



AN INVITATION TO SUPPORT
**TEEN AND YOUNG ADULT
ONCOLOGY & BOBBY'S COACHES**
AT DUKE UNIVERSITY

RESPECTULLY SUBMITTED TO
I'm Not Done Yet Foundation

APRIL 1, 2021



DukeHealth

BOBBY'S LEGACY

It all started with Bobby Menges, a force of a being who truly lived his life to the fullest. Bobby was constantly fundraising, volunteering, or speaking at events to raise money all while battling cancer. As a Duke undergraduate, Bobby was a member of Pi Kappa Alpha fraternity as well as the Duke Teen and Young Adult Oncology Patient Advisory Council. He was an active participant in the ATLAS Leadership group mentoring program and served as a mentor to teens with chronic health conditions who faced similar life challenges. Because of his personal journey navigating a lifetime of cancer treatments, Bobby voiced the need for specialized young adult care. He identified a gap between pediatric and adult patient experiences that left teens and young adults without the support and services they needed during their unique life stage.

Bobby's vision became his legacy. Today, Pi Kappa Alpha holds an annual event each year to raise money and awareness for cancer research. Bobby's family started the I'm Not Done Yet Foundation (INDY), which focuses on teen and young adult patients with cancer and other serious, chronic, and long-term illnesses as they transition from pediatrics to adults. Pi Kappa Alpha, INDY, and many donors have banded together to turn Bobby's dreams into reality for teens and young adults across the country.

Thanks to your generosity, we are pleased to share the following updates from your 2020 investment of \$150,000.

2020 GIFT IMPACT

Duke Onco-Fertility Services (\$75,000)

In 2020, the I'm Not Done Yet (INDY) foundation's funding supports the Duke Cancer Institute's (DCI) Onco-Fertility patient assistance fund, which aides in raising awareness of the financial barriers that exist for cancer patients within the DCI.

From this initiative, the Onco-Fertility Steering Committee which consists of 40+ medical providers, psychosocial providers, administrators, and hospital leadership from both adult and pediatric oncology was established. The main goals of the steering committee are to provide patient and provide education around fertility services for cancer patients, improve access to fertility preservation services, and expedite processing for any oncology patient whose treatment could impact their future fertility. Our team's mission is to provide patients with education and accessibility to allow them to make the most informed decision about their fertility and their future.

As a result of these efforts, patients at Duke who are seeking fertility preservation services due to a cancer diagnosis are no longer up against the financial hurdles that once existed. We would not have made it to this point without the support of the I'm Not Done Yet (INDY) foundation.

To ensure maximum benefit to patients in need, our financial services committee are working to increase the amount of assistance possible for each patient up to 75% of the total cost. Efforts will continue toward reducing this cost further to minimize financial burden as much as possible.

As we continue to refine 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 75% assistance
Egg preservation	\$5,250
Sperm preservation	\$750
Embryo preservation	\$6,759

Through the creation of this financial pathway, we have been able to see positive results that go beyond removing barriers to the financial constraints. This process initiates conversations and education about onco-fertility services. It also links teen and young adult oncology patients to general support services, educational needs, and a peer network.

Bobby's Coaches: Peer Support for Teens and Young Adults (\$75,000)

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

Within the past year, there has been exciting progress for Bobby's Coaches program, which includes young adults who have experience with cancer, diabetes, inflammatory bowel disease, among other conditions. 20 youth coaches/mentors facilitated over 200 encounters with 70 youth mentees. 10 of the peer coaches are former participants. One research study demonstrated that within a three-month period, coaches and participants completed an average of 13 telephone calls, participants sent 25 text messages, and coaches sent 39 text messages.

Coaches are hired as Duke employees and receive peer coach training, both through in person sessions and practice calls. We pivoted during the pandemic to deliver these trainings via Zoom over 9 weeks and includes both remote learning and live, virtual skills training and moderated practice sessions. Each coach is provided with ongoing training and robust, regular supervision and support through individual and group formats.

We are seeing the immense value of these peer-to-peer interactions. One coach noted the importance of the shared experience of living with a chronic condition to build trust and engagement: "At first she seemed really nervous to talk to me. It felt awkward. Over time, as a coach I was able to share more about myself to show that we are the same in many ways. Over time, relationship has grown. She was really shy and now she's open, engaged, and shares a lot."

The Bobby's Coaches team continues to pursue expansion to reach more youth and parents by leveraging grant and philanthropic funding. Our ultimate goal is to disseminate coach training as a model for other institutions so that this intervention can be available to teens, young adults and their families across the country.

OUR 2021 REQUEST

In order to execute our shared vision, we are seeking philanthropic support to sustain and grow the Teen & Young Adult and Bobby's Coaches programs. Your renewed commitment will support the below areas:

Teen & Young Adult Oncology (\$75,000)

In an effort to maintain and improve accessibility and visibility of the Onco-Fertility Program, we look to continue our partnership with INDY by investing in the consistency of patient navigation, patient assistance funding, and clinical services. These services are necessary to ensure education about, and referrals for, fertility preservation. Our hope is to empower every young patient whose fertility may be impacted by their cancer treatment to make an educated and timely decision about their fertility and future. The decision-making process is expedited and emotional, but without these clinical services, these patients would be without the needed awareness and support to best understand the impact of their cancer treatment on their future fertility. The workflow examples (see Appendix A) articulate the necessity of patient navigation in the success of onco-fertility services and the use of patient assistance funding for onco-fertility services. The first workflow illustrates the pathway that is generated when a medical provider initiates the referral to onco-fertility services. The second workflow illustrates the pathway for when a referral is initiated by the onco-fertility patient navigator. Both workflows have been developed by the team to meet our goals of informed decision making, and timely, coordinated care.

Bobby's Coaches: Peer Support for Teens and Young Adults (\$75,000)

We have built a strong foundation for *Bobby's Coaches* that we will continue to expand and disseminate in years to come. In fiscal year 2021, funds for *Bobby's Coaches* will support coach recruitment and training, provider supervision, peer and parent coach compensation, the secure technology platform, and patient recruitment. Our reach will continue to include teen and young adult patients navigating cancer and other chronic illnesses and their parents.

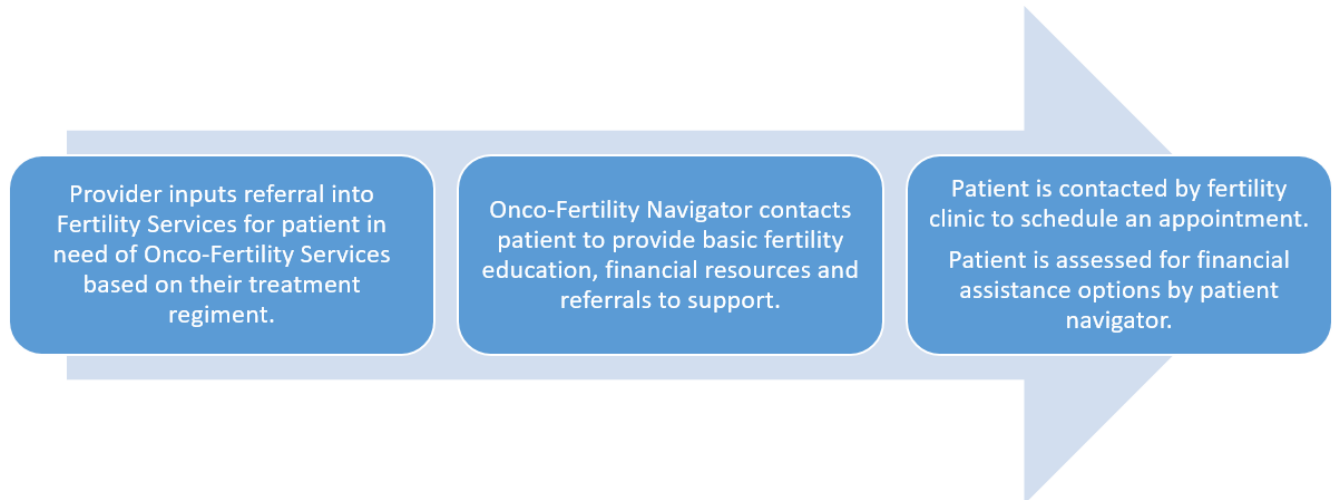
We respectfully request that you consider a gift of \$150,000 to be split evenly between the Teen & Young Adult Oncology Program and the Bobby's Coaches Program.

WITH GRATITUDE FOR
YOUR SUPPORT

Thank you for allowing us to present you with this impact report and 2021 proposal. We are grateful for your ongoing partnership and past support of Teen & Young Adult Oncology and the Bobby's Coaches programs at Duke. We feel these programs carry on in Bobby's spirit as a lasting legacy toward shaping the future of care for teens and young adults. We deeply appreciate your interest and invite you to join with us in advancing health together.

APPENDIX A

Onco-Fertility Workflow - 1



Onco-Fertility Workflow - 2

