

2015

Young Adult Patient
Navigation

MID YEAR REPORT

CANCER CHANGES LIVES...

... SO DO WE!

OUR MISSION

We change lives by creating a community of support for young adults, and their loved ones, impacted by cancer.

OUR VISION

We envision a world in which no young adult faces cancer alone.

UCFS VALUES

These are the values that drive and define our work with young adults and their loved ones impacted by cancer:

- Be Human
- Be Better
- Be Courageous
- Be Committed

PATIENT NAVIGATOR PROGRAM

INTRODUCTION

About Our Young Adult Patient Navigation Program:

Young adults (ages 15 – 39) with cancer are burdened with challenges unique to their developmental stage and age group. This population also possess unique capacities that, when realized, can help them effectively cope with cancer and thrive, no matter what the outcome may be. Our Young Adult Patient Navigation program aims to help young adults understand and utilize those capacities.

Working in conjunction with the medical care teams at institutions and within the community, our Young Adult Patient Navigators provide a holistic approach to patient care, addressing various needs of young adults who face a cancer diagnosis, treatment, and life with cancer. UCF Young Adult Patient Navigators provide tailored emotional and practical support to young adults, and their loved ones, to help them recalibrate their life with cancer.

Our Young Adult Patient Navigation Program is built upon the “4E” framework: **educate, empower, engage, encourage.**

- **EDUCATE** patients and their families of their disease, treatment options, and lifelong implications of treatment choices;
- **EMPOWER** young adults take an active role in their cancer experience and support them as they face the many unique challenges and realities specific to their age group;
- **ENCOURAGE** effective communication with the clinical care team, family, friends, community and others in their support network; and
- **ENGAGE** young adult patients and their loved ones in direct support programs, services, events, and opportunities that help them cope, connect, and thrive.

Our Young Adult Patient Navigation Program services are free of charge and available to young adults at any stage in their cancer diagnosis.

UCF has established onsite Young Adult Patient Navigation program through partnerships with the following institutions:



The Impact of UCFs Young Adult Patient Navigation Program:

In January 2015, UCF launched a preliminary evaluation of the Young Adult Patient Navigation program to assess its impact on patient and families. Data collected since then reflects the following:

100% reported that their UCF Young Adult Patient Navigator:

- Connected to resources within the community and hospital that helped improve their overall cancer experience
- Made them feel less anxious about their diagnosis and treatment
- Helped them establish a healthier lifestyle during and/or after cancer treatment

93% reported that their UCF Young Adult Patient Navigator:

- Was a trusted source of support during their cancer experience
- Helped them adjust to life after cancer in an effective and positive way
- Empowered them to advocate for themselves during their cancer experience

Meet Our Team!

PATIENT NAVIGATORS

For full bios of our patient navigation team, please visit <http://ulmanfund.org/meetourteam/>



Meghan Fitzgibbons, MSW, LGSW

*Young Adult Patient Navigator –
Walter Reed National Military Medical Center*

Meghan is UCF's Young Adult Patient Navigator at Walter Reed National Military Medical Center's Murtha Cancer Center (American Building). Meghan's work with YAs spans between all outpatient adult oncology clinics, as well as Pediatric Hematology Oncology, and the inpatient oncology wards. In addition to the core services of the Patient Navigation program, Meghan facilitates the young adult cancer support group at Walter Reed and helps young adults treated at Walter Reed balance their cancer diagnosis and life in the military.



Allie Isaacson

*Young Adult Patient Navigator -
Children's National Medical Center*

Allie is UCF's Young Adult Patient Navigator at Children's National Medical Center in Washington, DC. Allie is housed in the Teen Room on 4 East in the Center for Cancer and Blood Disorders. In addition to providing core patient navigation services, Allie manages the Teen Room and plans monthly social events for YAs on the floor to meet each other and connect. Allie works closely with child life specialists and the nursing team to ensure that YAs at CNMC have access to age-appropriate resources and activities.



Alexandra Gubin, MSW, LCSW-C

*Young Adult Patient Navigator –
Johns Hopkins Hospital*

Allie is UCF's Young Adult Patient Navigator at Johns Hopkins Hospital's Sidney Kimmel Cancer Center. At Johns Hopkins, Allie works with all YAs ages 15 through 25 treated inpatient and outpatient within the pediatric oncology department. As a licensed clinical social worker, Allie provides supportive counseling related to issues such as fertility preservation, communication strategies to ensure quality of care, coping strategies that help patients adjust to their illness, and survivorship-related issues.



Mary Sharon Curran, RN, MS

*Young Adult Patient Navigator –
Greater Baltimore Medical Center*

Sharon is the UCF's Young Adult Patient Navigator at Greater Baltimore Medical Center and a Clinical Associate Professor of Nursing at Towson University. She brings her experience as an educator and psychiatric and mental health nurse to her Patient Navigation role by providing psychological and emotional support to AYAs and their families from the time of diagnosis, through their treatment and survivorship. Sharon also supports YAs affected by cancer on the Towson campus and co-founded the Institute for Well-Being's Cancer Wellness Program and Art Therapy Program. As a parent of a young adult survivor, she has a uniquely personal perspective in helping parents of YA cancer patients.



Elizabeth Saylor, MSW, CPN

Young Adult Patient Navigator – University of Maryland

Elizabeth is UCF's Young Adult Patient Navigator at the University of Maryland's Greenebaum Cancer Center. She works with AYAs and their families throughout the Cancer Center, but primarily those seen in Stoler Pavilion (Infusion Center and Outpatient Clinic), Radiation Oncology and Pediatric Oncology. She also supports inpatient cancer center units as well as bone marrow transplant units. She brings her experience as an educator, community outreach worker, researcher, and survivor of childhood cancer to her role as a Patient Navigator, particularly when supporting young urban families from medically underserved communities. At UMGCC, Elizabeth serves on the multidisciplinary Patient Education Committee representing the YA voice. Elizabeth received her certificate in Patient Navigation from the Harold P. Freeman Institute and has served on numerous committees including the Maryland Comprehensive Cancer Control Plan and the LIVESTRONG Young Adult Alliance.



Julie Lanahan, MA

Young Adult Remote Patient Navigator – UCF Offices

Julie is UCF's Young Adult Remote Patient Navigator. She is based out of the Baltimore, MD office and works with YAs affected by cancer in the local community as well as nationally through phone and online support. A young adult breast cancer survivor herself, Julie offers a unique perspective having been on the patient side as a young adult. In addition to the core services provided by remote Patient Navigation, Julie organizes UCF's YA quarterly social events and oversees UCF's college scholarship program.

STATISTICS*



Number of patients seen
53



Number of new patients served
32



Number of family members/
loved ones served
5



Types of cancer
34% Leukemias
24% Sarcomas
17% Lymphomas
6% Brain
19% Other Blood Disorders



Gender split of patients
41% Male
59% Female



Cancer Trajectory
100% Active Treatment



Race/Ethnicity of patients
42% Caucasian/Non-Hispanic White
39% Black/African-American
11% Hispanic
5% Middle Eastern
5% Mixed Race



Geographic Location
47% Maryland
29% Washington, DC
23% Virginia

* % rounded to the nearest whole

PROGRAM HIGHLIGHTS

PROGRAM, PROTOCOL & WORKGROUP DEVELOPMENT:

Fertility Protocol at CNMC – Allie worked with UCF's Patient Navigator at University of Maryland, Elizabeth Saylor, to initiate a fertility preservation policy for young adults treated at CNMC. Elizabeth spoke about best practices in establishing a protocol to the Bone Marrow Transplant (BMT) team in April 2015.

EVENTS AND ACTIVITIES:

A Prom for Henry - Henry, a 17-year old BMT patient, could not attend his own prom. With the help of volunteers and donations, Allie was able to transform a room in his house into a ballroom, dining room and photo booth. It was a beautiful and memorable night for his family and everyone involved.

Luau Party - To celebrate summer, UCF brought Hawaii to the Teen Room at CNMC. Palm trees, leis, popsicles and Hawaiian pizza got patients in a hula mood. Everyone watched Teen Beach Movie later that day—a favorite among teenagers (...and the patient navigator!).

March Madness— The Teen Room got competitive in March when Allie gathered the patients on the floor to watch "Selection Sunday." Parents, staff members, and patients all had bracket competitions and kept up with the NCAA tournament. The winners received Starbucks gift cards!

Pitch Perfect Party - To get excited about the release of the sequel, Pitch Perfect 2, Allie organized a group of girls on the floor to get together for a viewing and sing along to the original film, Pitch Perfect. After the movie, they all learned the "Cups" song!

UCF PROGRAM PARTICIPATION:

Two CNMC patients participated in Cancer to 5K in the Spring of 2015.

Multiple patients participated in the 4K for Cancer's Days of Dedication postcard program.

Multiple patients and caregivers have written blog posts for UCF's Facing the Issues Blog- a blog that highlights the realities, challenges, and experiences of young adults facing a cancer diagnosis.

OTHER:

Happy Birthday to Our CNMC Program! The UCF Young Adult Patient Navigation Program celebrated its one year anniversary in May 2015.



"I am a cancer survivor two times over, and both times I was a teen at Children's Hospital in DC. My first cancer, the AYA Patient Navigator position was in its infancy, and though it was helpful to know that this resource was available, it was a shadow compared to what it has become. With Allie Isaacson, the resources available to teens on the oncology floor have truly flourished. As a patient that spends months at a time confined to the ward, the resources that Allie provides are incredibly important to my psycho-stability. The teen room is a place of escape from the confines of my hospital room, a place where Allie hosts parties, plays video games with us, and provides a safe space to meet other teens and talk about common issues. Two months ago, we did a music sharing/making session, and earlier this year we learned origami together. The AYA Patient Navigator position is an integral component in teens' healing and coping processes, and the passion with which Allie undertakes her job has truly defined my experience as a patient with secondary cancer. I know I am not the only one that this is true for."

-Celli, 18

Ewing's Sarcoma with Secondary AML

STATISTICS*



Number of patients seen
62



Number of new patients served
14



Number of family members/
loved ones served
23



Types of cancer
53% Breast
11% Colorectal
14% Lymphomas
6% Uterine
5% Melanoma
5% Ovarian
5% Testicular
1% Head and Neck



Geographic Location
66% Maryland- Baltimore County
21% Maryland- Harford County
7% Maryland- Howard County
2% Maryland- Anne Arundel County
2% Maryland- Baltimore City



Cancer Trajectory
81% Active Treatment
14% Short Term Survivorship (<2 Years)
5% Other



Race/Ethnicity of patients
73% Caucasian/Non-Hispanic White
23% Black/African American
4% Hispanic
2% Middle Eastern



Gender split of patients
18% Male
82% Female

PROGRAM HIGHLIGHTS**PROGRAM, PROTOCOL & WORKGROUP DEVELOPMENT:**

Sharon has worked with the GBMC Team to connect with a large endocrinology practice that serves patients at GBMC. Patients in this practice, due to treatment modality, do not typically get chemotherapy or radiation therapy. She was able to connect with one doctor and supported one patient seen through this practice.

Sharon is leading the development of a Young Adult Resource Library at GBMC. Through a grant from the Oncology Support Services Department, this library will include appropriate literature for the young adult cancer population at GBMC.

Sharon represents the young adult patient's perspective when working with the treatment teams in Oncology Support Services, Medical and Radiation Oncology clinical areas. She brings the unique perspective of the young adult cancer patient's experience to the Oncology Nurse's Journal Club. Additionally inter-professional clinicians without a psychiatric clinical background often consult with Sharon to guide them when caring for patients with coping with cancer, while struggling with psychiatric, mental health or addiction or family issues.

EVENTS AND ACTIVITIES:

In April 2015, Sharon spearheaded Young Adult Cancer Awareness Week at GBMC, which included distributing UCF Guidebooks and young adult-specific materials to patients, families, and GBMC staff and promoting the work of UCF to hospital visitors and staff.

Sharon supported the Oncology Support Services staff in their planning of the June 2015 Survivorship Party. Julie Lanahan, Program Coordinator for Outreach and Engagement, was the keynote speaker at the event.

PEER CONNECTIONS:

Sharon facilitated a connection between young women that shared a diagnosis, a common life stage with young children, and similar creative interests, that resulted in a natural and genuine peer connection. In addition, through a collaboration with the GBMC Patient Navigator, Sharon connected two young adults treated at GBMC.

CROSS-PROGRAM PARTICIPATION:

UCF hosted two GBMC Oncology patients and their spouses at the UCF Blue Jeans and Bow Ties Ball in January. This opportunity led to enhanced peer support not just between the two couples, but with other couples in attendance in similar situations due to the patient cancer experience as young mothers.

Sharon continued to offer GBMC patients opportunities to attend UCF quarterly social events, such as the Orioles and Ravens games. She also connected three GBMC patients to UCF's Meet Up Group "Where YA Meet" in Baltimore.

OTHER:

Sharon guided discussions of fertility and parenting options with a few young women diagnosed with cancer that for various reasons were unable to preserve eggs for future fertility interventions.

HOW WE CHANGE LIVES



"The Ulman Cancer Fund has been such a blessing throughout my fight with cancer. Since my very first treatment, they have continued to be so supportive in everything, from sending my husband and I grocery gift cards to help offset the cost of medical bills to Sharon sitting and talking with me during treatments, and everything in between. They are such a huge part of the reason I've been able to get through this bump in the road."

-Megan K.O., 24
Non-Hodgkin's Lymphoma



"I am writing this to compliment Sharon's involvement with our young cancer patients. She has a good rapport with our young cancer patients and her calm and friendly demeanor helps to allay anxiety while in our infusion center. She has been very helpful in the lives of two of our young men who were uncomfortable in our center surrounded by much older patients. Her interactions with them were instrumental in each of them opening up the communication lines with staff and other patients. I also keep up to date on patient's progress in their lives outside of treatment by asking Sharon. Her approach and focus on their complete lives and interests outside of cancer helps them adjust to their new and unwanted role as a cancer patient. As a staff we are very pleased to have her special interest in our young cancer patients lives."

-Judy Feeney, RN, GBMC

STATISTICS*



Number of patients seen
41



Number of new patients served
10**



Gender split of patients
54% Male
46% Female



Number of family members/
loved ones served
42



Types of cancer
41% Sarcomas
37% Leukemias
12% Lymphomas
7% Brain
1% Other Blood Disorders



Race/Ethnicity of patients
67% Caucasian/Non-Hispanic White
15% Black/African-American
10% Hispanic
7% Asian
1% Mixed race



Geographic Location
15% Maryland- Baltimore County
12% Maryland- Baltimore City
10% Maryland- Howard County
7% Maryland- Prince George's County
7% Maryland- Anne Arundel County
7% Maryland- Eastern Shore
5% Maryland- Montgomery County
5% Virginia
5% Pennsylvania
5% Maryland- Montgomery County
5% Maryland- Southern Maryland
1% Maryland- Harford County
1% New Jersey
1% Maryland- Frederick/Carroll County
1% International
1% New York
1% California



Cancer Trajectory
72% Active Treatment
27% Active Treatment with a Relapse or Recurrence
1% Short Term Survivorship (<2 years)

* % rounded to the nearest whole

**Note that from February through May 2015, the Patient Navigator was not accepting new patients due to existing caseload size and additional programmatic obligations.

PROGRAM, PROTOCOL & WORKGROUP DEVELOPMENT:

Fertility Preservation:

- In collaboration with the fertility preservation team of physicians and nurses, Allie continues to build the fertility preservation program within the Division of Pediatric Oncology at Johns Hopkins.
- She has helped to grow a partnership between the Johns Hopkins Fertility Center and Reprotech, a long-term storage facility. Allie regularly counsels patients about their fertility risk and available options for preservation.

Adolescent and Young Adult Workgroup:

- Allie has collaborated with an inpatient Pediatric Oncology nurse and two faculty physicians, including the Director of the Pediatric Oncology Bone Marrow Transplant Program, to create a workgroup dedicated to improving the health care of Hopkins' Pediatric Oncology Adolescent and Young Adult (AYA) patients.
- As a co-chair of the AYA workgroup, Allie develops educational initiatives to ensure that medical and psychosocial training is offered to all Pediatric Oncology providers to enhance the knowledge base of and comfort level in serving the AYA oncology population.
- Allie facilitates bi-monthly "lunch and learns" which address various AYA-related care issues such as the social and cognitive development of the AYA brain.

PRESENTATIONS, AUTHORSHIP & COMMUNITY WORKGROUPS:

CancerCON - Allie was selected to present on the partnership between The Ulman Cancer Fund and The Johns Hopkins Hospital and the potential psychosocial benefits for AYA survivors to engage in advocacy related work at Stupid Cancer's "CancerCon" conference in April 2015.



Authorship - Allie was invited to co-author a chapter of a textbook entitled Pediatric Psycho-Oncology on the biopsychosocial care of AYAs with cancer. The textbook is slated to be published in 2016.

CROSS-PROGRAM PARTICIPATION:

Where YA Meet - Allie continues to co-facilitate a UCF-sponsored social support group for cancer patients in their 20's and 30's.

Scholarships - UCF awarded 2015 young adult higher education scholarships to two of Allie's patients at Johns Hopkins.

RECOGNITION & ACCOLADES:

AYA Workgroup Leader - Allie was selected to serve as the co-chair of the Johns Hopkins AYA Pediatric Oncology workgroup in January 2015.



"Allie and the Ulman Cancer Fund showed compassion, care, and concern for me during my treatments. They provided my family assistance to help get me back and forth to treatments. For that I am truly thankful."

-Lashonda Webb, 24

*Malignant Peripheral Nerve Sheath Tumor
Cancer Survivor*

"The Ulman Cancer Fund has been great...this is an excellent program for people like myself...I'm 24 years old, last year I was diagnosed with Rhabdomyosarcoma and I just recently had a child before this happened. Life has been really hard and when you're this age, you really don't want to ask for much help from anyone, not even family sometimes. This program has helped me financially with things I need. Talking with my social worker Allie, she really helps me get things off my chest that I keep bottled up and I am forever grateful to have someone to talk to, I hope this program stays around for a long time for us young adults. We are kind of overlooked compared to other age groups but you guys see us, thank you."

-Ebony Green, 24

Rhabdomyo Sarcoma Survivor

STATISTICS*



Number of patients seen
74



Number of new patients served
35



Gender split of patients
48% Male
52% Female



Cancer Trajectory
77% Active Treatment
9% Short- Term Survivorship (<2 years)
7% Active Treatment with a Relapse or Recurrence
7% Long-Term Survivorship (>2 years)



Number of family members/
loved ones served
50



Race/Ethnicity of patients
51% Caucasian/Non-Hispanic White
34% Black/African American
8% Hispanic
5% Others



Geographic Location
23% Maryland- Baltimore City
19% Maryland- Baltimore County
11% Maryland- Prince George's County
10% Maryland- Frederick/Carroll County
7% Maryland- Eastern Shore
7% Surrounding States
7% Maryland- Montgomery County
7% Maryland- Southern Maryland
6% Maryland- Anne Arundel County
5% Maryland- Harford/Cecil County
3% Maryland- Howard County
1% Western Maryland
1% California



Types of cancer
32% Lymphomas
29% Leukemias
8% Breast
7% Testicular
5% Brain
4% Head and Neck
4% Sarcomas
3% Lung
3% Colorectal
3% Multiple Myeloma
1% Other Blood Disorders

PROGRAM HIGHLIGHTS

PROGRAM, PROTOCOL & WORKGROUP DEVELOPMENT:

Caregiver Support Group - The Caregiver Support Group began in January and meets weekly at UMGCC. While the group is for caregivers of all-aged patients, multiple parents of young adults have participated in the psycho-educational group. Several participants have been young adult children who are caring for parents.

Fertility Preservation - Elizabeth spearheaded a relationship between UMGCC and Reprotech® to pilot a fertility preservation program for young men diagnosed with cancer at UMGCC.

Financial Burden at End of Life Study - Elizabeth serves as a focus group participant (to represent the young adult perspective) to contribute to the development of the intervention (based at the School of Social Work at University of Maryland).

Exploring New Opportunities – Elizabeth met with the director of newly initiated UMMC Sarcoma and Soft Tissue Program (Vincent Ng, MD) to outline strategies and practices for UCFs to work with young adult patients.

Patient and Family Education Committee - Elizabeth continues to serve on the UMGCC Patient and Family Education Committee, representing the young adult patient and caregiver perspective.

Resource Guide for Young Adults - Elizabeth developed a resource guide entitled “Individual Counseling Resources for Young Adults” and, at the request of UMGCC Patient and Family Education Committee, adapted the brief guide for patients of all ages who have time and budget challenges.

EVENTS & ACTIVITIES FOR YOUNG ADULTS:

Young Adult Cancer Awareness Week - Elizabeth organized all young-adult specific resources for patients in Stoler Pavilion. The Stoler Pavilion Nurse Manager asked to continue to maintain in Outpatient Center so young adults have continuous access.

PROGRAM HIGHLIGHTS

PEER CONNECTIONS:

- Elizabeth facilitated a connection between a young mother with blood cancer to another young mother blood cancer survivor who also had to be separated from her toddler-aged daughter during treatment. Additionally, she connected husbands for caregiver support.
- Elizabeth connected a transplant survivor with UCFs Board of Young Adult Advisors members for peer support.
- Elizabeth introduced a wife of stem cell transplant patient to young adult survivor for peer support related to weight loss surgery. Wife had her weight loss surgery at UMMC and was able to share her experience with the young adult survivor.

PRESENTATIONS & COMMUNITY WORKGROUPS:

Cancervention – Elizabeth presented at Cancervention, a young adult cancer conference in Philadelphia, in April 2015 on "Self-advocacy for the Young Adult With Cancer."

Community Workgroups - Elizabeth continues to serve as a member of the Komen Maryland Grant Review Committee and Development Team for 2016 RFPs and as a member of Johns Hopkins Young Women's Breast Cancer Program Community Stakeholder Advisory Group.

Baltimore City Patient Navigation - Elizabeth represents UCFs and the young adult cancer perspective at the Baltimore City Patient Navigation committee meetings. This year, she has presented on her experience as a young adult navigator to the committee.

CROSS-PROGRAM PARTICIPATION:

Cancer to 5K - One of Elizabeth's patients, a brain cancer survivor (off treatment for < 2 years) completed Cancer to 5K in Spring 2015.

Chemo Care Bag Project - Elizabeth worked with UCFs Remote Patient Navigator, Julie Lanahan, to set up a chemo care bag delivery to patients. Bags were delivered and assembled by Baltimore-based media firm, Millennial Media.

In-Services - As a leader in providing fertility preservation guidance to young adults with cancer, Elizabeth presented an in-service on UMGCC's fertility preservation process and UMGCC-UCFs model for the Bone Marrow Transplant team at Children's National Medical Center.

HOW WE CHANGE LIVES



"My Ulman Fund Patient Navigator, Elizabeth, has been very easy to work with. I first met her when I was in the hospital and now she visits me in the outpatient center too. We have talked about resources for my son as well as ways to help me adjust to changes in appearance that come with treatment. I live on the Eastern Shore so the gas card the Ulman Fund gave me is very helpful!"

-Keayra, 25
Non-Hodgkins Lymphoma Survivor

"I'm very lucky to have the support of family and friends, especially my mother. I have noticed that not everyone is as fortunate as me. It's good to know there are people out there to support all young adults like my patient navigator, Elizabeth, and organizations like the Ulman Fund."

-Dan E, 30
Acute Myeloid Leukemia Survivor



STATISTICS*



Number of patients seen
73



Number of new patients served
35



Gender split of patients
45% Male
55% Female



Cancer Trajectory
88% Active treatment
9% Short term survivorship (<2 Years)
3% Long term survivorship (>2 Years)



Number of family members/
loved ones served
24



Race/Ethnicity of patients
55% Caucasian/Non-White Hispanic
31% Black/African-American
5% Asian
4% Hispanic
3% Mixed Race/Other



Geographic Location
65% Maryland- Montgomery County
37% On Base (Walter Reed)
36% Maryland
22% Virginia
19% Maryland- Anne Arundel
8% Maryland- Southern MD
4% Maryland- Frederick/Carroll County
4% Maryland- Harford/Cecil County
1% Washington, DC
1% New York
1% Wisconsin



Types of cancer
29% Breast
11% Brain
11% Sarcomas
10% Leukemias
5% Lymphomas
4% Lung
4% Head and Neck
3% Colorectal
3% Ovarian
3% Testicular

3% Thyroid
3% Neuroendocrine
3% Other Blood Cancers
1% Cervical
1% Kidney
1% Melanoma
1% Pancreatic
1% Multiple Myeloma
1% Gastrointestinal
1% Undetermined

* % rounded to the nearest whole



PROGRAM, PROTOCOL & WORKGROUP DEVELOPMENT:

Fertility Preservation for Young Adults - Meghan facilitated the process of having in-hospital sperm banking kits delivered and available for use by inpatients and those for whom travel to a cryobank would be difficult or impossible.

Service Dog Training - With Recreational Therapy, a Service Dog Training was set up for young adult cancer patients to take part in on a bi-monthly basis. The dogs are being prepared to go to service members with significant physical needs, so patients are taught how to socialize and train the dogs during these sessions. Benefits to patients include increased patience, improved communication, and better emotional regulation.

Young Adult Caregiver Group - Meghan and the cancer center's psychologist, Dr. Leslie Cooper, started a Young Adult Caregiver Support Group for those caring for young adults with cancer. They have facilitated 11 support group meetings, to include 6 unique attendees. Special topic speakers have included Genetics, Nutrition, and Physical Therapy and Stress Reduction.

Adolescent and Young Adult Workgroup Development - Meghan began meeting with the AYA Program workgroup, which includes the Pediatric Hematology Oncology chief and social worker. Together, they are working to formalize a program for adolescents and young adults with cancer.

Medical Oncology Workgroup – Meghan began meeting with a Medical Oncology workgroup, including one physician and two nurse case managers, around improving fertility preservation awareness and processes.

EVENTS & ACTIVITIES FOR YOUNG ADULTS:

Young Adult Support Group - With the Pediatric Hematology Oncology social worker, Meghan facilitated 13 meetings of the Young Adult Support Group at Walter Reed, which included an average of 7 attendees, and 29 unique individuals. This group continues to address needs and issues that are specific to young adults, as well as those in the military. Two well-attended special topic groups were held to address concerns and questions related to the military's medical evaluation board process, in the context of a cancer diagnosis. Another group included Occupational Therapy and Clinical Nurse Specialist guest speakers, who addressed sex and intimacy – important topics for the young adult oncology population.

Walter Reed Wizards Game - On February 28th, 9 patients and their 10 guests attended dinner and a Wizards game. Many experienced their first NBA game and a good time was had by all.

Mini-Golf Event - Six patients and eight guests came out for lunch and mini-golf in Gaithersburg on May 16. Though it was warm, everyone did their best and had a nice time connecting with others outside of the hospital.



PROGRAM HIGHLIGHTS



PEER CONNECTIONS:

- Meghan connected a young cancer survivor with a UCF supporter and mechanical engineer in order to facilitate career field mentorship.
- Meghan facilitated having a UCF volunteer cook a few native dishes for a Haitian patient and his family – these foods are thought to heal and the family was extremely grateful.
- Meghan and the UCF navigator at CNMC introduced their patients and their guests at the UCF Blue Jeans Ball – the group shared their cancer stories and had a nice time at the event.



CROSS-PROGRAM PARTICIPATION:

Cancer to 5K - Four Walter Reed patients and one caregiver participated in Cancer to 5K this spring. Three participants were on the Montgomery County team, along with one volunteer sherpa and caregiver; another patient trained with the DC/Northern Virginia Team. All five completed the goal race on June 13th, 2015. The DoD blog highlighted the Cancer to 5K stories of three Walter Reed participants.

PRESENTATIONS & COMMUNITY INVOLVEMENT:



Young Adult Cancer Awareness Week - Meghan presented to Medical Oncology's disease-specific teams each morning of Adolescent and Young Adult Cancer Awareness Week – major topics included delayed diagnosis, fertility preservation, social isolation, and survivorship.

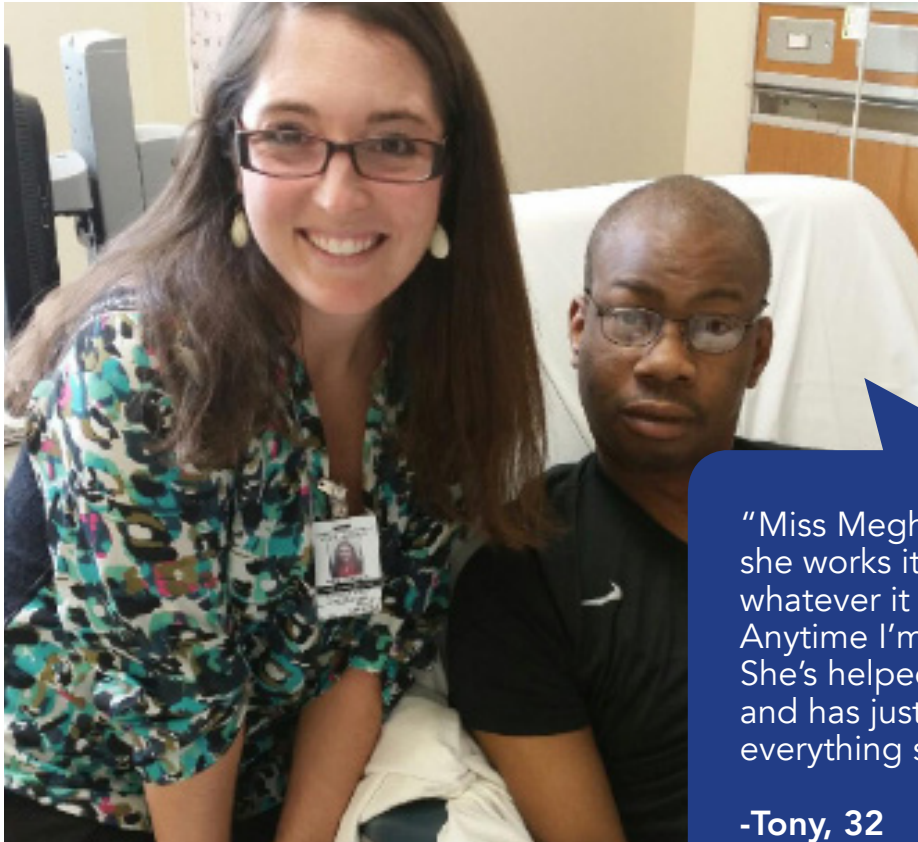
Cancervention - With Elizabeth Saylor, the UCF patient navigator at UMGCC, Meghan presented on self-advocacy to more than 30 patients and supporters at Cancervention, a young adult cancer conference in Philadelphia.



RECOGNITION & ACCOLADES:

Excellence in Care - Meghan received the Dr. Paul Florentino Patient and Family Centered Care Excellence Award with Stacey Springer, LCSW, ACSW, OSW-C. They were awarded for their work to improve psychosocial support to adolescents and young adults with cancer.

HOW WE CHANGE LIVES



"Miss Meghan is very reliable – any issue I have, she works it from every avenue. She'll research whatever it is I need and just gets things done. Anytime I'm in the hospital, she's there for me. She's helped me to feel better about my care and has just really done a lot for me. I appreciate everything she does."

-Tony, 32
Active Duty Osteosarcoma Patient

"Ms. Fitzgibbons has worked tirelessly to bring resources to our young adult cancer patients and their family members. I have personally shared many patients with her and consider her help exceptional. The medical team that provides services to our cancer patients agrees that Meghan is indispensable. The value that she brings to this population as a patient navigator is greatly appreciated. Thank you for the opportunity to express my and our admiration and gratitude for her work."

-Leslie Cooper, Ph.D., ABPP

STATISTICS*



Number of patients seen

63



Number of new patients served

58



Gender split of patients

24% Male

76% Female



Number of family members/
loved ones served

14



Cancer Trajectory

95% Active Treatment

5% Off Treatment (<2 years)



Race/Ethnicity of patients

82% Caucasian/Non-Hispanic White

14% Black/African American

2% Hispanic

2% Middle Eastern



Geographic Location

7% Maryland- Baltimore County

4% Florida

4% Minnesota

4% Kentucky

4% Maryland- Baltimore City

3% California

3% Massachusetts

3% Georgia

2% Idaho

2% Illinois

2% Maryland- Anne Arundel County

2% Maryland- Harford/Cecil County

2% Maryland- Howard County

2% Maryland- Montgomery County

2% New York

2% North Carolina

2% Rhode Island

2% Virginia

2% Alabama

2% Arkansas

2% Connecticut



Types of cancer

40% Breast

15% Brain

13% Lymphomas

5% Cervical

5% Colorectal

4% Sarcomas

4% Kidney

4% Other

4% Testicular

4% Thyroid

2% Head and Neck

2% Ovarian

* % rounded to the nearest whole

PATIENT ASSISTANCE

UCF's Patient Assistance Fund program exists to help young adult patients with significant financial need offset some their expenses related to their cancer diagnosis. Patients working with UCFs Patient Navigators are eligible for up to \$100 per calendar year in the following areas:

- Transportation
- Groceries
- Medical Co-pays
- Telephone & Utilities

In addition, UCF provides up to \$200 for expenses related to fertility preservation, such as annual storage fees, for young adults.

With 2015 Patient Assistance Funds, UCF has provided:

- 35 young adults with transportation assistance;
- 10 young adults and their families with grocery assistance; and
- 10 young adults with fertility preservation assistance.

