

FIGIJ and NASPAG Advocacy Statement Supporting Fertility Preservation for Pediatric and Adolescent Patients Receiving Gonadotoxic Therapy



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Introduction

Fertility preservation is an emerging opportunity for at risk pediatric and adolescent patients.

Children and adolescents who have received gonadotoxic treatments for cancer (of whom over 80% survive in high income countries), chronic rheumatologic or renal disease may be at risk of infertility.^{1,2} A wide range of non-oncological medical conditions (sickle cell, thalassemia, multiple sclerosis, metabolic conditions) may now be treated by stem cell transplant. Furthermore, there are diverse genetic and endocrine conditions which may cause premature ovarian insufficiency. Future fertility is also an important consideration for gender diverse and intersex populations.³ Medical progress has enhanced the survival rates of children with diverse health conditions, resulting in a growing pool of affected individuals who face serious late effects which impair quality of life. Infertility can be a source of psychological trauma.⁴ In some cases for at-risk youth, fertility preservation can protect reproductive ability.

The reproductive and gonadotoxic impacts of medical treatments should always be considered and minimized when possible. It is an international standard of care to discuss the impact of gonadotoxic treatment in all patients with curative intent, including families of children and ado-

lescents, and to implement fertility preservation measures prior to gonadal damage when indicated.^{5,6} Fertility preservation evaluation refers to the consultation with patient and family, and shared decision making for measures to protect fertility as much as possible. Fertility preservation techniques include the cryopreservation of gonadal tissue, oocytes or sperm, and shielding or transposition of reproductive organs away from a radiation field.^{5,6} Institutions caring for pediatric and adolescent oncology populations are encouraged to develop structured programs for fertility preservation.⁷ Such programs are a criterion for centers of excellence in children's hospitals.⁸

FIGIJ and NASPAG acknowledge that fertility preservation techniques are in varying stages of translation from experimental to standard practice. The field of fertility preservation requires levels of governance, resourcing and monitoring of competency.⁹ Health providers need training, guidance, models of care, governance structures or protected time to be able to navigate this discipline. Studies have shown that FP procedures are safe to implement with careful selection, do not delay cancer treatment, and are important to young people and their families.¹⁰ FIGIJ and NASPAG recognize that some of the fertility preservation options are resource intensive which can create economic barriers and result in disparities in care across the globe.⁷

Fertility preservation is grounded within "the right to an open future" which attempts to protect a child's rights in trust until they are old enough to make decisions for themselves.^{11,12} Under the Convention of the Rights of the Child,

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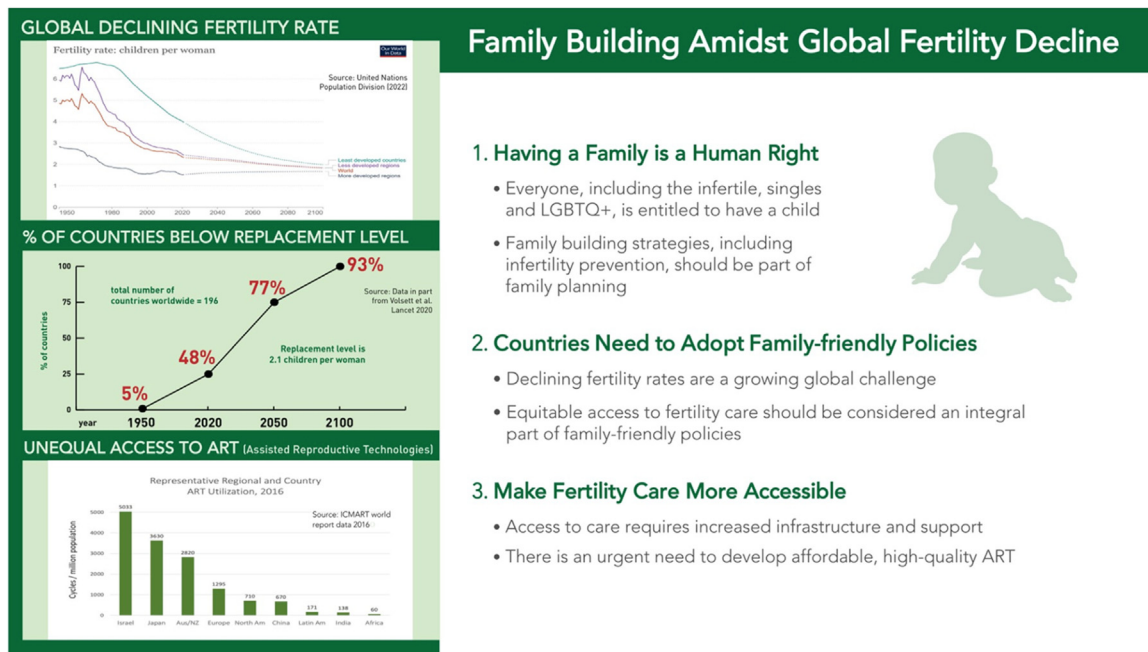


Fig. 1. Family building amidst global fertility decline. Graphic abstract from the International Federation of Fertility Societies (IFFS) consensus document. This article highlights the major disparities in access to fertility care.¹⁵

health providers are required to implement active measures that protect the rights of children, including bodily integrity and autonomy.¹³ In recognition of these rights, FIGIJ and NASPAG advocate for fertility preservation as an intervention to promote the health and well being of children and adolescents. **FIGIJ and NASPAG urge the following calls to action:**

- **Policy Support:** Legislators, institutions, healthcare providers and consumer groups should advocate for resources for clinical care, insurance coverage and other funding, tissue storage, oncofertility coordinator networks, review and consistency of assisted reproductive technology laws in minors.
- **Service Delivery:**
 - Training and awareness of fertility preservation methods should be increased for all healthcare providers utilizing potentially gonadotoxic therapy or treating patients at risk of premature gonadal insufficiency.
 - All families of children at risk of iatrogenic fertility loss, outside the strictly palliative context, should receive a discussion about the impact of their treatment or medical condition on fertility. Fertility discussions should occur irrespective of socio-economic factors, culture, education or gender. They should occur even if risk to fertility is low, cancer treatment needs to start urgently, and/or fertility preservation is not possible.
 - Centers of excellence in pediatric and adolescent fertility preservation should be established, and capacity in regional hospitals and primary care built to deliver stepped care and survivorship models of care, as well as referral pathways to fertility centers.

- Quality assurance should be monitored through development of governance frameworks within institutions, standard operating protocols, consensus guidelines, accreditation of pediatric institutions, credentialing and maintaining competencies of staff across the pediatric and adult sectors.
- **Research:**
 - Pediatric and adolescent oncofertility clinical trials networks should be established to improve patient centered outcomes through national and regional fertility preservation registries.
 - Reproductive and fertility outcome measures should be included in clinical trials of novel agents (immunotherapies and small molecules).
- **Accessibility and affordability:** In many nations across the globe, the utilization of assisted reproductive technology (ART) remains suboptimal. High expenses associated with ART, coupled with inadequate reimbursement, render it unaffordable for a significant portion of the population. This, in turn, leads to reduced access. Conversely, in a commercial environment where reimbursement is not regulated or consumer behavior is unchecked, there may be a tendency towards ART over-utilization.¹⁴ The availability of comprehensive and reliable data would greatly assist health authorities in formulating appropriate ART policies. See [Figure 1](#).
 - Countries need to prioritize and develop strategies to make fertility treatment affordable and minimize impact of unintended multiple-gestation pregnancies.
 - Policies regarding accessibility and affordability should address cultural concerns and remove structural barriers of access to fertility care.

Resources for patients and providers: International Federation of Gynecology and Obstetrics (FIGO) Fertility Tool (<https://fertilitytool.com/>).

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Conflicts of Interest

Nothing to disclose.

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