

The National Infertility Support and Information Group Statement to the Joint Committee of Health in relation to the General Scheme of the Assisted Human Reproduction Bill

19th December, 2018

The National Infertility Support and Information Group (NISIG) appreciates this opportunity to participate in the pre-legislative proceedings relating to the General Scheme of the Assisted Human Reproduction Bill. This statement will briefly detail the areas of interest to NISIG and its members following on from our submission in February 2018.

The National Infertility Support and Information Group is a patient group formed in 1996, and is the only charity in the Republic focusing on infertility. Our mission has been to provide practical and emotional supports to, and advocate on behalf of, those experiencing reproductive challenges and to provide support to families created using AHR. We provide support at all stages of the fertility journey, from trying to conceive, to IVF through donor conception and surrogacy. Of particular importance to our members is the peer to peer support and networking opportunities provided through our regional support groups. NISIG also supports families created using AHR, running Family Conversations events where we support families of donor conceived children starting to discuss their children's origins. Funding is critical for our organisation to continue to provide these services. Funding has been challenged over recent years with the lack of national lottery funding, so we would ask that this be reviewed.

NISIG broadly welcomes this long overdue forward thinking legislation and welcomes the proposed introduction of a regulatory body, with its proposed inclusion of patient voices on this body.

- We sincerely hope the legislation lays the ground work for public funding for fertility treatment for the one in six people in Ireland who will be affected by infertility. Ireland is only one of three countries (Lithuania and Cyprus included) in Europe that does not currently provide public funding. Assisted Human Reproduction has become increasingly commercialised over the last decade with the lack of public funding in Ireland and the entry of multinational companies into the sector leaving those involved potentially open to financial exploitation. We would ask that consideration be given to the number of cycles to be publicly funded, we would suggest that 3 cycles should be funded. In addition, we would ask whether funding will be provided for those having to travel abroad for treatments not currently available in Ireland (i.e. double donation, embryo adoption and egg sharing). We would also ask that funding be considered for those facing secondary infertility, and also for

the transfer of frozen embryos in situations where people are expanding their families after treatment.

- As an organisation that provides emotional support through our 24-hour helpline and regional support meetings, we recognise the inherent value of counselling for those undergoing fertility treatments, particularly at points where treatments have failed and in situations like donor conception and surrogacy. Counselling should be encouraged and made available to patients without causing further financial burden, but not arbitrarily so, and it might best be separated from the treatment provider.
- NISIG also has concern with the upper age limited of 47 for women undergoing IVF treatment, which is unnecessarily restrictive, particularly as reproductive technologies continue to evolve. NISIG therefore feels that there should be room for flexibility to be exercised by experienced clinicians.
- We would like clarification on whether egg sharing will be permitted in Irish clinics. We would also like clarification on whether a male surviving partner can use embryos via a surrogate. Regarding single embryo transfer, we would defer to clinicians' recommendations on this and agree that this might be best decided on an individual basis. Also, the limit on storing embryos for just 5 years is unnecessarily restrictive for those trying to complete their families.
- Regarding the proposed national surrogacy and donor conception registers under the Children and Family Relationships Act, we feel that the proposal whereby a donor-conceived person who applies for a birth certificate would be told by the State that he or she was donor conceived without ever seeking that information is a dangerous invasion of privacy that needs to be reviewed.
- Finally in relation to surrogacy, restricting surrogacy to domestic arrangement, will effectively rule out surrogacy as an option for many couples, in addition to leaving the children and prospective parents of foreign surrogacy arrangements in a legal limbo. Also the prohibition on providing technical, professional and medical services, save for domestic surrogacy arrangements will cause unnecessary further distress to many couples in the state whilst also potentially leaving clinicians open to fines or criminal action. We appreciate that surrogacy is a very complex area, however the legislative framework will need to reflect the actual realities of surrogacy in Ireland, namely that most of it takes place outside of the country. We would also like clarification on whether parental rights like maternity/paternity leave will extend to the parents of children born via surrogacy.

NISIG thanks the Joint Committee of Health for the opportunity to submit this statement and to speak at the hearing on December the 19th, and we would ask that due time and consideration be given to review the questions and issues raised in this statement as they reflect the concerns of our membership.