

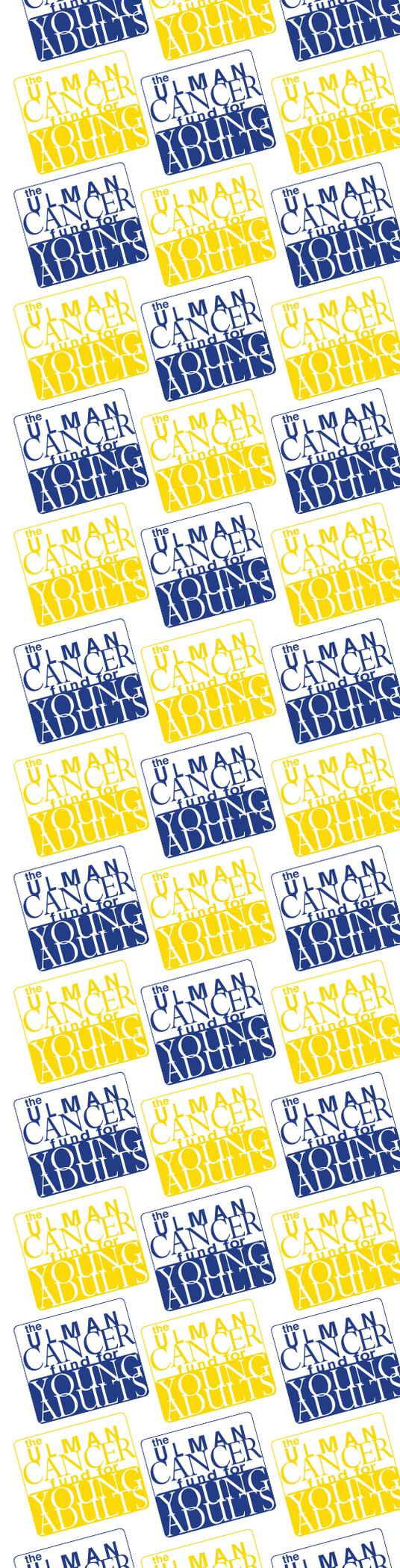
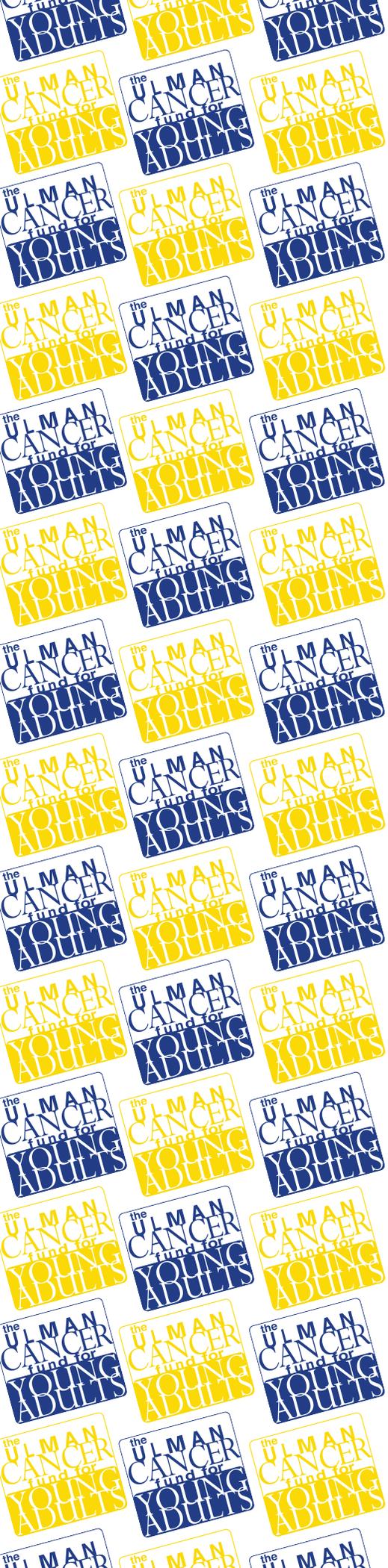
PATIENT  
NAVIGATION

Q4

Quarterly Report

2014

the  
ULMAN  
CANCER  
fund for  
YOUNG  
ADULTS



## PROGRAM OVERVIEW

The Ulman Cancer Fund's (UCF) Adolescent and Young Adult (AYA) Patient Navigation program provides one-on-one support, direct services, and tailored programs and resources to AYAs to ensure they never feel alone during their cancer experience. Working in conjunction with each Cancer Center's multidisciplinary medical care team, our Patient Navigators assist patients in managing their own cancer journey. They serve as a friendly voice, a cheerleader and a supporter, helping AYAs navigate the unique medical, emotional, financial, educational, and physical needs they have during treatment and into survivorship.

While UCF's Patient Navigation program provides core services, our Patient Navigators tailor the program to each institution based on their patient population and varying needs.



JOHNS HOPKINS  
MEDICINE



Children's National Medical Center (CNMC) is a 283-bed general facility and teaching hospital located in Washington, DC. There are approximately 14,000 admissions annually, with about 5,000 inpatient and 11,000 outpatient surgeries. The hematology and oncology unit, where the UCF Patient Navigator is located, is a 37-bed floor, treating patients from infant to 29 years of age. Patients do not receive radiation at CNMC.

The partnership between the UCF and CNMC resulted in the placement of an AYA patient navigator at CNMC in December 2013. The position is currently funded by the Shearer Family in memory of their daughter, Jacqueline Shearer, as part of the Jacqueline Shearer Memorial Fund. For more information on Jacqueline and her story, please visit <http://ulmanfund.org/donate/the-jacqueline-shearer-memorial-fund/jacquelines-story/>

The Johns Hopkins Hospital's Sidney Kimmel Cancer Center is an NCI-designated comprehensive cancer center in Baltimore, MD. It is the only comprehensive cancer center in the state. UCF's Adolescent and Young Adult (AYA) Patient Navigator is housed within the Kimmel Cancer Center's Department of Pediatric Oncology.

The innovative partnership between UCF, the Department of Pediatric Oncology and the Kimmel Cancer Center launched in January 2012. A UCF-funded AYA Patient Navigator, who serves patients 15 to 25 years old within pediatric oncology, is the centerpiece of this partnership. The AYA Patient Navigator works in conjunction with the Cancer Center's multi-disciplinary team to assist patients and their families through: individual/family counseling, fertility preservation guidance, resource activation for housing, transportation, and other cancer treatment-related needs, financial assistance, and community/social support.

Walter Reed National Military Medical Center (WRNMMC) is the Nation's Medical Center, proudly serving military beneficiaries in the Washington, D.C. area as well as those from across the country and around the globe. The Murtha Cancer Center at WRNMMC is a modern, patient-centric, tri-service military healthcare facility. As the only DoD Cancer Center of Excellence within the Military Health System, the Murtha Cancer Center offers its patients access to cutting-edge cancer diagnostic and treatment technologies.

UCF and WRNMMC officially launched the placement of an Adolescent and Young Adult (AYA) Patient Navigator in May 2013. The Patient Navigator works closely with the Cancer Center's multidisciplinary team to support our AYA service members, and their families, that are facing a cancer diagnosis. The UCF Patient Navigation Program offers a unique approach to military readiness by providing direct support and access to resources tailored specifically to AYAs within the Uniformed Services.



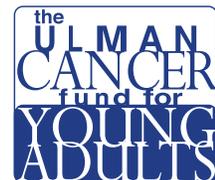
Greater Baltimore Medical Center (GBMC) is a 255-bed medical center (acute and sub-acute care) located in Towson, MD that sees over 26,700 inpatient cases annually. The Malcolm and Sandra Berman Cancer Institute at GBMC provides comprehensive, multidisciplinary cancer care that combines leading specialists with state-of-the-art technology. GBMC is one of the largest community hospitals in the mid-Atlantic region with over 1,300 physicians and 1,100 nurses serving on its medical staff.

The UCF and GBMC partnership began in 2011 and resulted in a part-time Adolescent and Young Adult (AYA) Patient Navigator. At GBMC, the Patient Navigator works closely with physicians, nurses, social workers and administrators to support young adults in treatment.



The University of Maryland Marlene and Stewart Greenebaum Cancer Center (UMGCC) is a National Cancer Institute (NCI)-designated cancer center located in Baltimore, MD. At UMGCC, young adult patients receive direct navigation services and support throughout the medical center on the three adult inpatient oncology units, in Stoler Pavilion (Infusion Center and Outpatient Clinic), Radiation Oncology and Pediatric Oncology.

Since the program's inception in 2008, UCF's AYA Patient Navigation program has provided direct services and resources to young adults and their families living with and surviving cancer. As part of an academic medical community, the UCF Patient Navigator works with the University of Maryland School of Law and Dentistry. AYA patients are served directly in the community through a variety of supportive services such as home visitation, resource coordination and accompanied visits to social services.



Our UCFs Remote Patient Navigation Program helps adolescents and young adults (AYAs) faced with a cancer diagnosis make sense of it all. We are a friendly voice, a cheerleader and a supporter as you and your loved ones fight cancer and embrace survivorship.

UCF offers Remote Navigation services through telephone and email communication support out of our Baltimore, MD office. This one-on-one support is a free service for AYAs, and their loved ones, at any stage in their cancer diagnosis and from anywhere in the country. For young adults who live local to the Baltimore area, our Remote Patient Navigator can also provide in-person one-on-one support at our offices or onsite at a hospital.

AYAs and their families may access our Remote Navigation services by calling **1-888-393-FUND ext 105** or emailing Julie Lanahan at [julie@ulmanfund.org](mailto:julie@ulmanfund.org).

# Meet Our Team!

## PATIENT NAVIGATORS

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



**Allie Isaacson**  
*Adolescent and Young Adult Patient Navigator –  
Children’s National Medical Center*

Allie is UCFs AYA 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 AYAs on the floor to meet each other and connect. Allie works closely with child life specialists and the nursing team to ensure that AYAs at CNMC have access to age-appropriate resources and activities.



**Alexandra Gubin, MSW, LCSW-C**  
*Adolescent and Young Adult Patient Navigator –  
Johns Hopkins Hospital*

Allie is UCFs AYA Patient Navigator at Johns Hopkins Hospital’s Sidney Kimmel Cancer Center. At Johns Hopkins, Allie works with all AYAs 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.



**Meghan Fitzgibbons, MSW, LGSW**  
*Adolescent and Young Adult Patient Navigator –  
Walter Reed National Military Medical Center*

Meghan is UCFs AYA Patient Navigator at Walter Reed National Military Medical Center’s Murtha Cancer Center (American Building). Meghan’s work with AYAs 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.



**Mary Sharon Curran, RN, MS**  
*Adolescent and Young Adult Patient Navigator –  
Greater Baltimore Medical Center*

Sharon is the UCFs AYA 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 AYAs 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 AYA cancer patients.



**Elizabeth Saylor, MSW, CPN**  
*Adolescent and Young Adult Patient Navigator –  
University of Maryland*

Elizabeth is UCFs AYA 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 AYA 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**  
*Adolescent and Young Adult Remote Patient Navigator –  
UCF Offices*

Julie is UCFs AYA Remote Patient Navigator. She is based out of the Baltimore, MD office and works with AYAs 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 UCFs young adult quarterly social events and oversees UCFs scholarship program.



## STATISTICS FROM Q4



Number of patients seen  
**33**



Average age of patients  
**17**



Direct Services Provided to Patients  
Connections to other adolescents and young adults

Family and home life adjustment

Normalization during treatment

Platforms to prevent social isolation

Returning to work or school after cancer



Number of new patients seen  
**10**



Types of cancer\*

**24% Acute Leukemia**

**21% Sarcoma**  
(Bone, Ewings, Rhabdomyo)

**3% Brain Cancer**

**3% Non-Hodgkins Lymphoma**

**7% Unrecorded**

**41% Other Blood Disorders**



Gender split of patients  
**59% Male**  
**41% Female**



Location

**65% Maryland**

41% Prince George's Country

24% Montgomery County

**14% Virginia**

**10% Washington, DC**

**3% West Virginia**

**7% Unrecorded**



Race / Ethnicity of patients  
**55% Black or African-American**  
**21% Caucasian/Non-Hispanic White**  
**14% Hispanic**  
**7% Middle Eastern**  
**3% Other**



Cancer Trajectory

**76% Active treatment**

**17% Off Treatment**

**7% Relapses**

\*Percentage numbers are rounded to nearest whole

## PROGRAM HIGHLIGHTS

- Attended physical therapy appointments with 4 AYA patients and helped with distraction and normalization.
- Organized a "Halloween Movie Marathon" for AYAs in October 2014. Candy apples, Halloween cookies and scary movies made the party a lot of fun!
- Worked with nursing to host a Tie-Dye party in November 2014. AYAs tie-dyed hats, socks, towels, pillowcases, shirts, and much more with family and friends.
- Two patients enrolled in the Cancer to 5K program starting in the spring.
- Three patients attended the Jacqueline Shearer Memorial Gala and helped demonstrate the work UCF does at Children's.
- Collaborated with the psychosocial team at CNMC to organize and run holiday parties, gift drives, donations and other festivities throughout December.
- Started a pen pal chain on the Bone Marrow Transplant unit.
- Identified three families for UCF's Holiday Gift drive.



## HOW WE CHANGE LIVES



### Alex Herndon

I never went to the Teen Room until Allie started working here. She makes it fun and inviting. There are usually other teens in there and it's great to meet others on the unit. My favorite game is "Just Dance" and when the nurses join in and dance with us it's a hilarious and really fun time!

### Alexis Foltz RN

Allie has brought teens together at CNMC. Last chemo celebrations, origami-making sessions and movie marathons are just some of the things that happen here because the Teen Room is open and available. Teens connect with each other and remember what it's like to be a regular teenager thanks to the Teen Room and the Patient Navigator here.



## PROGRAM GOALS

- Develop and implement a plan for outpatient clinic to engage more young adults at CNMC.
- Enhance skills and knowledge around patient navigation and young adult resources relevant to CNMC patients.
- Attend at least one conference related to AYA Oncology and bring relevant lessons learned and best practices back to CNMC.

## STATISTICS FROM Q3



Number of patients seen  
35



Average age of patients  
32



Direct Services Provided to Patients  
One-on-one support to patients



Number of new patients seen  
17



Types of cancer\*  
**58% Breast Cancer**  
**11% Colorectal Cancer**  
**11% Ovarian Cancer**  
**5% Head / Neck Cancer**  
**5% Hodgkins Lymphoma**  
**5% Thyroid Cancer**  
**5% Testicular Cancer**

Fertility Counseling  
 Financial Assistance & Types-referral to UCF P Assist Fund

Resource Coordination with GBMC services and providers

Enhancement of Social Support Network through GBMC peer to peer support

Support to Families / Caregivers

Work / Job / School Re-Entry

Transportation Support

Support Group referrals



Gender split of patients  
**91% Female**  
**9% Male**



Race / Ethnicity of patients\*  
**89% Caucasian / Non-Hispanic White**  
**6% Black / African-American**  
**3% Hispanic / Non-White**  
**3% Other**



Cancer Trajectory\*  
**68% Active treatment**  
**26% Relapses**  
**5% Other**



Location\*  
**100% Maryland**  
 88% Baltimore County  
 6% Anne Arundel County  
 3% Baltimore City  
 3% Harford County

\*Percentage numbers are rounded to nearest whole

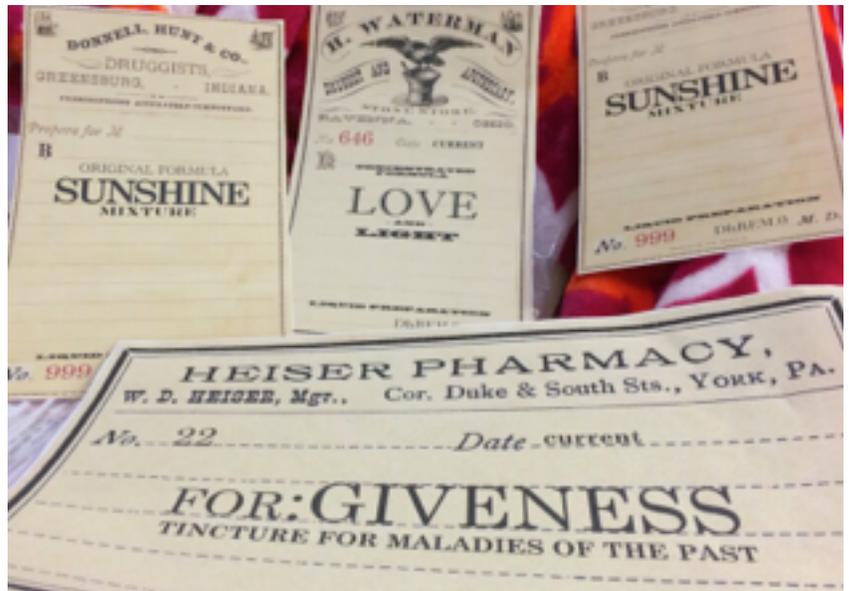
## PROGRAM HIGHLIGHTS

- Presented a Lunch & Learn in October 2014 at GBMC. Open to GBMC physicians and staff members, the focus of the talk was "Managing Difficult Clinical Patient Situations."
- Attended GBMC Oncology Quarterly Staff Meetings, Oncology Lunch & Learns, and Oncology Grand Rounds, and John Adams Compassionate Caregiver Rounds.
- Supported GBMC Oncology Patients to access Community Support such as HOPEWELL Programs and Towson University Programs dedicated to cancer patients well-being and survivorship, such as the Institute's for Well-Being's Cancer Wellness Program and Cancer Survivor Art Therapy Program. Other such support offered include Red Devils, Catastrophic Health Planners, American Cancer Society, Leukemia & Lymphoma Society, Cervivor for GYN Cancers, Stupid Cancer, Livestrong, etc.
- Served as an active member of the GBMC Oncology Support Services team of oncology health care professionals, regularly engaging the survivorship nurse, the infusion nursing team, the social workers, the oncology research nursing staff, the dedicated oncology registered dietician, the NPs, PAs and MDs, to assist in the management and coordination of care for the patients at GBMC.
- Served as an active and presenting member of the Oncology Nursing Journal Club at GBMC. Present at this meeting are oncology nurses from the inpatient unit, the infusion center, The Dance Center and The Breast Center. Topics presented on have included cancer patient's body image, emotional responses to diagnosis and treatment, and art therapy for cancer patients and survivors.

## HOW WE CHANGE LIVES

Sharon provided frequent and intense support to a 33 year-old breast cancer patient. The patient was proactive in her approach to her illness from a physical, emotional and spiritual perspective. At the time of diagnosis she was struggling with external stressors unrelated to cancer, and, therefore she has benefited from a strong therapeutic relationship with Sharon as her patient navigator. Sharon served as a resource throughout her cancer experience thus far, connecting able to connect her early on with services in the community. More importantly, Sharon was able to connect her to a peer-mentor that she instinctively knew would be a good match for her intellectually, emotionally and spiritually.

The patient is artistic, and has created personalized inspirational labels for her chemotherapy infusion bags and has shared these labels with other patients.



### Felicity Kirby, RN, BSN

"Sharon continues to interface with our newly diagnosed young patients as they arrive at GBMC. Through her conversations with them, she is able to connect them to a variety of resources such as peer support, as well as provide them individual insight and information regarding what to expect in the road ahead. Once this connection is made, she follows them with visits and phone calls as they move through their prescribed treatment. We are grateful to have someone like Sharon to provide this special service to our younger patients."

## PROGRAM GOALS

- Plan a patient /caregiver event at GBMC for Spring, potentially in March 2015
- Order literature for a dedicated Young Adult Cancer Patient section of the GBMC Oncology Support Services Patient Library through funds offered by GBMC Oncology library donors and supporters.
- Seek opportunities, patient navigator and UCF resources, to sit on clinical meetings at GBMC, such as case conferences, with the goal of increasing visibility as the UCF patient navigator and UCF resources and showcasing the UCF brand.



## STATISTICS FROM Q4



Number of patients seen  
**36**



Average age of patients  
**19**



Direct Services Provided to Patients  
Connections to other adolescents and young adults  
Family and home life adjustment  
Normalization during treatment  
Platforms to prevent social isolation  
Returning to work or school after cancer



Number of new patients seen  
**8**



Types of cancer\*  
**33% Sarcoma**  
(Bone, Ewings, Rhabdomyo)  
**28% Acute Leukemia**  
**14% Brain Cancer**  
**8% Hodgkins Lymphoma**  
**6% Non-Hodgkins Lymphoma**  
**3% Head/Neck Cancer**  
**8% Other**



Gender split of patients  
**58% Male**  
**42% Female**



Location  
**32% Maryland**  
14% Baltimore City  
14% Howard County  
11% Montgomery County  
8% Anne Arundel County  
8% Prince George's County  
6% Eastern Shore (Kent & Queen Anne's)  
3% Baltimore County  
3% Calvert County  
3% Frederick/Carroll Counties  
3% Harford/Cecil Counties  
**3% New Jersey**  
**3% New York**  
**3% Pennsylvania**  
**3% Virginia**  
**6% International**



Race / Ethnicity of patients  
**53% Caucasian / Non-Hispanic White**  
**39% Black or African American**  
**8% Asian**



Cancer Trajectory  
**81% Active treatment**  
**11% Relapses**  
**3% Off Treatment**  
**3% Long Term Off Treatment**  
**3% Unrecorded**

\*Percentage numbers are rounded to nearest whole

## PROGRAM GOALS

- Educate health care staff on adolescent and young adult biopsychosocial development and disseminate clinical best practices for working with this patient population
- Reinitiate Ulman Cancer Fund support group for young adults in their 20's and 30's in treatment for cancer
- Continue to grow partnership with Hopkins Fertility Center and Reprotech to further support young adults in need of fertility research.
- Finalize book chapter for **Pediatric Psycho-Oncology**



## PROGRAM HIGHLIGHTS

- **Mission to Vine** Allie was engaged in Mission to Vine – a 700 mile run up the coast of California to broaden awareness of young adult cancer. She monitored an Ulman Facebook page that connected runners to patients and vice versa. A few of her patients who were inpatient recovering from a bone marrow transplant participated in the Facebook group and connected with the runners who provided social support to patients along the run.
- **Fertility Preservation** Allie, collaborating with the fertility preservation team of physicians and nurses, continues to build the fertility preservation program within the Division of Pediatric Oncology at The Johns Hopkins Hospital. The patient has made greater strides to foster a relationship with The Johns Hopkins Fertility Center so that fertility services are more affordable and accessible to patients. In addition, Allie has helped to grow a partnership between Hopkins Fertility Center and Reprotect, a long-term storage facility. In addition, she continues to counsel patients about their fertility risk and available options for preservation.
- **UCF Support Group** Allie has collaborated with members of the UCF team to re-initiate support group for cancer patients in their 20's and 30's. The goal of the group is to provide information and support on relevant issues for young adults facing cancer such as navigating work/school, negotiating changes in one's personal identity, and managing social and intimate relationships. The group is slated to re-launch April 2015.
- **AYA Working Group** The Patient Navigator collaborated with a pediatric oncology nurse to re-initiate a work group dedicated to improving the care of adolescents and young adults with cancer on the Hopkins Pediatric Oncology service. A few key AYA care initiatives in which the Patient Navigator has been actively involved are the following: end-of-life care planning and the administration of advance directives with patients and families; fertility preservation and counseling; and general education of health care providers with the aim to improve the knowledge base and comfort level of working with the adolescent and young adult population.
- **Conference Presentations** An abstract highlighting the partnership between The Ulman Cancer Fund and Johns Hopkins, and specifically the patient navigation program, was accepted for presentation at "CancerCon" – the first multi-dimensional conference produced by the leading adolescent and young adult advocacy organization, [stupidcancer.org](http://stupidcancer.org). The presentation, which takes place April 2015, will focus specifically on the psychosocial benefits, of patient participation in advocacy organizations such as The Ulman Cancer Fund.
- **Authorship** The Patient Navigator was invited to co-author a chapter of a textbook entitled Pediatric Psycho-Oncology on the biopsychosocial care of adolescents and young adults with cancer. The Patient Navigator submitted a first draft in December 2014 and revisions continue over the next several months. The textbook is slated to be published in the summer of 2015.

## HOW WE CHANGE LIVES



### Allison Martin, MD *Division of Pediatric Oncology/Hematology*

"During difficult medical discussions Allie provides that balancing voice reminding us to consider whole patient in our treatment approach. She has remarkable insight into the needs of this often neglected young adult patient population and as such is a valuable asset to the pediatric oncology team."

### Bi'ja Thatch 21, *Pediatric Oncology*

"Over the last three years I have had the pleasure of working with Ms. Allie. She has been there to listen to me during my breakdowns about how much I have to deal with concerning my health. As I became an adult Ms. Allie informed me how I could start making my own decisions when it came to my health care, she also provided my mom and I gas cards because of how often we had to drive back and forth to my doctor appointments. While admitted to the hospital Ms. Allie constantly made visits to my room to talk to me about how I was dealing with everything going on, provided my family with information that we could use whenever I was discharged from the hospital, and made numerous calls on my behalf to ensure I would have transportation and a place to stay after discharge such as the Ronald McDonald House. The one thing I appreciated most about having Ms. Allie as a social worker is how determined and focused she was on me as one of her patients. I can always depend on her to do what she says she will do to help me."



## STATISTICS FROM Q4



Number of patients seen  
**34**



Number of new patients seen  
**15**



Gender split of patients  
**65% Male**  
**35% Female**



Cancer Trajectory  
**68% Active treatment**  
**18% Relapse**  
**9% Off Treatment**  
**6% Long-Term Off Treatment**



Average age of patients  
**28**



Types of cancer\*  
**32% Acute Leukemia**  
**18% Hodgkins Lymphoma**  
**12% Head/Neck Cancer**  
**12% Non-Hodgkins Lymphoma**  
**6% Brain Cancer**  
**6% Colorectal Cancer**  
**3% Breast Cancer**  
**3% Cervical Cancer**  
**3% Melanoma**  
**3% Sarcoma**  
(Bone, Ewings, Rhabdomyo)  
**3% Testicular Cancer**



Race / Ethnicity of patients  
**56% Caucasian/Non-Hispanic White**  
**32% Black or African-American**  
**12% Hispanic**



Direct Services Provided to Patients  
Connections to other adolescents and young adults  
Family and home life adjustment  
Normalization during treatment  
Platforms to prevent social isolation  
Returning to work or school after cancer



Location\*  
**91% Maryland**  
18% Baltimore City  
12% Anne Arundel County  
12% Baltimore County  
12% Howard County  
9% Frederick/Carroll County  
9% Montgomery County  
6% Harford/Cecil  
6% Prince George's County  
3% Southern Maryland  
**6% Virginia**  
**3% New York**

\*Percentage numbers are rounded to nearest whole

## HOW WE CHANGE LIVES



### Sharmane, Cancer Survivor

Having cancer as a young adult is hard. I am not just a patient but a mom, girlfriend, cousin, friend and woman. The Ulman Fund has been a real blessing to me. Elizabeth is my patient navigator. She encourages me talk about my feelings and think about what treatment choices are best for me. I have a very rare cancer and she connected me to other survivors with the same kind. Brock is the Director of the Ulman Fund. When I first met him I thought he looked so young to be a director and a father. He and his wife helped us for Christmas through the Ulman Fund gift drive. He knows what it is like to want the best Christmas for your children and I am so grateful for his generosity!

## PROGRAM HIGHLIGHTS

- In the community, Elizabeth has provided transportation and overall case management to a young adult patient with complex social and home circumstances and disease progression. Because of the unique nature of her navigator position, Elizabeth works in the community and on multiple units, and can help transition patients through a variety of medical care providers.
- Elizabeth worked to introduce and connect a young adult patient to the palliative care team. She also spent significant time with a young adult patient and family at Season's Hospice – Franklin Square.
- Elizabeth was invited to join a community stakeholder advisory group for Centers for Disease Control-funded young women's breast cancer program at Johns Hopkins. Elizabeth will share her perspective as both an UCF Patient Navigator and fellow stakeholder in the young adult support community.
- The general cancer support group and specific bone marrow transplant (BMT) caregiver support group will begin in February 2015. These two groups are a collaborative effort between University of Maryland Medical System, the School of Social Work, and the UCF's Young Adult Patient Navigation Program. The groups will be open to patients of all ages, but will have significant young adult participation.
- Worked with pediatric oncology nurse practitioner, to facilitate complex sperm banking/fertility preservation, which involved a newly diagnosed Non Hodgkin's Lymphoma patient in early twenties. Required coordination of adult oncology, pediatric oncology, UM urology, UM surgery, and Shady Grove Fertility. Two different attempts/methods were used which ultimately resulted in a successful sperm cryopreservation for this young man. The UCF was able to provide the family with financial assistance for fertility preservation.
- Connected Young Adult Patient Navigator at Johns Hopkins, Allie Gubin, directly to pediatric oncology nurse practitioner (NP) at University of Maryland to provide assistance to a young adult patient transferred to Hopkins. The NP was able to assist Allie in identifying key family members and providing essential background on patient's challenges with treatment adherence over the years.
- Continue to serve as co-investigator with the University of Maryland Medical System Clinical Pharmacy Department and School of Pharmacy on a research evaluation of young adults' adherence to oral chemotherapy. Data collection will begin mid-January. The research team will be speaking at a number of UMGCC staff meetings, which will allow further promotion of young adult issues.

## PROGRAM GOALS

- Work with the Patient Navigation Team to pilot the Young Adult Patient and Caregiver Feedback survey
- Establish a more formalized referral method for UMGCC providers to refer to me and UCF in general and programs
- Identify new ways to highlight the UCF brand at UMGCC (my clothing, small giveaways to providers like pens and notepads, lanyards, mini young adult info/resources libraries)
- Collect and report qualitative and quantitative metrics on a regular basis to show impact at UMGCC
- Work with the Helping Others Fight program at UCF to formally pilot and collect evaluation feedback on "Chemo Companions"/Peer Mentors at UMGCC
- Establish formal Fertility Preservation Workgroup at UMGCC. This quarter, the goal is to identify and ask already invested key staff members for support and interest level.



## STATISTICS FROM Q3



Number of patients seen  
**50**



Average age of patients  
**33**



Direct Services Provided to Patients  
Connections to other adolescents and young adults  
Family and home life adjustment  
Normalization during treatment  
Platforms to prevent social isolation  
Returning to work or school after cancer



Number of new patients seen  
**25**



Types of cancer\*  
**34% Breast**  
**14% Sarcoma**  
(Bone, Ewings, Rhabdomyo)  
**12% Brain**  
**6% Colorectal**  
**4% Acute Leukemia**  
**4% Testicular**  
**4% Lung**  
**4% Melanoma**  
**4% Non-Hodgkin Lymphoma**  
**16% Other**



Location  
**42% Maryland**  
13% Anne Arundel County  
13% Montgomery County  
12% Southern Maryland  
(Charles, Calvert, St.Marys)  
2% Howard County  
**26% Walter Reed Base**  
**26% Virginia**  
**6% DC**



Gender split of patients  
**52% Female**  
**48% Male**



Race / Ethnicity of patients  
**48% Caucasian / Non-Hispanic White**  
**32% Black or African-American**  
**6% Hispanic**  
**4% Native Hawaain / Pacific Islander**  
**10% Other or Unrecorded**



Cancer Trajectory  
**80% Active treatment**  
**16% Off Treatment**  
**4% Long-Term Off Treatment**

\*Percentage numbers are rounded to nearest whole

## HOW WE CHANGE LIVES

During the horseback riding event at the Columbia Horse Center on an unseasonably warm December afternoon, many meaningful connections were made. In addition to the five Walter Reed patients and their guests in attendance, the majority of the horse center's staff also had strong cancer connections, or were survivors themselves. The event was many patients' first opportunity to engage with UCF. Two breast cancer patients who brought their young children quickly recognized one another from the Walter Reed treatment room, but they'd never spoken. By the end of the day, they knew one another's stories, had connected over having opposite hormone receptors, and they departed with "see you soon in the infusion room!"





## PROGRAM HIGHLIGHTS

- A patient and her sister, who is her caregiver, were engaged as volunteers at the Victoria Gastro Pub Running Festival, benefiting UCF. The patient's sister also joined Team Fight and participated in her first 5K, already raising more than \$1300.
- Helping Others Fight Projects were set up for one breast cancer patient whose surgery and treatment have significantly impacted her ability to take care of household chores. UCF volunteers helped her by hanging photos and home decorations and installing a wall-mounted television. Another group completed household cleaning and laundry and decorated for the holidays.
- The young adult support group, facilitated by the pediatric social worker and UCF patient navigator, engaged 11 unique patients and loved ones over 5 group sessions between October and December.
- A reception was held at Walter Reed in November to celebrate UCF's patient navigation program starting earlier in the summer. A bell was presented by UCF so that patients can audibly mark the end of their chemotherapy treatment in the infusion room.
- Meghan worked with Walgreens Specialty Pharmacy to set up a direct billing process to make egg and embryo cryopreservation easier for female patients. The Ulman Cancer Fund is now set up to cover up to \$200 of patients' medication costs for fertility cryopreservation via Ferring's Heartbeat Program.
- With the pediatric social worker, Meghan met with the oncology inpatient unit head nurse to address the issues that young adult patients had brought up during support group meetings. These issues included the importance of sleep hygiene while on the unit, technology and entertainment access, and care coordination.
- Meghan worked with the oncology inpatient unit head nurse to reinstate weekly multidisciplinary rounds, to include nursing, social work, discharge planning, and palliative care.
- Meghan and pediatric social worker presented to the Warrior Transition Brigade regarding the psychosocial needs of the active duty service member with cancer. The patient navigator provided pertinent information related to adolescent and young adult patients and families dealing with cancer.
- Meghan worked with the chief of pediatric oncology to create medication compliance bags, provided by UCF, to young adult patients. The bag includes a 30-day pill box, a water bottle, and a hand out with information about various phone apps designed to assist with medication compliance.
- Meghan distributed UCF information and resources during the Breast Care Center's Breast Cancer Awareness event in October.
- Meghan helped to facilitate celebrations for two patients' last chemotherapy treatments. UCF board member, Jess Tanner, and remote patient navigator Julie Lanahan shared their survivorship stories and provided inspiration for the patients and loved ones in attendance at these events.
- Five patients and their guests spent a beautiful afternoon at the Columbia Horse Center with several of their volunteer trainers and UCF staff. Most patients had never ridden before, so the experience was a very special one.
- Meghan assisted five patients with fertility preservation at the Fairfax Cryobank.

## PROGRAM GOALS

- Determine whether a more formal referral process would be beneficial and begin to research and implement the most efficient and effective methods.
- Join the workgroup being formed to start planning an AYA program at WRNMMC
- Offer two off-base social activities for young adult patients
- Continue polling patients' caregivers regarding their interest in a caregiver support group, to be facilitated by the oncology psychologist and UCF patient navigator

## STATISTICS FROM Q4



Number of patients seen  
**10**



Average age of patients\*  
**29**



Direct Services Provided to Patients  
Directed patients in seeking financial resources and programs



Gender split of patients  
**70% Female**  
**30% Male**



Types of cancer  
**20% Breast Cancer**  
**20% Sarcoma**  
(Bone, Ewings)  
**10% Acute Leukemia**  
**10% Hodgkins Lymphoma**  
**10% Lung Cancer**  
**10% Ovarian Cancer**

Encouraged patients to apply to our scholarship program

Introduced Cancer To 5K program

Engaged in peer to peer discussions

Introduced Helping Others Fight program

Connected patients to support group

Directed patients towards financial services



Location  
**50% Maryland**  
20% Montgomery County  
10% Baltimore City  
10% Baltimore County  
10% Howard County  
**20% Texas**  
**10% Indiana**  
**10% Missouri**  
**10% International**



Race / Ethnicity of patients  
**60% Caucasian / Non-Hispanic White**  
**20% Black or African American**  
**10% Middle Eastern**  
**10% Hispanic White**



Cancer Trajectory  
**40% Active Treatment**  
**20% Recently Diagnosed**  
**20% Active Treatment - Relapse**  
**10% Lost A Parent**  
**10% OFF Treatment**

\*Percentage numbers are rounded to nearest whole

## PROGRAM HIGHLIGHTS

- Developed relationships with Upper Chesapeake Medical Center, Mercy Medical Center and Union Memorial social workers. Met with each institution to explain UCF mission, UCF's direct services, and how we can better serve their patients through our remote Patient Navigation program.
- This year, 47 families were adopted during this holiday season by individuals, families or businesses for UCFs annual holiday gift drive.
- Worked with a young mom in treatment for ovarian cancer to secure hair prosthesis by utilizing the Jacqueline Shearer Memorial Fund. This was possible through a partnership with the Shearer Family and Versacchi Hair Studio in Owings Mills, MD.
- 511 scholarship applications have been started on the STARS system.

## HOW WE CHANGE LIVES

### Laura, Cancer Survivor

"I am so honored to be an Ulman Cancer Fund for Young Adults scholarship recipient. The scholarship provides great financial support, and its wonderful staff offers terrific emotional support. They truly understand the special needs of young adults. I proudly display my signed Mission to Vine flag, which reminds me that my family and I are not alone. As I know well, cancer changes lives, but as I now know, just as the mission statement says, so does the Ulman Cancer Fund. Knowing that there are people out there who care about young adults affected by cancer helps sustain my family as we continue to face our challenges."



## SCHOLARSHIPS

Victoria Diana Ricardo Memorial Scholarship awarded to Laura McKinnon on Mission to Vine in October 2014. This scholarship was made possible by Eric Ricardo, an alum of the 2014 Key to Keys journey, in memory of his mother.

## PROGRAM GOALS

- Identify and implement ways to increase attendance at support group meetings.
- Identify recipient of Satola Family Scholarship; to be awarded on Key to Keys 2015.
- Plan quarterly event in Harford County to engage young adults being treated in the Harford County and Cecile County areas further.
- Plan scholarship reviewer "How To" sessions as a way to prepare volunteers for reviewing scholarships.