

Meeting of the Joint Oireachtas Committee on Health –Tuesday 17th December 2019

Opening Statement by Mr. Stephen Teap, advocate for CervicalCheck patients

Firstly, I would like to thank the joint committee on inviting Lorraine and I here today as patients' representatives on the CervicalCheck Steering Committee and as also representatives of the 221plus support group.

I would like to take this opportunity at the outset to highlight the importance of the Cervical Screening Programme, since the beginning of this debacle I along with Vicky, Lorraine and others have spoken about the importance of women continuing to get their smears taken and continue to participate in the screening programme, screening saves lives and the CervicalCheck Screening programme has saved many many lives, the odds of the screening programme are in the favour of the women who participate in it in picking something up, this has been a very difficult conclusion for me to overcome given how it completely, 100%, failed my late wife Irene, however the facts are there and even Cervical Check Screening, a programme "doomed to fail" as described by Dr Gabriel Scally, has saved lives.

However that been said, many lives have been lost to this also, many families torn apart and destroyed, many women's lives who have beaten cervical cancer but have to live with the high price of beating such a disease with life long complications such as infertility and physco sexuality just to name a few.

When I went public in May 2018, it was to raise myself to a level where I could have a voice in this, a voice to get the answers for my family on what happened to Irene, but also influence those to uncover the failures in our screening programme, to ensure what happened to my family never happens to anyone else's again.

If the true meaning of failure is to highlight the mistakes of the past, learn from them, correct them to ensure they never happen again in the future, then Dr Gabriel Scally's recommendations are key to this and should remain the backbone in addressing these failures.

Right now out of the 116 actions that the HSE has identified in Dr Scally's Recommendations 95 of those are now complete, that is just over 80% of the Implementation plan completed. I want to acknowledge the hard work of many people in the HSE who have been working tirelessly in achieving this and the transparency they've given to Lorraine and I over the last year in oversight of this plan. However that being said, I do have concerns about it's fulfilment and it reaching 100% completion.

Oversight of the Implementation Plan will drive it to fulfilment, we need to continue to shine a light on the progression of this plan, the oversight needs to continue but we must also ensure there is a plan in place to review the ongoing actions that have been implemented, whilst following to ensure they are still being worked on into the future.

Restoring trust in the screening programme won't be achieved by just this plan, we need to start listening to the voices on the ground especially the Doctors, Consultants and nurses in the clinics around the country and also the staff within CervicalCheck.

Currently in the Colposcopy Clinics around the country the wait time for referrals to be seen within 4 weeks for HG abnormalities is at 70%, for those waiting to be seen within 8 weeks for LG abnormalities is at 57%.

This in addition to what we've been listening to with regard to the staffing issues, the inability to retain staff due to the massive stress levels the staff face daily on the ground is of huge concern. If we don't get this right, it will only continue to worsen as we see the introduction of HPV Screening next year.

While the HSE and DOH will argue that there has been additional funding put in place to address this I'm concerned that not enough is being done and this will be another problem that we will all face next year.

I have spoken on a number of occasions about the importance of Patient Representatives and Medical Professionals working together with one voice to give a view from the ground up, we talk about the "Culture" in our Healthcare System that needs to be changed, we know this can't be changed overnight, but what we can do today is start to dilute that culture by voicing our concerns together on the back of our common goal, to improve Healthcare for everyone, not just for those who rely on the system but for those that also work within it.

I've spoken to the Minister of Health and the DOH on a number of occasions about setting up a proper structured Patient Representative platform to help with this. Patient Representatives who enter our Healthcare System do so to make positive change but most like Lorraine and I do so coming from tragic backgrounds, there needs to be more of a structured platform to support us whilst proactively encouraging the Patient Voice to be involved in shaping our healthcare system, instead of exploiting those who enter on the back of a tragedy.

It needs buy in from the Medical Professionals along with the Colleges to be a part of shaping this platform also.

I want to acknowledge those who have spoken out recently in relation to the ongoing issues on the ground and commend them on their courage, in particular to those voicing their concerns around the staff in the clinics and CervicalCheck, their voice is limited in what they can say and I just want to thank them for speaking out.

Working together will be the key stepping stone as we move forward to not only restore trust and confidence back into our screening programme but also rebuilding the confidence in the key relationships in our Medical Care, and also that of our GP's who we all rely on around our country.

Now that RCOG has finally reached a conclusion our focus has been on those who now have been impacted by this and I want to especially highlight the 159 women and families who over the last 3 months have received discordant results from their participation in the Cervical Check Screening Programme.

These women and families like the 221 last year have come to learn of missed opportunities due to a delayed diagnosis on the back of slides that could have been read differently first time round.

Now all these families are left in the dark LIKE those of us in the 221 who received audit results last year.

They too now face the many questions we faced when receiving this news,

What does all this mean?

For the last 17 months Lorraine and I have been requesting that funding be put in place so those who wish to have their own independent reviews can have access to them in order to get to the truth of what went on.

Many of the families can't afford to do this as the only system that is available to us is a complicated one and is not cheap. As one gentleman who called to my house recently who had learnt about the misreading's of his late wife's smear tests said to me, "I owe it to my wife to find out the truth on what

happened to her, I also owe it to my family”, this is what this is all about, the truth, to us the truth matters.

Why I never bought into the RCOG review from day one was because I knew it wouldn't give the women and families all of the answers they require.

We are all fully aware of the “limitations” of screening and for some an independent review has highlighted this for them, and now these families can get closure, for others we've haven't been to lucky and our journey continues in the adversarial system only available to us in getting to the truth on what went on in these reviews.

The limitations of screening has been spoken about on a number of occasions, for some critics they refer to these limitations as the only thing at play here.

Without a proper defined explanation of these limitations the conversation has gone askew and for many of us has been hurtful to listen to.

Without a proper recognised published document we can all refer too we've started to see this term being used as a blanket excuse to downplay exactly what is going on here.

We must remember that yes, screening isn't perfect, yes it does come with its limitations but we must also remember the LABS that outsourced smear tests to other LABS behind the HSE's back without approval, we must remember the lack of QA that was in place and that none of these LABS that were outsourced to were ever checked.

We must also remember that Dr Gabriel Scally only visited 7 out of the 16 LABS he found as the remainder either didn't exist anymore or there was no point in visiting them today, we must remember that Dr Scally couldn't comment on the quality of those LABS back in the day as he physically can't go back in time to review this, he himself was clear that any opinion he had was based on whatever information that was provided to him and for the best part that information was extremely difficult for him to obtain.

For all these reasons it is why it is so very important for us to find out the truth individually and is why we've been asking for the support of the Government in helping us achieve this, not supporting the women and families in this debacle in determining the truth will be this Governments biggest failure in this debacle.

Contracting our screening programme to labs in the states, the systemic failures within Cervical Check, the lack of QA around the additional LABS that the HSE was unaware of all of this has had a devastating impact on many lives in this country.

We are years away from determining a final conclusion on all of this as we wait to hear how many of these slides either fall within the limitations of screening and how many of these slides breached the duty of care of the women who participated in this programme.

For now, all we can do is focus on the women of Ireland today and prioritise on correcting the wrongs of the past, screening will and should save lives, focus needs to continue on implementing Dr Scally's recommendations so we can have to best possible screening programme, one that the women and families of Ireland can rely on.

We also need to continue to build on the incredible legacy the amazing Laura Brennan left behind for us and continue to move forward as is being done with the HPV Vaccinations for girls and boys.

To get to the point of eradicating this dreadful disease in Ireland we need to look after the women of Ireland today with the best Cervical Screening programme we can all trust and rely on.

While at the same time protecting our future from HPV by educating and supporting the parents of today on the importance of the HPV Vaccination.

I very strongly believe we can achieve this, I very strongly believe that we can prevent what happened to my wife and family happening other families in the future.

Thank you