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## Developing a Hospital-Wide Fertility Preservation Service for Pediatric and Young Adult Patients

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#### ABSTRACT

**Purpose:** Gonadal damage is a common consequence of treatment for pediatric malignancies. Nononcologic conditions may also utilize treatments with potential impact on fertility. Models for oncology fertility preservation programs have emerged and demonstrate that a multidisciplinary team approach can have a positive impact on referral patterns, appropriate risk counseling, and access to fertility preservation options. Expansion of programmatic breadth is needed, providing improved care to nonmalignant conditions where the disease itself may impact reproductive health or treatment modalities.

**Methods:** With support from the Department of Pediatrics Chair's Initiative, a multidisciplinary, hospital-wide Fertility Preservation Service was created at the Children's Hospital of Philadelphia. A centralized team provides fertility consults across the institution, allowing for risk-based counseling and facilitation of fertility preservation options (both standard care and experimental). **Results:** Team structure, consult process, and available fertility options for prepubertal and pubertal males and females are described. Preinitiative and postinitiative referral patterns were analyzed. Postinitiative referrals from divisions outside oncology more than doubled (34% vs. 15% at baseline). **Conclusions:** A comprehensive model for fertility counseling provides accessible, high-value fertility preservation care to pediatric and young adult patients with a wide variety of diagnoses. A centralized point of contact ensures timely referrals and risk-based counseling and streamlines access to fertility preservation procedures.

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#### IMPLICATIONS AND CONTRIBUTION

Children and adolescents with a variety of medical conditions may be at risk for impaired fertility. Fertility preservation is an important quality of life issue. A hospital-wide Fertility Preservation Service provides a centralized resource for fertility counseling and helps improve timely access to fertility preservation procedures as appropriate.

Gonadal damage is a common consequence of treatment for pediatric malignancies, often caused by exposure to alkylating agents as well as radiation therapy [1,2]. As cure rates for

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pediatric cancer have continued to improve, more children are surviving well into their reproductive years [3]. Fertility has been identified as an important quality of life concern for these patients [4]. Over the past two decades, there has been a concerted effort within oncology to highlight the importance of integrating discussions about fertility into the provider-patient dialogue and to provide options for fertility preservation procedures before gonadotoxic therapy [5]. Special considerations for fertility

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preservation in pediatric patient populations have also emerged, including the need for access to research-based options for fertility preservation in prepubertal males and females [6]. The concept of oncofertility has been established in the medical community, joining oncology with reproductive science to ensure that cancer patients are counseled appropriately and are offered the opportunity to maximize their reproductive potential. A key tenet of the oncofertility movement is that success requires collaboration across specialties including clinicians from a variety of medical disciplines, research scientists, nursing, psychology, laboratory experts, and ethicists [7]. Guidelines are established by both the Association for Reproductive Medicine and the American Society of Clinical Oncology which state that oncology providers must address the impact of therapy on reproductive health and offer access to specialist expertise and fertility preservation procedures as appropriate [8].

Pediatric malignancies are not the only diseases treated with gonadotoxic agents. Diseases such as systemic lupus erythematosus, severe lupus nephritis, rheumatoid arthritis, Wegener's granulomatosis syndrome, refractory nephrotic syndrome and central nervous system vasculitis also may use Cyclophosphamide in disease management. While dosing schedules vary based on the disease, some patients may receive cumulative doses which in males are unequivocally enough to cause permanent sterility or in females enough to place one at significant risk for premature ovarian failure. In addition, the pathophysiology of the disease itself can produce autoimmune and other physiologic processes that negatively impact gonadal organ function and reproductive outcomes for these patients [9–11]. Studies have shown that fertility counseling and subsequent referral for fertility preservation among practitioners that treat these conditions are highly variable, with providers identifying barriers including the lack of adequate training, a discordant view of gonadotoxic dose limits versus actual cumulative dose exposures, and poor access to a referral network for fertility preservation procedures [12].

It is also important to consider the fertility preservation needs of transgender youth and children with disorders of sexual development (DSD) [13]. Transgender medicine is an expanding field, and these adolescent and young adult patients are faced with fertility preservation challenges as they pursue hormone therapy for transition. Recent data suggest that utilization of fertility preservation procedures in transgender youth is low, and further research is needed to understand decision-making influences in this population [14]. Increasing attention is now being paid to both the counseling needs of this population and the nuances of fertility preservation methods as it relates to the transition process [15]. Children with DSD, where chromosomal, gonadal, or phenotypic sex is atypical, also have unique needs with regard to fertility preservation. Conditions such as Turner syndrome, Klinefelter syndrome, androgen insufficiency syndromes (as well as other XY DSD), congenital adrenal hyperplasia, and mixed gonadal dysgenesis are associated with early gonadal failure, and in some cases, the risk of the development of gonadal malignancy. Management of fertility in these patients requires early intervention and specialized clinical expertise [16.17].

Models for oncology fertility preservation programs have emerged in both adult and pediatric settings and demonstrate that a multidisciplinary team approach can have a positive impact on referral patterns, appropriate risk counseling, and access to fertility preservation options [18–20]. There is an increasing awareness that models need to expand their breadth to include other nonmalignant conditions where reproductive health and fertility are impacted by the disease or treatment modalities. Our experience at the Children's Hospital of Philadelphia (CHOP) with developing a hospital-wide, multidisciplinary Fertility Preservation Service is described.

#### Methods

In 2004, The Department of Pediatrics at CHOP began a program called the Chair's Initiatives. The goal of this program was to establish new models of care in pediatrics and tackle some of the most daunting challenges in pediatric health care [21]. As part of the Cancer Survivorship Program at CHOP, there was an established team for fertility preservation, with the goal of identifying and counseling patients at risk for infertility in oncology and facilitating fertility preservation procedures as appropriate. In 2015, as part of cycle 5 of the Chair's initiatives, applications were requested for projects that emphasized quality, patient safety, value, and innovation. Our team was granted 2 years of funding to expand beyond oncology and develop a hospital-wide, comprehensive Fertility Preservation Service. The ultimate goal was that all patients across the institution in need of fertility preservation would be counseled appropriately and would have the opportunity to pursue whatever option they felt appropriate without interfering with the treatment of their primary medical condition (Figure 1). This service provides comprehensive fertility-related care to children, adolescents, and young adults ranging in age from infancy to 21 years. Within that cohort, there are a significant number of patients that fall within the adolescent age range (10–19 years), both prepubertal and postpubertal. This guality improvement initiative did not require Institutional Review Board review or approval as it did not involve a fixed protocol or randomization of patients into intervention groups and was a project that implemented existing knowledge to improve care.

#### Identifying champions in disciplines across the institution

As part of our foundational work for the Chair's initiative, we met with key team members in rheumatology, nephrology, neurology, urology, immunology, gender non-conforming clinic, and hematology to learn about the specific gonadotoxic risks of each patient population and to provide information about fertility preservation and the services of the Fertility Preservation Program. Providers were given information on how to request a consult, and we then established our group as a central resource in the hospital for fertility-related questions and referrals. Identified divisional champions helped to disseminate information about the Fertility Preservation Service to other providers in their division as well as to residents and fellows involved in the care of their at-risk patient populations. Ongoing communication with divisional champions was critical to the success of this initiative, allowing for early identification of potential patients in need of consultation as well as addressing any issues with the referral process or communication with the fertility team. Maintaining a dialogue with these individuals also provided important feedback to the fertility team about the most up-to-date treatment strategies for the diseases managed in their departments so that risk-based counseling was concordant with current practice.

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