



**TEEN AND YOUNG ADULT
ONCOLOGY & BOBBY'S COACHES**
PROGRESS REPORT

PRESENTED TO
I'm Not Done Yet Foundation
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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.

2021 PARTNERSHIP

2021 marked the fourth year of the tremendous partnership between I'm Not Done Yet Foundation and Duke's Teen and Young Adult Oncology and Bobby's Coaches programs. We are so grateful for the past and ongoing support. I'm Not Done Yet Foundation has been with us from the beginning as we have built up these programs in a way to become an industry leader and significant example to other health care institutions for how to bring increased support to adolescent and young adults dealing with cancer and other chronic illnesses. The philanthropic support and ongoing awareness I'm Not Done Yet has provided has been instrumental to our success.

One significant development in 2021 was Peter and Liz Menges joining the Duke Cancer Institute's (DCI) Development Board of Advisors. The Board of Advisors is a collection of around 40 friends and families nationally that support the DCI mission to harness breakthrough discoveries that drive global advances in treatments and cures. Board members serve three year terms and support the DCI as knowledgeable advocates, passionate ambassadors and generous donors.

In March of 2021 an article was written by Duke Health Communications staffer, Angela Spivey, titled "[A Blue Angel](#)". The article tells the story of Bobby Menges and how his experience and love for Duke brought increased exposure and support to the often underfunded area of adolescent and young adult patients dealing with cancer. The story was highlighted in a variety of Duke communication news sources including [Duke Today](#), a daily email that goes out weekdays to nearly 50,000 Duke faculty, staff, students and numerous alumni, parents, and Durham neighbors and friends. It was also highlighted in The Catalyst, an e-newsletter of DCI supporters and donors that went out to 4,700 individuals as well as the DCI E-News that is shared with around 2,900 DCI faculty and staff.

An additional article was recently written in January 2022 titled [“Unique Coaching Model Allows Patients to be Themselves”](#) and is currently being shared via Duke Health communication channels. The article highlights the impact Bobby’s Coaches has had on two participants.

2021

GIFT IMPACT

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

Duke Teen & Young Adult Oncology Program (TYAO) and Onco-Fertility Program have seen a year of growth. With the support of the I’m Not Done Yet Foundation, the Supportive Care & Survivorship Center has dedicated time and resources to advancing these areas; keeping them a priority in the strategic plan.

Duke Teen & Young Adult Oncology Program New patient navigator

We have had an exciting year that included the hiring of a new patient navigator, Jackie Balliot, who was previously an oncology nurse at UNC Hospital. As a dedicated patient navigator, Jackie is the first point of contact for both the TYAO and Onco-Fertility Programs.



Since Jackie joined our team in late August, she has worked with 64 patients, for a total of 122 encounters, before the close of 2021. Through providing education and support during these encounters, she identifies additional needs, facilitates referrals, and connections to other vital services provided by our Supportive Care & Survivorship Center team. Jackie made 26 referrals in 2021.

Dedicated TYAO medical family therapist

In 2021, we also dedicated one of our medical family therapists, Geoff Vaughn, to TYAO on a full time basis. Geoff had previously focused on TYAO patients, but still provided services to patients outside of the 15 to 29 age range. Given the demand, and Geoff’s expertise in care of TYAO patients and their families, Geoff now solely serves the TYAO population.

Education initiative for TYAO patients and caregivers

Through working with patients and their families, we have heard a common theme: the need for education materials that address common topics and issues involving living with cancer as a teen or young adult. Age-appropriate education materials, especially around emotional support, are just not available otherwise. This initiative will be the first of its kind nationally, and can be disseminated broadly. We have established a committee to create materials that address the following topics:

- What is cancer
- How to talk to your friends about cancer
- How to be a friend to someone who has cancer
- How to set boundaries around when to talk about cancer
- How to be a sibling to someone with cancer
- How to be a parent or guardian to someone with cancer

- How can cancer impact your thinking
- How can cancer impact you emotionally
- How can cancer impact your spirituality
- Am I going to die from cancer
- Where do I find good information about cancer

Program development presentation

On December 1 at the 4th Global Adolescent and Young Adult Cancer Congress, Caroline Dorfman, PhD, presented on *using the national comprehensive cancer network clinical practice guidelines to develop a standardized clinical program for teen and young adult oncology patients*. Through this session, Caroline was able to teach other hospitals how to create a successful TYAO program on an international platform.

Research

In 2021 Caroline Dorfman, PhD, received a \$25,000 grant to research cardiovascular disease risk factors in survivors of adolescent and young adult cancer with obesity. She will be piloting a behavioral weight and symptom management intervention with these individuals.

We are also continuing our efforts with the TYAO database study and psychosocial assessment. With this data, we are analyzing treatment outcomes, working toward improved clinical trial enrollment, providing appropriate resources for patients as they bridge into survivorship, and performing longitudinal assessment of psychosocial metrics. Currently, we have 52 patients enrolled.

Onco-Fertility Program

Improved referral process

Our team has developed a workflow that notifies us when a provider refers an oncology patient to the fertility center. We also created a 'hard stop' within that referral that requires providers to include the patient's specific cancer treatment plan information to better prioritize urgent versus routine referrals for fertility preservation (to ensure we have rapid access for those needing to make decisions prior to starting cancer treatment).

INDY patient assistance fund

In our work with patients considering fertility preservation, we have seen continued barriers, particularly for those with lower household incomes, to their ability to pay the up-front, out-of-pocket cost of fertility preservation (particularly for egg or embryo cryopreservation). The INDY patient assistance funds have been critical to enabling these patients to preserve with up to 75% of the costs. We are excited to share that our team has worked diligently to enhance our program, and we are now able to offer up to 100% financial assistance for eligible patients.

To date, **\$23,792.50** of INDY funding has been used to support seven patients (3 males and 4 females) all within the lowest household income bracket, who would not have been able to even consider preservation without financial assistance.

New Onco-Fertility virtual support group

In an effort to address the identified need for connecting women with cancer who have experienced impaired fertility, we have created a professionally facilitated support group on the 1st Thursday of the month, from 5:30 - 6:30pm. This group launched in August and continues to grow.

Publication

In October, our team was published in the Journal of Oncology Navigation & Survivorship. The article highlighted the critical role of onco-fertility patient navigation in addressing barriers to fertility preservation within an academic onco-fertility program.

Dorfman, C.S., Stalls, J.M., Mills, C., Voelkel, S., Thompson, M., Acharya, K.S., Baker, K.C., Wagner, L.M., Miller, N., Boswell, A. and Corbett, C., 2021. Addressing Barriers to Fertility Preservation for Cancer Patients: The Role of Oncofertility Patient Navigation. Journal of oncology navigation & survivorship, 12(10), p.332.

Program Development Abstract

On December 1 and 2 at the 4th Global Adolescent and Young Adult Cancer Congress, our Onco-Fertility team consisting of Juliann Stalls, Mallori Thompson, Coleman Mills, Rebecca Shelby, Kelly Acharya, Dave Van Mater, Cheyenne Corbett, and Caroline Dorfman presented their program development abstract. The abstract characterized fertility preservation rates and related concerns among a sample of teen and young adult cancer patients at Duke Cancer Institute.

Direct Impact

In our continuing evaluation of the impact our TYAO and Onco-Fertility programs have on direct patient care, our team recently conducted a preliminary data analysis from our TYAO online survey research project for AYAs aged 15-29 who had received cancer treatment within the last two years. The data showed that 83 % (n=40) had been told that their cancer treatment may affect their fertility and had received information about fertility preservation options.

In response, the Director of the Duke Fertility Preservation Program at the Duke Fertility Center, Kelly Acharya, MD, shared, "Congratulations for the great work you guys are doing. One of our resident physicians did a secondary analysis of some cancer survivor data from the past 10 years (n=100, and majority were from >2 years ago), and only about 20% recalled being offered fertility preservation counseling. So this 80% value from the past two years is GREAT!"

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

"I've made leaps and bounds since joining Bobby's Coaches in June 2020. My peer coach understands what I am going through when no one else does. My feelings and reactions feel validated. I feel like I can be myself."

- Young adult Brain Tumor Survivor

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, the number of young adult cancer patients receiving coaching as part of the clinical Bobby's Coaches program has increased with three coaches specifically focused on

young adult cancer patients. Participants have worked with coaches on a variety of areas, including finances, communicating with providers, professional goals, nutrition, exercise, and identity post-treatment. In addition, as part of the ongoing affiliated research programs 109 young adults with a range of chronic conditions have received peer coaching from 25 peer coaches.

Coaches are hired as Duke employees and receive peer coach training, both through in person sessions and practice calls. Training during the COVID-19 pandemic has been delivered via Zoom over nine 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, the 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.

WITH GRATITUDE FOR YOUR SUPPORT

We are grateful for your ongoing partnership and past support of Teen & Young Adult Oncology and the Bobby’s Coaches programs. These programs are making a strong impact in the Duke community and beyond, as the models we have developed can be replicated in other academic institutions. We feel Bobby’s legacy casts a shining light on shaping the future of care for teens and young adults.

FOR MORE INFORMATION

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