



Stewardship Update for I'm Not Done Yet Foundation

**Respectfully submitted to
The Menges Family and
I'm Not Done Yet Foundation**

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OVERVIEW

The mission of the Duke Teen and Young Adult Oncology (TYAO) Program is to provide teen and young adult patients and their families with specialized care, psychosocial support, and community during a cancer diagnosis, treatment, and survivorship. We bridge care between Duke Children's Hospital, Duke University Hospital and the Duke Cancer Institute for patients ages 15 to 29.

Because Duke serves both pediatric and adult cancer patients, we are well positioned to provide care to individuals throughout treatment and survivorship. In particular, our TYAO team is trained to identify, treat and support the needs of oncology patients who are in this transitional period between childhood and adulthood.

Thanks to your generosity, we are pleased to share the following updates from your initial investment of \$75,000.

YOUR IMPACT

Duke Onco-fertility Services (\$20,000)

The Duke Cancer Institute and Duke Fertility Services are currently partnering to counsel teen and young adult oncology patients about the potential impacts of cancer treatment on their fertility. Our teams have worked together to formalize an expedited referral process that allows a patient to be seen within 48 hours of being referred to Duke Fertility Services, oftentimes very soon after receiving a cancer diagnosis. Currently, patients who need these services are underserved.

TYAO leadership has created an onco-fertility steering committee with over 40 providers from adult and pediatric oncology. This is the first committee of its kind. Within this steering committee, five work groups have formed with the commitment to improve: 1) overall clinical care and service pathways, 2) patient and provider education, 3) financial services, 4) research, and 5) ovarian cryopreservation. The main goal of the steering committee is to improve referrals and access to fertility preservation services for any oncology patient whose treatment could impact future fertility. By simply creating this committee, there has been an increase in referrals to fertility preservation services from oncology providers. We hope to ensure this increase continues by implementing better standards of care via the TYAO patient navigator and the TYAO program manager who will lead these efforts once hired.

To ensure maximum benefit to patients in need, our financial services committee will provide assistance up to 50% of the total cost. Efforts will continue toward reducing this cost further to minimize financial burden as much as possible. An onco-fertility patient assistance fund is available which includes I'm Not Done Yet's 2018 contribution. Duke will help connect patients to external resources to help cover the remaining balance.

Over the past 10 months, as the onco-fertility steering committee has developed an evaluation process to assess patients' financial needs, we have learned that peer institutions lack a formal system. As we have refined our process, Duke's goal has been to create a framework that can be replicated at other centers across the country.

Type of Fertility Service	Cost of 50% assistance
<i>Egg preservation</i>	<i>\$3,500</i>
<i>Sperm preservation</i>	<i>\$500</i>
<i>Embryo preservation</i>	<i>\$4,500</i>

Bobby's Coaches: Peer Support for Teen and Young Adult Oncology (\$50,000)

Bobby's Coaches will promote independence while building communication and cooperation between parents and their children. Through the use of secure communications, we will support teens and young adults across North Carolina regardless of their physical location. Bobby's Coaches will offer a connection to the Duke medical team, even for individuals who are college-bound or entering the work force. In addition, this program will provide a meaningful opportunity for teen and young adult cancer survivors to give back and help others.

Since January 2019, the focus of the Bobby's Coaches program has been to recruit and train coaches and to develop and implement the coaching curriculum for TYAO patients. A parent and youth coach have been hired and have been fully trained, including usage of a secure communications platform. This team of a parent and youth coach have developed an outreach strategy to recruit more participants.

The Bobby's Coaches team has also received NIH funding for Peer i-Coaching for Activated Self-Management Optimization (PiCASO), a study to conduct a 5 year evaluation of a similar type of coaching for adolescents and young adults with multiple chronic conditions. Leveraging the PiCASO grant, the team is pursuing additional NIH funding to study the youth/parent coaching model, which is the basis of the Bobby's Coaching intervention. We anticipate enrolling additional Bobby's Coaches participants in the coming months.

Duke Children's Prom (\$5,000)

The Duke Children's Prom is an annual event held in the spring that engages Duke students who help host this event for adolescent and young adult patients. This celebration of adolescents and young adults with chronic conditions could become a platform to highlight teens and young adults with cancer as well.

The third annual Duke Children's Prom presented by ATLAS (Adolescents Transitioning to Leadership and Success) was held on April 6, 2019. The event was filled to capacity in the lobby of the Children's Health Center. Over 150 adolescents and young adults, their parents and caregivers attended. Several young adults who were patients in the hospital participated in the evening's events. As a result of the success of this event, additional

foundation support has been secured for the 2020 Prom, which will be held at Duke Cancer Institute to allow for a larger event.