringing representation from across various specialties and from different parts of the country was to ensure that we could answer the committee's questions and that we might get as much information as possible out there, albeit from a particular scientific perspective. We are certainly not rubbishing the experience of patients.

Deputy Marc MacSharry: That is contradictory.

Dr. Ronan Glynn: The Infectious Diseases Society of Ireland submission is clear. The society understands that there are patients with a range of symptoms, some of which are not readily explained by the medical community. That has always been the case. Since the start of medical practice, there have been conditions in respect of which we have not had answers. That is still the case and, despite best scientific advances, it will remain the case. This does not mean that we are not doing our best to progress scientific and medical practice. It was in that spirit that I tried to ensure we had an accurate and good representation of people to meet the committee.

Vice Chairman: In many respects, that is welcome. However, Dr. Glynn will appreciate that it is unusual and Deputy MacSharry pointed that out. It is unusual. We can leave it at that.

There can be no disputing the evidence of the people from whom we heard before. They spoke about their personal experiences. They were gravely ill and now they are not. Rather than dismiss them, we want to engage with them. We want to engage with the professionals and we want to get a full and round picture.

Has Deputy MacSharry finished asking his questions?

Deputy Marc MacSharry: Doctors differ.

Vice Chairman: Senator Conway-Walsh has a very brief question.

Senator Rose Conway-Walsh: What role can our guests play in ensuring that the situation about which I was informed will not be repeated? A person presented to a hospital and the clinician laughed in her face and told her to go home. Subsequently, she attended the surgery of a sympathetic GP who asked whether it could be Lyme disease. The GP performed the test and the result was positive. Is there a role our guests could play to ensure that does not happen and that clinicians treat patients seriously? The issue is when the relationship between clinician and patient breaks down. When a patient suggests that he or she might have a condition, what is the simplest way forward? How can we ensure that patients are at the centre of the treatment? I think that is the way of quelling any of these issues. The professionals have the expertise and nobody is denying that. It is a matter of filling the information gaps in order to ensure that patients are treated in the way they should be treated.

Professor Karina Butler: Despite Deputy MacSharry's comments, I totally agree with the Senator. The Deputy might indicate that I would not have agreed. We listen to the patients and

I absolutely believe that we should approach patients with an open mind and listen to them. Patients deserve to have their ailments fully investigated, not just in the context of Lyme disease but also regarding other causes of their symptoms. There may be some cases where a diagnosis is made and where treatment should be given. There will be others who may have symptoms for which there is not a defined infectious cause. For some, they will need other care treatment pathways to aid their recovery.

I do not think that any physician should laugh in the face of a patient if he or she raises a serious question. That is absolutely not acceptable. That is what we try to teach our trainees as they come through.

Senator Rose Conway-Walsh: In terms of the checks that GPs and clinicians carry out, does the information with which they are provided prompt them to check for sepsis or Lyme disease? Is there a way of simplifying the process?

Professor Karina Butler: It is part of the increasing awareness campaign regarding the symptoms that are likely related to Lyme disease to identify when testing is or is not needed and when treatment is indicated. All of that can be improved.

Vice Chairman: I am going to give the final word to Dr. Sheehan.

Dr. Gerard Sheehan: I fully agree with Senator Conway-Walsh. The behaviour she described is unacceptable. At the heart of what good medicine is about is talking to patients, listening to them, gathering history, carrying out appropriate examinations and tests and then making one's best effort to arrive at a diagnosis and treatment. All of that takes time. One has to put patients at the centre of everything and one has to listen to them. Even if the ideas that come out of engagement with the patient do not necessarily make sense, one has to engage in a dialogue and to see about setting up a plan that gets them better. In terms of making engagement with the patient better, it is essentially the ongoing business of medical education to educate and train students and junior doctors to the best standards.

Vice Chairman: On behalf of the joint committee, I thank Dr. Glynn, Dr. McKeown, Dr. De Gascun, Dr. Sheehan and Professor Butler for their time. The reason we held this hearing today on this extremely serious issue is because we have been inundated with requests from people. We are pleased to be able to provide a platform but the experience described by Senator Conway-Walsh is very real and is a matter for reflection. We look forward to interacting with the witnesses in the future.

The joint committee adjourned at 1.30 p.m. until 9 a.m. on Wednesday, 12 December 2018.