



Pre Budget Submission 2023

About NISIG

The **National Infertility Support and Information Group (NISIG)** was founded 25 years ago and is the only charity in Ireland focusing on infertility. We provide a range of services including support meetings, a helpline, live web chat, resources, workshops and information for parents and intending parents, and undertake advocacy on behalf of those experiencing infertility.

We are very supportive of the Health (Assisted Human Reproduction) Bill 2022 – better known as the AHR Bill. NISIG was part of the AHR Committee back in 2005, and have been campaigning for this legislation to be introduced ever since. However, it is important to note that there are significant areas of the Bill that require clarity and amendments– we will address these in a separate submission.

We are also very supportive of the recommendations of the Committee report recommendations by the Special Committee on International Surrogacy. We support the calls for retrospective provisions and exclusions from the CFRA to be part of the AHR legislation.

NISIG are resolute in our mission that, as the national charity at the coalface of fertility issues, we seek funding for IVF, IUI, TSI and ICSI treatments included in Budget 2023. We believe this is crucial and the current passage of the AHR Bill compliments having this Budget line in place.

We must have AHR legislation that is fit for a modern Ireland for all those who find them in the position of requiring access to fertility treatment passed in Ireland as soon possible, and we look forward to working with everyone in Government and the Oireachtas to make that reality.

About infertility

The WHO¹ outlines the following facts about infertility:

- Infertility is a disease of the male or female reproductive system defined by the failure to achieve a pregnancy after 12 months or more of regular unprotected sexual intercourse.

¹ <https://www.who.int/news-room/fact-sheets/detail/infertility>

- Infertility affects millions of people of reproductive age worldwide – and has an impact on their families and communities. Estimates suggest that between 48 million couples and 186 million individuals live with infertility globally.
- In the male reproductive system, infertility is most commonly caused by problems in the ejection of semen, absence or low levels of sperm, or abnormal shape (morphology) and movement (motility) of the sperm.
- In the female reproductive system, infertility may be caused by a range of abnormalities of the ovaries, uterus, fallopian tubes, and the endocrine system, among others.
- Infertility can be primary or secondary. Primary infertility is when a pregnancy has never been achieved by a person, and secondary infertility is when at least one prior pregnancy has been achieved.
- Fertility care encompasses the prevention, diagnosis and treatment of infertility.
- Equal and equitable access to fertility care remains a challenge in most countries; particularly in low and middle-income countries. Fertility care is rarely prioritised in national universal health coverage benefit packages.

Infertility in Ireland:

The Health Service Executive (HSE) estimates that “around 1 in 6 heterosexual couples in Ireland may experience infertility”.²

Worldwide, it is estimated that there are approximately 2.5 million assisted reproduction cycles each year, resulting in the delivery of 500,000 babies.

In Ireland the number of treatment cycles grew in the period 2009-2020, from 7,589 in 2009 to a peak of 11,359 in 2018³. There were fewer treatment cycles in 2019 and 2020, but these figures were affected by the pandemic. We also do not have figures available here on people seeking treatment abroad.

Unlike in all other EU countries, in Ireland there is no specific legislation governing the area of Assisted Human Reproduction. Infertility treatment, such as IVF, takes place in private and not-for-profit clinics in Ireland.

Many clinics report making high profits running into several million each year, and often attract overseas investors.

Prohibitively high costs are a barrier and serious cause of stress to those experiencing infertility. The cost of a single IVF cycle in Ireland ranges between €4,100 and €6,000 and the cost of an ICSI treatment between €5,200 and €6,400.

There is no public funding available for AHR treatments in Ireland. Most related drugs costs may be covered and tax relief claimed on medical expenses. Public funding in other jurisdictions has been shown to increase access.

² https://data.oireachtas.ie/ie/oireachtas/libraryResearch/2022/2022-02-28_l-rs-note-assisted-human-reproduction-data_en.pdf

³ Data supplied to the Oireachtas Library & Research Service by the Health Products Regulatory Authority, February 2022.

In December 2021 Fertility Europe, in conjunction with the European Parliamentary Forum for Sexual and Reproductive rights developed the European Atlas of Fertility Treatment Policies. **Ireland was rated as 'exceptionally poor' coming out no 40 out of 43 countries** with just Albania and Armenia behind us.

Budget 2023

2023 has been earmarked at the year when Ireland will, for the first time introduce provision for IVF funding in line with commitments made aligned to the AHR legislation. This is a historic and pivotal moment in Women's Health in Ireland. NISIG are calling for Budget 2023 to include the following:

1. Provision for State IVF funding in line with the Health (Assisted Human Reproduction) Bill 2022 to come into effect for 2023.
2. Funding to include all other fertility treatments and blood tests undertaken by anyone within the definition by the WHO of experiencing infertility. These would include TSI, IUI and related costs in IVF such as embryo freezing.
3. In line with the AHR legislation, and the proposed new Assisted Human Reproduction Regulatory Authority (AHRRA), NISIG want a model introduced whereby private clinics can provide State funded treatment until such time whereby publicly funded fertility treatment is available in public health care settings, nationwide
4. NISIG believes it is key to continue to allow people continue to reclaim tax benefit on any privately undertaken fertility treatments in Ireland until such time as they can obtain them through the public health system. We do continue to have major concerns though that this excludes anyone who is not paying tax or is below the threshold.
5. NISIG believes that the drug prescription medical card must be kept in place long term to help alleviate the cost of prescriptions associated with AHR treatment.
6. Counselling is another expense that many face during fertility treatment, which some people also forgo because of the prohibitive cost. NISIG believes counselling support is an important part of the fertility journey and therefore should be made available freely to those wishing to avail of it. We do not believe that speaking to a doctor or nurse in a fertility clinic fills this role fully, therefore want to see a separate funding established for people to available of counselling via an independent therapy or counselling provider.

There has been significant discussion in relation to the requirement in the AHR Bill that anyone undertaking AHR treatment legally must undertake mandatory counselling. NISIG do not agree with this requirement due to the stigmatising effect. Infertility would be the only medical condition in Ireland to have such a requirement linked to it. However, we do agree that for certain treatments counselling plays an important role. Therefore, we call for increased investment in the number of counsellors in Ireland, and also for specialised training of counsellors involved in fertility counselling.

7. NISIG as a charity organisation, which receives no significant consistent Government funding for the services we provide. We are the only charity that deals with the issue of infertility, offering peer support meetings, live website chat, a helpline, resources and advocacy. We expect demand for our services will grow significantly when this legislation is passed, therefore we request to have our services supported financially for 2023 and onwards to allow us to continue to provide these supports and increase our services where required.
8. Data records of fertility treatment in Ireland are difficult to obtain, this has been acknowledged by many who are working in this area and those researching it. While figures show the level of treatment activity, they do not tell us anything about the outcomes from that treatment. Individual clinics publish 'success rates' but it can be difficult to compare

between them and there is no central, verified data source at present⁴. In 2023 we call on the Government via the HSE to undertake detailed research into the number of people undergoing fertility treatment in Ireland, the number of cycles, the success and failures of these cycles, the cost of these treatments (and all associated costs for each cycle). For the new AHRRA to get up and running as soon as possible we need this information to ensure it is fit for purpose from the outset. The research will require proper investment of resources which should therefore be included as part of Budget 2023.

9. Fertility is an issue that affects 1 in 6 couples, but it is not freely or widely spoken about in society today. We want to see that change in 2023. NISIG feel that from your teenage years upwards, the issue of fertility should be part of the normal conversation and sex education in each person's life. **Knowledge is crucial, as is time, when it comes to fertility.** Therefore, we need to inform people about fertility early on in life and make information easily accessible. NISIG call on the Government to rollout a fertility awareness campaign in 2023 in tandem with the new legislation and setting up of the new Authority.

While noting that publicly available figures in this area are difficult to obtain, and models used in other countries are being revised or not suitable to replicate in Ireland, NISIG are calling on Government to include provision for the above mentioned in the 2023 Budget.

An initial investment in these provisional resources of **€20m should be made available for 2023**, with the acknowledgement that as the new AHRRA is set up and treatment is provided, that figure will need to significantly increase year on year.

We are happy to discuss this further with you at any point and indeed any other details of work NISIG do in providing support to those on their fertility journey in Ireland.

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⁴ https://data.oireachtas.ie/ie/oireachtas/libraryResearch/2022/2022-02-28_l-rs-note-assisted-human-reproduction-data_en.pdf

