



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

PRESENTED TO  
**I'm Not Done Yet Foundation**  
JANUARY 11, 2023

## **BOBBY'S LEGACY**

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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.

## **2022 PARTNERSHIP**

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2022 marked the fifth year of partnership between the I'm Not Done Yet Foundation (INDY) and Duke's Teen and Young Adult Oncology (TYAO) and Bobby's Coaches programs. These programs would not be where they are today without the financial support, entrepreneurial vision, and advocacy that INDY and specifically Liz and Peter Menges provide. INDY has been with Duke every step of the way – helping us reach more patients through clinical and psychosocial support, peer to peer coaching with Bobby's Coaches, and providing many with the financial assistance and personal guidance toward fertility preservation. The support INDY provides has allowed us to expand and elevate these services and become nationally renowned for providing the highest quality medical and psychosocial care and for initiating innovative research.

In 2021-2022 Peter and Liz Menges joined the Duke Cancer Institute (DCI) Board of Advisors. Comprised of roughly 40 friends and families nationally, the Board of Advisor share in the DCI mission to discover, develop, and deliver the future of cancer care... now. Liz and Peter completed their first year of a three-year term participating and sharing with the group. The goal of the board is to become more knowledgeable advocates, passionate ambassadors, and generous donors.

In October 2022, a number of faculty, staff, and fellow board members joined the I'm Not Done Yet Foundation as they were highlighted by ringing in the Nasdaq opening bell in New York City. Additionally, that same month the DCI recognized Liz and Peter and the I'm Not Done Yet Foundation as the recipients of the 2022 Shingleton Award for Distinguished Service at the Shingleton Society Award Dinner. The award ceremony included a wonderful video that will continue to provide inspiration for other supporters to join the cause for years to come.

The Duke Cancer Institute greatly appreciates the ongoing partnership with the I'm Not Done Yet Foundation. We look forward to a continued partnership striving to reach more adolescent and young adult patients to meet their needs during the challenging times of diagnosis, treatment, and survivorship.

2022

## GIFT IMPACT

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### Teen and Young Adult Oncology (\$100,000)

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 DCI Supportive Care & Survivorship Center has dedicated time and resources to advance these areas; keeping them a priority in the strategic plan.

#### Duke Teen & Young Adult Oncology Program Update on Navigator position

Jackie Balliot joined our team in August of 2021 as a patient navigator. Your support helped us to pilot this position. Due to the positive impact of this role, Jackie is now fully funded through the hospital budget. Additionally, this year her position was reclassified from a patient navigator to the elevated role of a nurse navigator with expanded scope that leverages her clinical expertise to best support patients.

Below is a breakdown of the patients Jackie has served since starting in her role.

Fiscal Year	TYAO Unique Patients	Onco-Fertility Unique Patients	Total Patients
FY22	130	116	246
*FY23	69	74	143
<b>Grand Total</b>	199	190	<b>389</b>

\*FY23 includes patients seen up until 12/14/22. Duke fiscal year runs from July 1-June 30.

#### Quote regarding the benefits of navigation:

*"The nurse navigator helped me secure something from [Foundation] for paying for the injections...she went above and beyond but I remember it was the [Foundation] and other grants that funded things to help pay for some of that med so I could get started with the with the process. And their navigator over there was also another angel in my life and she walked you through everything. She really cared about each person and each thing."*

### 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. Geoff will also begin a monthly Art Therapy Support Group, slated to start February of 2023 at the Nasher Art Museum in Durham, NC.

Based on the chart below, it is clear that the demand for a full-time TYAO therapist is needed. Geoff is on track to double his patient volume in FY23.

Fiscal Year	Unique Patients	Total Encounters
FY21	45	321
FY22	58	371
*FY23	44	246
Grand Total	107	938

\*FY23 includes patients seen up until 12/14/22. Duke fiscal year runs from July 1-June 30.

#### Quotes regarding the benefits of having a medical family therapist

*"It's taken a long time, but looking back, I can't imagine going through treatment and beyond without this support. And I'm not done. I'm glad this can continue as long as I need it."*

*"Our talks make this way less scary."*

*"Thanks for seeing us all. My mom, my partner, my bestie, me. You've pulled us through."*

### Dedicated Clinical Psychologist

Caroline Dorfman, PhD is a licensed clinical psychologist. She has both a clinical and research interest in improving the wellbeing of TYAO patients. In addition to conducting brief cognitive screens for cancer reporting cancer treatment-related changes in memory, concentration, attention, and/or processing speed, Dr. Dorfman provides clinical supervision to clinical psychology trainees involved in the Teen and Young Adult Oncology Program. For example, she has supervised Dr. Juliann Stalls, a clinical psychology post-doctoral fellow in the development and delivery of the monthly Fertility Support Group for female cancer survivors. She also supervises clinical psychology graduate students and pre-doctoral interns in their delivery of evidence-based treatments to teen and young adult patients targeting concerns such as anxiety, depression, symptom management (e.g., pain, fatigue, anticipatory nausea, cognitive problems), and health behavior changes (e.g., weight management).

Dr. Dorfman also leads our team's research initiatives, having received internal funding from Duke, as well as external funding from the National Cancer Institute to better understand the experiences of teens and young adults with a cancer history and to develop and evaluate

behavioral interventions targeting the unique needs of this population. Dr. Dorfman serves on the Alliance for Clinical Trials in Oncology AYA working group and the North Carolina AYA Symposium planning committee to both expand her expertise in TYAO and to contribute to work being conducted at both the local and national level.

### **Research in Progress:**

In 2021, Caroline Dorfman, PhD, received a \$25,000 grant to understand the impact that cost plays on fertility preservation decision making among female cancer survivors. This project was completed in December 2022. Publications to follow.

In 2022, 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.

In September 2022, Dr. Dorfman received a two year grant from the National Cancer Institute (R21; total direct and indirect funds allocated to the project over two years: \$413,971) to develop and pilot test a behavioral intervention to improve the management of symptoms (i.e., pain, fatigue, emotional distress) among TYA patients with advanced cancer. Members of the Duke TYAO team will collaborate on this project including Drs. Corbett, Wagner, and Maslow.

In September 2022, Juliann Stalls, PhD received a mentored postdoctoral fellowship from the National Cancer Institute (F32) to design and refine a behavioral intervention to address unmet fertility-related information needs and fertility-related distress among female adult survivors of childhood cancer (aged 18-44). Over the course of this three year award, Dr. Stalls will receive direct mentorship from members of the Duke TYAO and Onco-Fertility program teams, including Dr. Dorfman and Dr. Kelly Acharya.

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 78 patients enrolled.

### **Research Publications and Presentations:**

#### Peer-Reviewed Publications

Dorfman, C.S., Stalls, J., Lachman, S., Shelby, R.A., Somers, T.J., Oeffinger, K.C. (2022). Symptom Communication Preferences and Communication Barriers for Young Adult Cancer Survivors and their Health Care Providers. *Journal of Adolescent and Young Adult Oncology*. doi: 10.1089/jayao.2021.0172. PMID: 35049386

Dorfman, C.S., Shelby, R.A., Stalls, J., Somers, T.J., Keefe, F.J., Weinfurt, K., Oeffinger, K.C. (2022). Improving Symptom Management for Survivors of Young Adult Cancer: Development of a Novel Intervention. *Journal of Adolescent and Young Adult Oncology*. doi: 10.1089/jayao.2022.0100. PMID: 36178972

#### Non-Peer-Reviewed Publications:

Dorfman, C.S., Balliot, J., Stalls, J.M., Corbett, C. (2022). A Family in the Future: Fertility Preservation for Young Adults Diagnosed with Breast Cancer. *Conquer: The Patient Voice*.

Poster Presentations:

Dorfman, C.S., Stalls, J.M., Shelby, R.A., Acharya, K.S., Davidson, B.A., Corbett, C.M. (May 2022). Fertility Preservation Discussions with Post-Pubertal Female Patients: Oncology Providers' Practice Behaviors and Barriers. Poster presented at the Annual Meeting of the Oncofertility Consortium, Pittsburgh, PA.

Arthur, S.S., Stalls, J.M., Shelby, R.A., Corbett, C.M., Acharya, K., Davidson, B., Dorfman, C.S. (November 2022). Factors associated with sexual function in female cancer survivors eligible for fertility preservation. Poster presented at the 8<sup>th</sup> Annual Meeting of the Scientific Network for Female Sexual Health and Cancer, New Haven, CT.

Research Presentations:

Dorfman, C.S., Stalls, J.M.\*, Shelby, R.A., Acharya, K.S., Davidson, B.A., Corbett, C.M. (May 2022). Fertility Preservation Discussions with Post-Pubertal Female Patients: Oncology Providers' Practice Behaviors and Barriers. Poster presented at the Annual Meeting of the Oncofertility Consortium, Pittsburgh, PA.

Stalls, J. M. \*, Dorfman, C.S., Arthur, S.S. \*, Shelby, R. A., Hartford-Todd, J., Somers, T. J., Corbett, C. (August 2022). Use of Psychosocial Support Services among Patients with Young Children at a Comprehensive Cancer Center. Poster presented at the International Psycho-oncology Society World Congress of Psycho-Oncology and Psychosocial Academy, Toronto, Canada.

Arthur, S.S. \*, Dorfman, C.S., Stalls, J. M. \*, Shelby, R. A., Hartford-Todd, J., Somers, T. J., Corbett, C. (August 2022). Families Facing Cancer: Psychosocial Experience of Parents with Cancer and their Families. Poster presented at the International Psycho-oncology Society World Congress of Psycho-Oncology and Psychosocial Academy, Toronto, Canada. Arthur, S.S. \*,

Stalls, J.M. \*, Shelby, R.A., Corbett, C.M., Acharya, K., Davidson, B., Dorfman, C.S. (November 2022). Factors associated with sexual function in female cancer survivors eligible for fertility preservation. Poster presented at the 8<sup>th</sup> Annual Meeting of the Scientific Network for Female Sexual Health and Cancer, New Haven, CT.

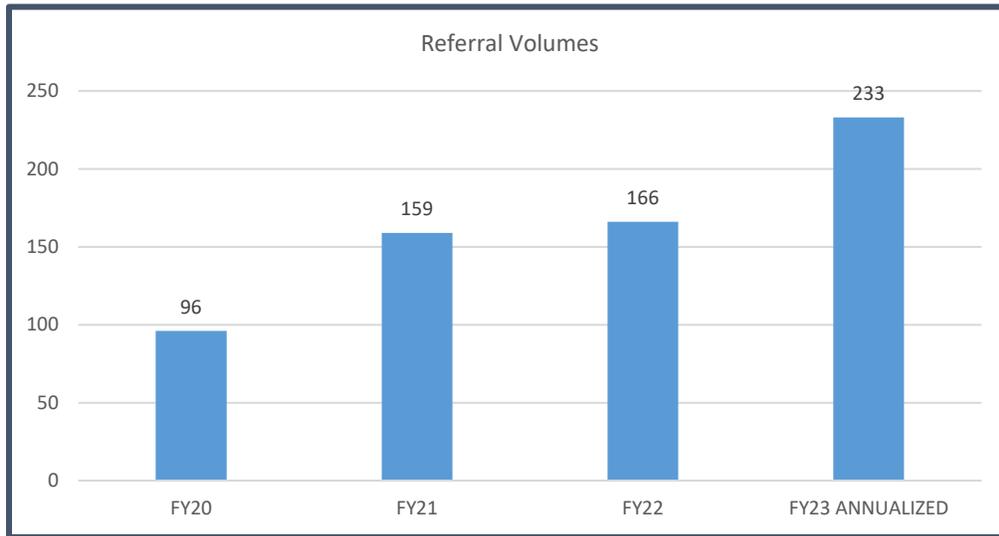
Stalls, J. \*, Dorfman, C.S., Arthur, S.S. \*, Somers, T.J., Nichols, K.R., Sarantopolis, S., Sung, A., Shelby, R.A. (2022, November). *Characterizing Sexual Interest and Satisfaction Following Hematopoietic Stem Cell Transplant (HSCT)*, 8<sup>th</sup> Conference of the Scientific Network on Female Sexual Health and Cancer, New Haven, CT.

\* designates trainees

**Onco-Fertility Program**

We have built a strong foundation for the onco-fertility program as demonstrated by our referral volumes increasing every year. Our onco-fertility steering committee remains active and continues to work toward an improved preservation experience.

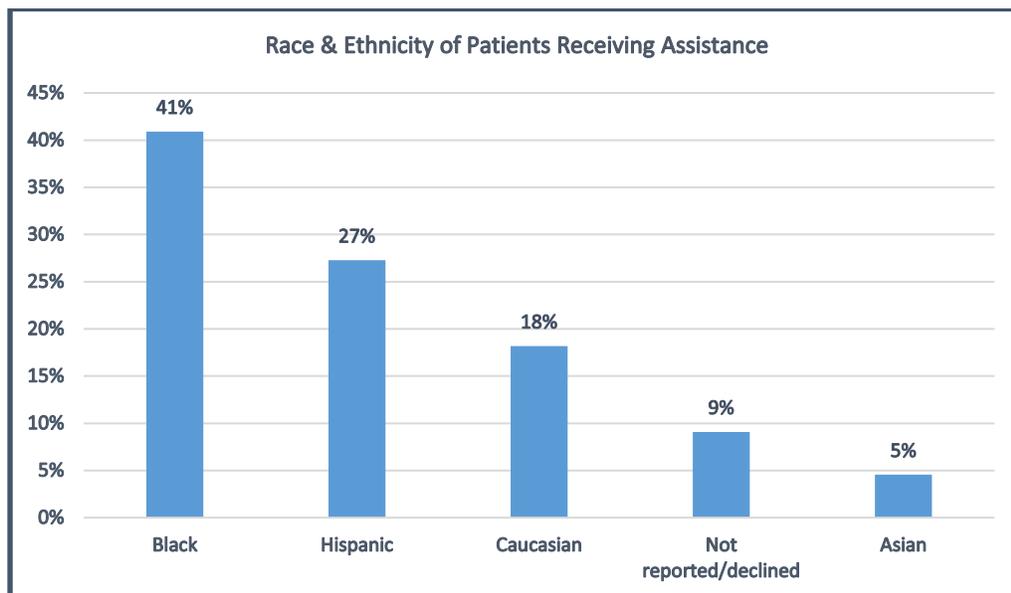
The following chart shows the yearly increase in referrals.



### INDY patient assistance fund

In our work with patients considering fertility preservation, we have seen continued barriers particularly for those with lower household incomes, in their ability to pay the up-front, out-of-pocket costs of fertility preservation (particularly for egg or embryo cryopreservation). The INDY patient assistance funds have been critical in 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, of the INDY patient assistance funding, **\$42,300.00** has been used to support 22 patients (12 males and 10 females), the majority within the lowest household income bracket, who would not have been able to even consider preservation without financial assistance. The overall average age of these patients is 25. The following chart and tables provide more data on the patient demographics and patient assistance funding used.



Gender	Patient Count	Average Amount Funded Per Patient
Female	10	\$3,914
Male	12	\$263
Grand Total	22	\$1,923

Year	Patient Count	Amount Funded
2020	3	\$3,931
2021	6	\$20,149
2022 (thru 11/1)	13	\$18,221
Total	22	\$42,300

**Quotes regarding the benefits of the financial assistance fund:**

*"I'm a college student, so I did not have the funds at all. I didn't have a job; I was just a full-time college student. I didn't have the funds to take care of it [fertility preservation] and although my parents were willing to dip into their savings, it just wasn't something that I wanted them to have to deal with. It was my problem so I didn't want them to have to dip into their savings and jeopardize their future."*

*"We had just gotten married and we had just spent a lot of money on our wedding and then we had just gotten an apartment. My husband, was just finished college and at the time of my diagnosis he was in boot camp. He was about to leave. We were young and had a lot of unexpected responsibilities at a very young age. And when you're young like that and just recently married, you don't have all those resources, like financial resources. You don't ever think about -- oh maybe I should plan for a catastrophe like this to happen."*

*"Me and my husband were both state workers living paycheck to paycheck. We didn't know how we were going to afford cancer treatments and surgery, let alone fertility treatments "*

**Onco-Fertility virtual support group**

Our Onco-Fertility Support Group is continuing to grow. The group is offered on the 1<sup>st</sup> Thursday of every month from 5:30 to 6:30 p.m. and is conducted by Juliann Stalls, PhD. This year, we have focused on recruitment which includes advertising across Duke Health and in the community. We have added guest speakers, such as Kelly Acharya, MD to talk about key topics of interest as identified by group attendees. We are truly creating a network of support for these individuals who are walking a similar path.

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

The support for the Bobby's Coaches program has been critical to the further development of the Duke Peer Coach Curriculum, the expansion of access to peer coaches for Duke patients, and to the further refinement of the peer coaching intervention to prepare for potential dissemination to other centers. With the support of the I'm Not Done Yet Foundation, the ATLAS/PiCASO team in the Department of Psychiatry and Behavioral Sciences has dedicated time and resources to growing the Bobby's Coaches program and learning from this program so that, in the future, Bobby's Coaches can expand to other institutions and also so that Bobby's Coaches could be deployed to support DCI patients with specific challenges, such as those looking for peer support as part of onco-fertility services.

### **Conducting peer support program research and disseminating findings**

Along with Dr. Sharron Docherty, Drs. Gary Maslow and McLean Pollock lead our ATLAS/PiCASO team's research initiatives, having received funding from the National Institutes of Health, the Adult Congenital Heart Association, Pfizer, and internal Duke funding. In addition, our team has presented on the peer support programs at both local and national conferences. Below is a list of publications and presentations conducted over the past year.

#### Peer-Reviewed Publications

Pollock, MD, Brotkin SM, Denio E, Dave S, Fisher EB, Docherty SL, Maslow GR. Clinical Application of a Peer Coaching Intervention to Enhance Self-Management for Adolescents and Young Adults with Inflammatory Bowel Disease. *Clinical Practice in Pediatric Psychology, Pediatric Adherence and Self-Management: Topical Reviews and Clinical Applications of Evidence-Based Assessment and Intervention*, 10, no. 4 (December 2022): 409–27. <https://doi.org/10.1037/cpp0000468>.

#### Peer-Reviewed Research Presentations

Manning AS. Navigating Healthcare and Psychosocial Transitions Through the Lifespan; Peer Coaching for Adolescents and Young Adults. Invited symposium at the North American Cystic Fibrosis Conference, Philadelphia, PA. November 2022.

Ihle EC, Ganguly M, Rajagopalan A, Ort K, Turkel S. Targeting Transitions in Care for Transitional Age Youth with Complex Medical Illness. Virtual symposium at ACLP Annual Meeting. November 2022.

Maslow GR, Docherty SL, Pollock MD, Manning AS, Brotkin SM, Craig L. Positive Youth Development and Transition. 23rd Annual Chronic Illness and Disability (Virtual) Conference: Transition from Pediatric to Adult-Based Care. October 27, 2022.

Brotkin SM, Aragon V, Beskie C, Bonner MJ, Pollock MD, Fisher EB, Maslow GR, Docherty SL. Young adult peer coaching for adolescents with chronic illness: Where is the sweet spot? Society of Behavioral Medicine Annual Meeting, Baltimore, MD, April 7, 2022.

## **Synergy with DCI and TYAO Programs**

In coordination with the TYAO program described above and the DCI onco-fertility program, we have created New Bobby's Coaches positions. The goal is to recruit and hire three new, fertility-focused coaches who have lived experience with going through the process of fertility treatment and who could serve as a peer support for young adults throughout the process including 1 male coach and 2 female coaches to be sure to cover a range of experiences. This is an expansion of the close collaboration between the TYAO program and the Bobby's Coaches program with McLean Pollock, PhD, MSW and Caroline Dorfman, PhD taking the lead in creating this synergistic position.

## **Overview of Bobby's Coaches and Peer Coaching Programs at Duke**

The ATLAS/PiCASO suite of peer support programs serves many young adult patients at Duke with chronic illness. These programs include the ATLAS young adult mentoring group, the ATLAS summer camp/program, the ATLAS young adult peer support group, the PiCASO research program, the peer coach training program, and Bobby's Coaches. Currently across these programs there are 20 peer coaches, and eight peer mentors who are young adults providing support to other adolescent and young adult patients with a range of chronic conditions.

### **Impact of peer coach training**

*"The training has changed the way I interact with and support others in daily life! Also some aspects of managing my condition have improved as a result."*

*"I feel like I really improved my listening skills and connected with the other coaches. It was a really good experience for me overall."*

Across all programs there are currently over 100 young adults receiving individualized peer coaching, as well as several dozen participating in group mentoring programs. The majority of young adults receiving coaching have participated in the NIH supported PiCASO research study, and across all of the coaching programs there have been 32 young adult cancer survivors who have received coaching.

The peer coach training curriculum has continued to be refined and 37 young adult peer coaches have been trained. The curriculum can be delivered in person or virtually and has received high satisfaction marks from participants, who have also noted that the training experience has improved their own lives and connections with others. In the fall of 2022, the team conducted a training for the first time of peer coaches from outside of Duke. The team trained several members from Next Step – a young adult program in Boston that serves many young adults with cancer. This first opportunity to train coaches outside of Duke was successful and the Next Step team will be using elements of the peer coaching model as they work with young adults in Boston.

## **Bobby's Coaches in 2022**

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.

The Bobby's Coaches program has continued to grow over 2022 with now having four peer coaches available to DCI patients. One of Bobby's Coaches actually participated in the PiCASO research study after receiving one year of coaching. Subsequently, they expressed interest in coaching other young adult cancer survivors as a way to "pay it forward" and have been able to start coaching as part of the Bobby's Coaches program. Twenty-four young adults have enrolled in the Bobby's Coaches program as participants with 12 receiving coaching, while the others have expressed interest but not yet participated.



#### **Peer coach and former participant**

*"Becoming a coach was a no-brainer for me. I was very excited to be able to take what I've learned through being a participant and pay it forward to someone else. It sounded like an amazing opportunity, and it definitely has been so far. Just giving the participant a supreme level of empathy, and just being able to walk with them through that difficult time, is really important to me."*

With the PiCASO research study ending recruitment in March of 2023, individuals who might have been coached through the PiCASO study will still have Bobby's Coaches as an opportunity. It is quite rare for a research study level of intervention to be sustained after the completion of study recruitment, and we are grateful for the support of I'm Not Done Yet to be able to continue to employ young adult peer coaches even after the study is completed. We expect the number of young adults receiving coaching from Bobby's Coaches to grow over this year. Individuals who have received peer coaching have noted the importance of connecting with someone who understands their experience. The shared experience and coaching process provide a validating and supportive space for them to explore their health, wellness and goals.

The ATLAS/PiCASO and Bobby's Coaches team had a significant loss in August of 2022. Jodie Neukirch Elliott, MSW, the lead social worker died of complications related to her heart transplant from 2020. Jodie had been instrumental in leading the peer coach program including being a major partner in developing the curriculum and leading the transition to an online format during the pandemic. Jodie's family has created a small fund at Duke to carry on her legacy through support of peer support programs. The support of INDY was seen by Jodie's family as a strength of the program and served as a beacon for them of a way to contribute to her mission and legacy.

### **Participant experiences**

*“My 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.”*

*“I learned that when I have someone encouraging me to do something and that’s really my side on it, it makes me better at it.”*

*“...it’s hard to know what I would have done (without a peer coach), but I probably wouldn’t have been as successful with those goals. I probably wouldn’t have made them in the first place.”*

*“You can talk with someone that understands in a way that most people can’t -- even doctors.”*

*“I think that it’s something that every cancer patient needs because you’re just looking at having cancer and you’re like, okay I just got through this but life goes on after having cancer, so this was really a big part of putting that into perspective.”*

### **INDY support of peer coaching**

The support of the I’m Not Done Yet Foundation has been critical to the creation of this peer coaching program for young adult cancer survivors. The investment in the team at Duke has led to the creation of a powerful curriculum that can be used to train peer coaches at Duke and beyond. There has been a strong synergy between the support from INDY and the NIH funded research such that we are able to provide this high quality intervention to patients immediately while also conducting the research study to evaluate efficacy. We strongly believe that all young adult cancer survivors would benefit from peer support and peer coaching and are committed to partnering with INDY to make this possible at Duke and beyond.

### **WITH GRATITUDE FOR YOUR SUPPORT**

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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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Bart Smith  
Director of Development, Duke Cancer Institute  
300 W. Morgan Street, Suite 1200, Durham, NC 27701  
919-385-0017 (office) 919-724-1677 (mobile)

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