

PATIENT
NAVIGATION
Quarterly Report

Q1

First Quarter Report

2014

the
ULMAN
CANCER
fund for
YOUNG
ADULTS

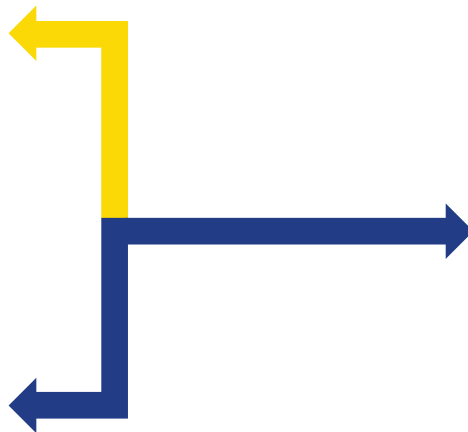
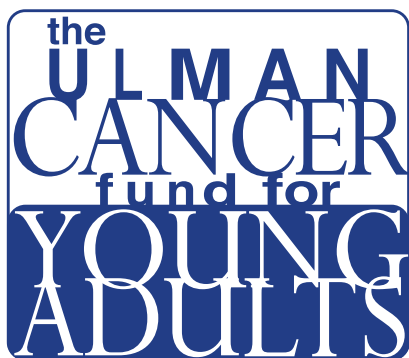


INSTITUTION OVERVIEW

Children's National Medical Center (CNMC) in Washington, DC is a 283-bed general facility and teaching hospital. There are approximately 14,000 admissions annually, with about 5,000 inpatient and 11,000 outpatient surgeries. The emergency room has over 81,000 visits per year.

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 Ulman Cancer Fund for Young Adults (UCF) and CNMC resulted in the placement of a patient navigator at CNMC in December 2013. The position is funded by the Shearer Family in memory of their daughter, Jacqueline Shearer, who was treated at CNMC during her cancer fight, as part of the Jacqueline Shearer Fund.



ABOUT THE UCF PATIENT NAVIGATOR

Meghan Fitzgibbons, MSW is the interim patient navigator at CNMC. She is part of the psychosocial team, which includes art, music, and yoga therapies as well as child life and an education specialist. This group is part of the larger care team, including social work, psychology and nursing.

Currently, Meghan works out of the Teen Room, which is a designated room on the hematology and oncology floor that provides a space for adolescents and young adult patients (AYA) ages 12 and over to socialize, participate in activities, play video games, watch DVDs, use the computers, read books, etc.

In the interim role, Meghan focuses on outreach to all adolescent and young adult patients (ages 12 and older), explaining the Teen Room and its equipment and functions, and encouraging patients to spend time in the room and to interact with others. Several times per month, Meghan plans age-appropriate activities and events that are offered in the Teen Room.

For AYAs being treated at a pediatric facility, connecting with others their age can be difficult. The Teen Room provides a designated location for AYAs to come together in a social setting and hosts activities that are more in-tune with the AYA age group.



Meghan Fitzgibbons, MSW
Interim patient navigator

STATISTICS FROM 1Q



Number of patients seen
65



Number of new patients seen
47



Types of cancer

Sickle Cell
Hgb Sickle Beta Thal
Medulloblastoma
AML
Lymphoma
Osteosarcoma
Choroid Plexus CA
Fanconi Anemia
IL 10 Receptor Defect
Hemophilia
Hodgkin's Lymphoma
Ewing's Sarcoma
Epitheloid Sarcoma
Sarcoma
Auto-immune Hemolytic Anemia
Myelodysplastic Syndrome
Ganglioneuroblastoma
Craniopharyngioma
Carcinoma

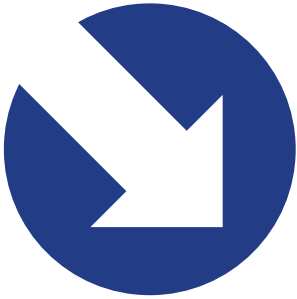


Age range / Average age of Patients
2-21 / 13.7

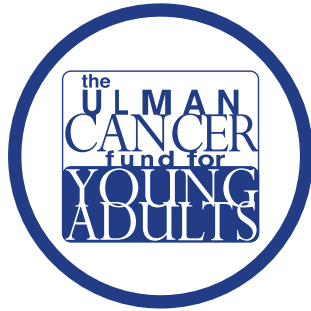


Race / Ethnicity of patients
64.6% African American
15.4% White
12.3% Hispanic
7.7% Middle Eastern

STATISTICS FROM 1Q



Direct Services Provided to Patients
One-on-one support to AYAs
Connection to Other AYAs in the hospital



Number of referrals to UCF services and resources & types of resources

- 1** CT5K
- 1** Support Groups
- 5** Helping Others Fight/Chemo Care Bags
- 7** Hospital Programs
- 2** Scholarships



This quarter, the Ulman Cancer Fund allocated the following in patient assistance funds to patients and their families at Children's National Medical Center:

\$100 Transportation Assistance

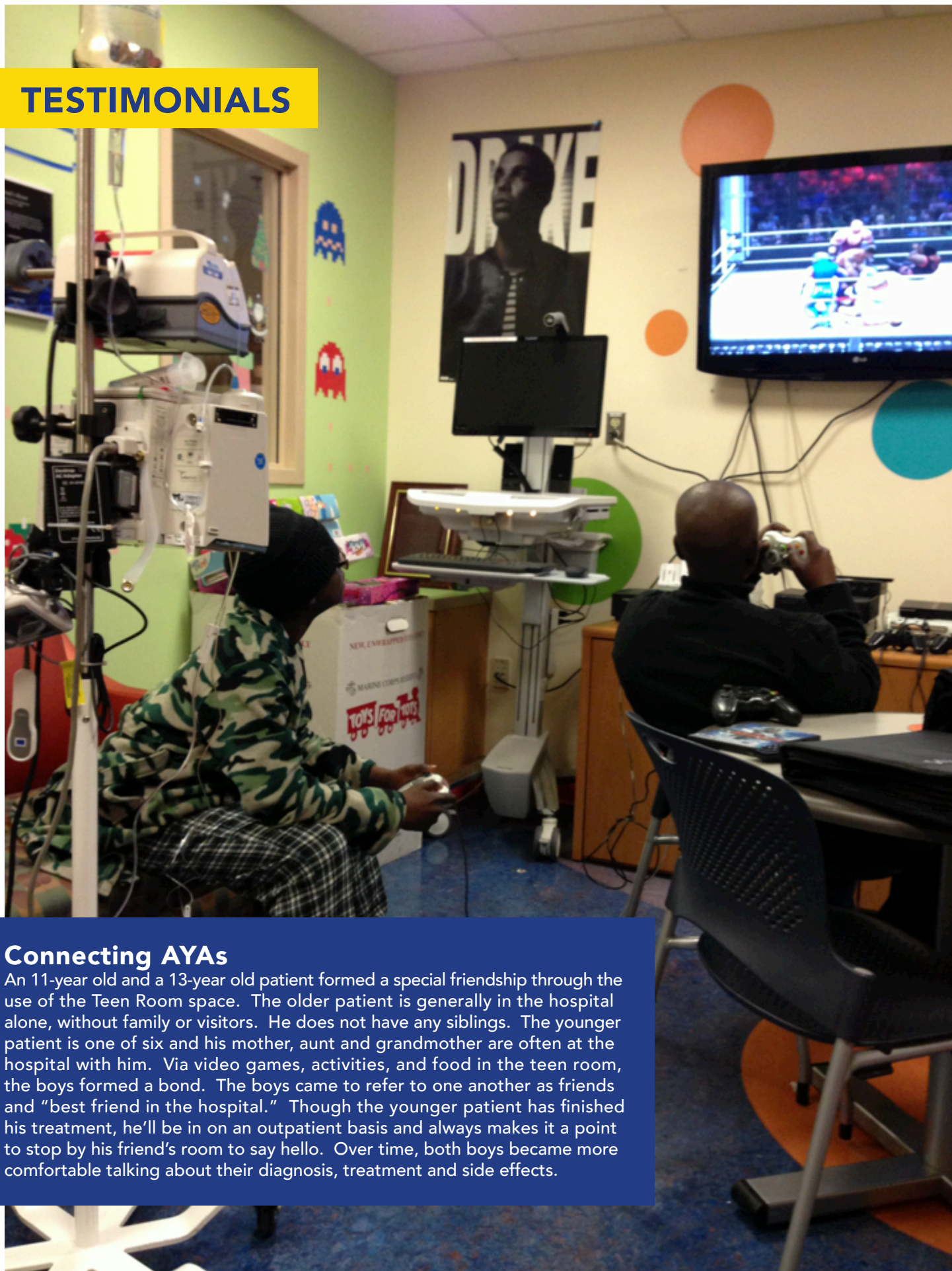
INSTITUTIONAL PARTNERSHIPS / DEVELOPMENT

- This position launched in December 2013. Since its launch, this position has focused on establishing relationships with both the clinical and psychosocial teams.

PROGRAM HIGHLIGHTS

- Reopened Teen Room
The Teen Room, which provides a central location for teens and young adults to come together, connect, socialize and participate in activities is now open four days per week for at least six hours per day.
- Drafted a letter reaching out to new AYA patients on the floor
- Hosted four events that were age-appropriate for AYAs
Served food / snacks and provided a venue for AYAs to connect and socialize
- Teen Room Grand Re-Opening
Pizza Party
- Olympic Opening Ceremonies Event
Screened "Cool Runnings"
- A Valentine's Day Party
Screened "The Notebook"
- Olympic Closing Ceremonies Event
Screened "Miracle"
- Engaged over ten AYA patients to connect others their age

TESTIMONIALS



Connecting AYAs

An 11-year old and a 13-year old patient formed a special friendship through the use of the Teen Room space. The older patient is generally in the hospital alone, without family or visitors. He does not have any siblings. The younger patient is one of six and his mother, aunt and grandmother are often at the hospital with him. Via video games, activities, and food in the teen room, the boys formed a bond. The boys came to refer to one another as friends and "best friend in the hospital." Though the younger patient has finished his treatment, he'll be in on an outpatient basis and always makes it a point to stop by his friend's room to say hello. Over time, both boys became more comfortable talking about their diagnosis, treatment and side effects.

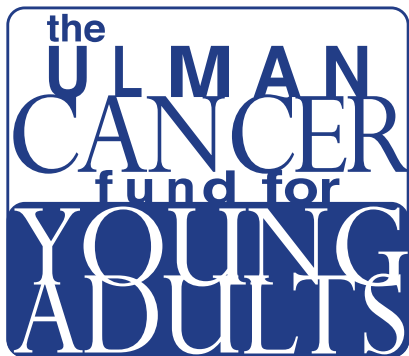
GOALS FOR NEXT QUARTER

- 1** Begin planning off-site activities for outpatients that could take place every month or every other month and provide a way for outpatient AYAs to connect in a social setting.
- 2** Plan more enticing activities and secure more equipment in Teen Room for inpatients that meet their interests and needs.
- 3** Work with the psychosocial and clinical team to open up the Teen Room "services" to outpatient clinic area.

INSTITUTION OVERVIEW

Greater Baltimore Medical Center (GBMC) is a 255-bed medical center (acute and sub-acute care) located in Towson, Maryland sees over 26,700 inpatient cases and approximately 60,000 emergency room visits annually.

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, making it among the largest of any community hospital in the mid-Atlantic region.



ABOUT THE UCF PATIENT NAVIGATOR

Sharon Curran, RN, is UCF's Patient Navigator at the GBMC's Sandra and Malcolm Berman Cancer Institute. Sharon is a Master's Prepared Nurse with a focus in Psycho-Oncology. She functions in the role of a Clinical Nurse Oncology Patient Navigator in a volunteer status at GBMC in the Oncology Support Service Department. Sharon primarily provides services to young adult cancer patients ages 18-40 and their families.



Sharon Curran, RN

STATISTICS FROM 1Q



Number of patients seen
16



Number of new patients seen
4



Types of cancer
Breast
Lymphoma
Sinus
Uterine
Ovarian
Colon
Parotid Gland

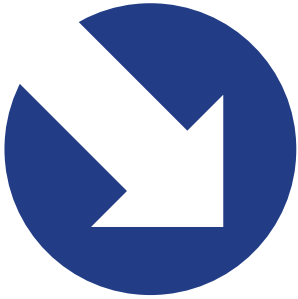


Age range / Average age of Patients
26-44 / 35



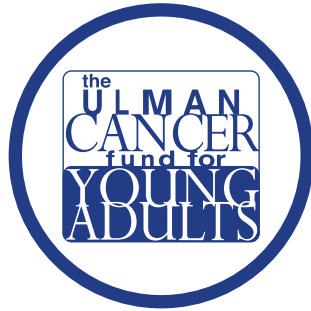
Race / Ethnicity of patients
87% Caucasian
13% African American

STATISTICS FROM 1Q



Direct Services Provided to Patients

- **One-on-one support**
- **Fertility Preservation / Counseling**
- **Financial Assistance**
- **Resource Coordination**
- **Enhancement of Social Support Network**
- **Support to Families / Caregivers**
- **Work / Job / School Re-Entry**
- **Health Insurance / Medical Assistance**
- **Transportation Support**
- **Support Group**
- **Connection to Other AYAs**
- **Other Direct Services**



Number of referrals to UCF services and resources & types of resources

- 16** CT5K
- 16** Support Groups
- 16** Helping Others Fight
- 2** Hospital Program
- 16** Community Program
- 2** Peer Connection



There were no patient assistance funds allocated in Q1 to GBMC patients.

INSTITUTIONAL PARTNERSHIPS / DEVELOPMENT

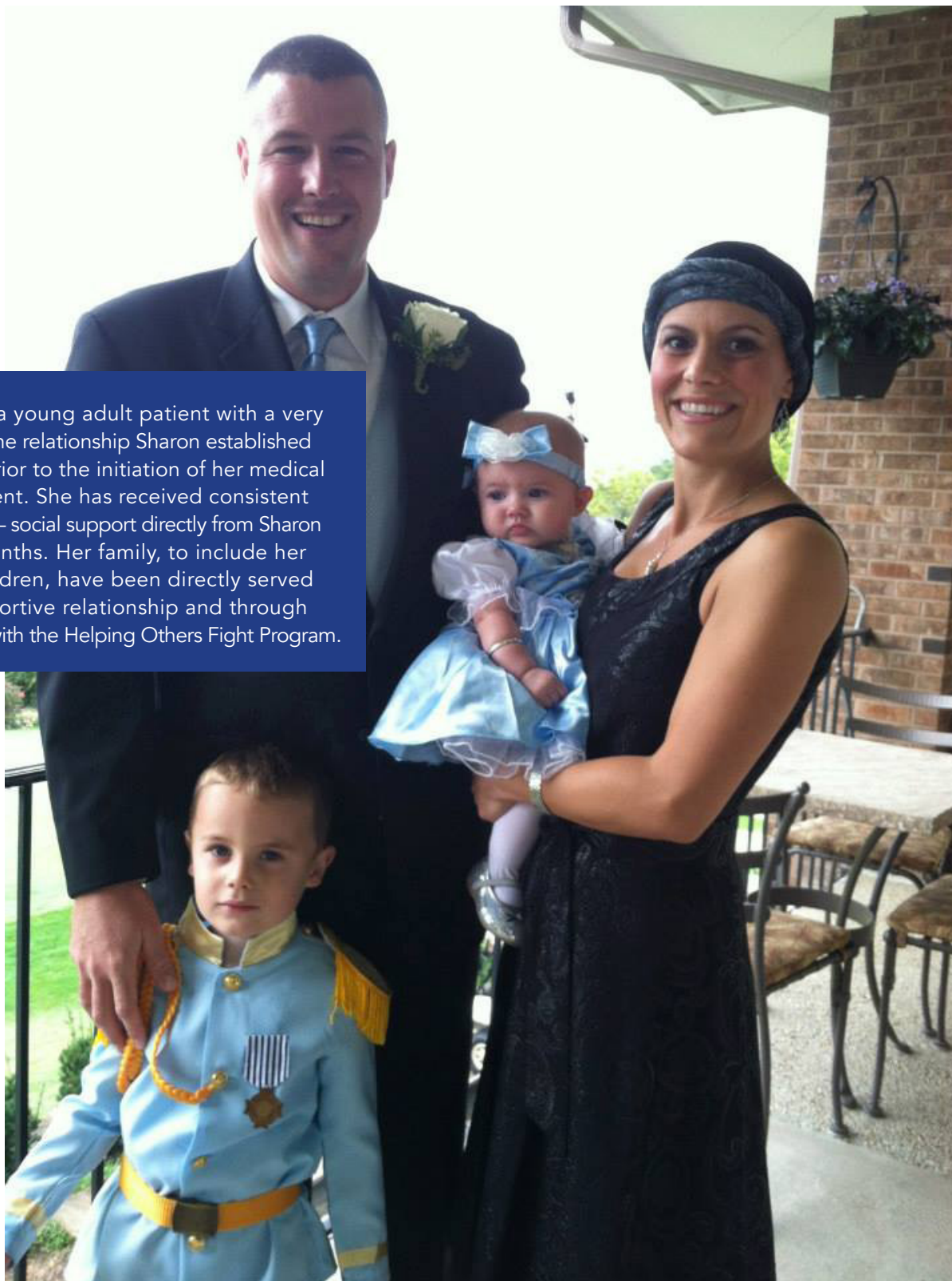
- Sharon as an active member of the GBMC Oncology Support Services team of oncology health care professionals, regularly engaging the survivorship nurse, the infusion nursing team, the social workers and management in the coordination of care for the patients and families she serves. She also coordinates at times with the oncology dietician/ nutritionist, Pas, NPs, MDs.
- Sharon is an active member of the Oncology Nursing Journal Club at GBMC.
- Sharon attends Oncology Quarterly Staff Meetings, Oncology Lunch & Learns, and Oncology Grand Rounds, and Compassionate Care Rounds.

PROGRAM HIGHLIGHTS

- Engagement with the purpose of supporting, educating and advocating for patients and families.
- Sharon receive positive feedback on a regular basis from the nursing , oncology support and medical oncology staff for my work in building therapeutic relationships with the patients and families that support the patient from the time of diagnosis through their survivorship.
- Connecting patients and families at GBMC with UCF programs such as Helping Others Fight.

TESTIMONIALS

Kristin Kohnle is a young adult patient with a very complex illness. The relationship Sharon established with her began prior to the initiation of her medical oncology treatment. She has received consistent psycho-emotional – social support directly from Sharon for the past 9 months. Her family, to include her husband and children, have been directly served through my supportive relationship and through connecting them with the Helping Others Fight Program.

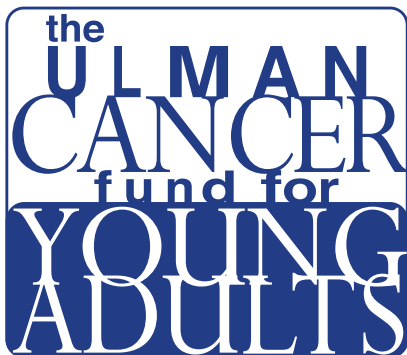


GOALS FOR NEXT QUARTER

- 1** Enhanced engagement with the GBMC oncology treatment team to increase patient referrals.
- 2** In-service planning with other UCF Patient Navigators for first presentation to the team hopefully presented in July 2014.
- 3** Meeting and further collaboration with Oncology Patient Navigation/ Social Work/ Survivorship Nurses at GBMC.

INSTITUTION OVERVIEW

In January 2012, Ulman Cancer Fund for Young Adults launched an innovative partnership with the Department of Pediatric Oncology at The Johns Hopkins Hospital and The Sidney Kimmel Comprehensive Cancer Center at Johns Hopkins. The centerpiece of the partnership is a UCF-funded Adolescent and Young Adult (AYA) Patient Navigator (Alexandra Gubin, MSW, LGSW), who serves 15 to 25 year old patients in Pediatric Oncology at The Johns Hopkins Hospital. The young adult patient navigator works in conjunction with the Cancer Center's multi-disciplinary team to assist patients and their families through the following: individual/family counseling, fertility preservation guidance, resource activation for housing, transportation, and other cancer treatment-related needs, financial assistance, and community/social support.



ABOUT THE UCF PATIENT NAVIGATOR

Alexandra Gubin, MSW, LGSW serves as the Young Adult Patient Navigator at The Johns Hopkins Hospital. She comes to the program with a Master of Science in Social Work from Columbia University and also has an extensive background in establishing and executing programmatic and clinical support initiatives for adolescent and young adult cancer patients.



Alexandra Gubin, MSW, LGSW

STATISTICS FROM 1Q



Number of patients seen
35



Number of new patients seen
10



Types of cancer
Lymphoma
Leukemia
Sarcoma
Brain
Liver
Nerve Sheath

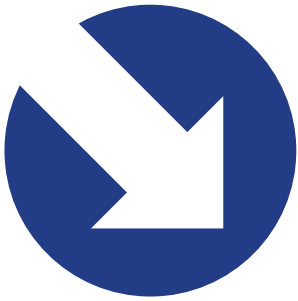


Age range / Average age of Patients
15-24 / 19.5



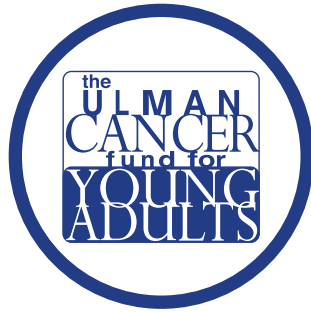
Race / Ethnicity of patients
70% Caucasian
23% African American
3% Hispanic
3% Asian

STATISTICS FROM 1Q



Direct Services Provided to Patients

- 30** One-on-one support
- 2** Fertility Preservation / Counseling
- 5** Financial Assistance & Types
- 25** Resource Coordination
- 10** Enhancement of Social Support Network
- 30** Support to Families / Caregivers
- 2** Work / Job / School Re-Entry
- 1** Health Insurance / Medical Assistance
- 3** Transportation Support
- 4** Support Group
- 2** Connection to Other AYAs
- 5** Other Direct Services



Number of referrals to UCF services and resources & types of resources

- 1** CT5K
- 4** Support Groups
- 4** Helping Others Fight
- 30** Community Program
- 1** UCF Staff
- 2** Scholarships



This quarter, The Ulman Cancer Fund allocated the following in patient assistance funds to patients and their families at The Johns Hopkins Hospital and Sidney Kimmel Cancer Center:

There were no patient assistance funds allocated in Q1.

INSTITUTIONAL PARTNERSHIPS / DEVELOPMENT


Allie continues to expand upon the AYA Work Group that she and a fellow nurse initiated last year. The purpose of the group is to examine clinical practices and policies around adolescent and young adult oncology care. Currently, Allie is focused on strengthening the practice of utilizing advance directives with young adult patients as well as developing strategies for honoring patient confidentiality of young adult patients.

PROGRAM HIGHLIGHTS

- Allie received approval to start a Young Adult Cancer Group for the Cancer Center, a partnership between Adult and Pediatric Oncology.
This group would serve people in treatment in their 20's and 30's throughout the Cancer Center. (in both pediatric and adult oncology)

TESTIMONIALS

Gino D. was finishing his junior year of high school when he was diagnosed with Acute Myeloid Leukemia. It was bad timing. He was working at a job, finishing driving school, and getting ready for AP exams. Summer was right around the corner. But he couldn't kick a cough and runny nose for over 5 weeks and as soon as the doctors did blood work, they saw the leukemia cells. Everything changed for him in an instant.



Gino was treated at Johns Hopkins Sidney Kimmel Cancer Center, where he had five months of inpatient treatment, including a bone marrow transplant. It was there that he met UCF's Patient Navigator, Allie Gubin. When Gino finished treatment, Allie introduced him to other UCF programs, such as Team Fight and Cancer to 5K, and it opened his eyes to the variety of ways that UCF helps survivors like him. He joined Cancer to 5K in the Fall of 2013 and proudly finished UCF's Half Full 5K on October 6, 2013.

"Allie helped me and my family a lot. It was her job to make me feel like I was at home. If there was anything I needed, she would find a way to get it for me. If I needed someone to talk to, she was there. When it was time for me to apply for college, she found me some scholarships and fee waivers so the cost wouldn't be so much, and when school started, she tried to find a tutor for me."

GOALS FOR NEXT QUARTER

1

Continue to grow AYA Work Group with the goal to educate healthcare providers on AYA-related health care issues and to enhance AYA clinical care practices.

2

Launch Young Adult Support Group at Hopkins.

3

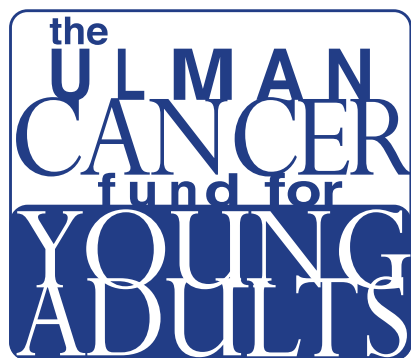
Expand UCF program offerings to include other relevant services/support programs for Hopkins' patients.

INSTITUTION OVERVIEW

University of Maryland Greenebaum Cancer Center (UMGCC) is located in downtown Baltimore, Maryland. Patients come from all areas of the state and the Baltimore-Washington region. A small percentage of patients come from Pennsylvania. While patients come from a variety of socio-economic backgrounds UMGCC does serve a significant percentage of patients from challenged financial and social circumstances.

Young adult patients are served through the Ulman Fund Patient Navigation Program throughout the medical center. This includes the three adult inpatient units (N9W, N8W, BMT), Stoler Pavilion – Infusion Center and Outpatient Clinic, Radiation Oncology, and Pediatric Oncology Inpatient and Outpatient Units. Young Adult patients and their families are also seen in the MICU and on post-surgical care units, in Interventional radiology, medical office building with specialists (16 S. Eutaw and 419 W. Redwood).

The majority of young adults served are ages 18-40 years.



UNIVERSITY of MARYLAND
MARLENE AND STEWART GREENEBAUM
CANCER CENTER

ABOUT THE UCF PATIENT NAVIGATOR

The Ulman Fund Young Adult Patient Navigation Program has operated at the University of Maryland Greenebaum Cancer Center since March 2008.

Elizabeth Saylor, MSW, directs the young adult patient navigation program at UMGCC. She works in conjunction with the Cancer Center's multi-disciplinary treatment teams, social work staff and other care providers to improve the ability of young adults to manage their own cancer experiences and long-term cancer survival.



Elizabeth Saylor, MSW

STATISTICS FROM 1Q



Number of patients seen
52 (UMGCC)
3 (Non-UMGCC)
55 (Total)



Number of new patients seen
18 (UMGCC)
1 (Non-UMGCC)
19 (Total)



Types of cancer
Acute Leukemia (AML & ALL)
Chronic Leukemia (CML, CLL, CMML)
Lymphoma (Hodgkins & various NHL)
Cervical
Testicular
Esophageal
Pancreatic
Sarcoma
Carcinomas - Head & Neck
Lung
Brain - variety
Breast



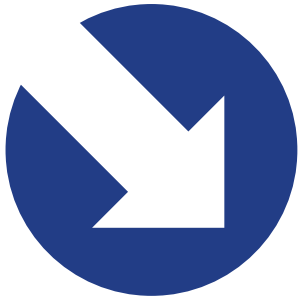
Age range / Average age of Patients
17-46 / 31.5
Patients below 18 are seen in Pediatric Oncology and are either fertility consults or LTFU (young adult survivors of childhood cancer)

Patients over 40 are either fertility consults or consults relating to young adult children coping with a parent's cancer.



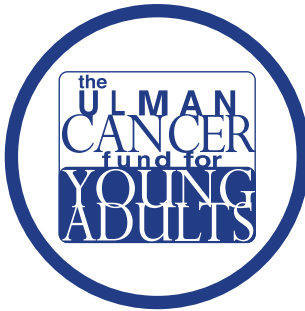
Race / Ethnicity of patients
49% Caucasian
38% African American*
9% Hispanic
4% Asian
**2 patients immigrated from the continent of Africa*

STATISTICS FROM 1Q



Direct Services Provided to Patients

- **One-on-one support**
- **Fertility Preservation / Counseling**
- **Financial Assistance**
- **Resource Coordination**
- **Health Insurance / Medical Assistance**
- **Transportation Support**
- **Support Group**
- **Connection to Other AYAs**



Number of referrals to UCF services and resources & types of resources

- **Financial assistance related to transportation**
- **Financial assistance related to fertility preservation**
- **Helping Others Fight (HOF)**
- **Cancer to 5K**
- **Comprehensive Cancer Wellness Program at Towson University**
- **Peer support/mentoring**



This quarter, The Ulman Cancer Fund allocated the following in patient assistance funds to patients and their families at UMGCC:

\$900 Transportation
\$600 Fertility Preservation

INSTITUTIONAL PARTNERSHIPS / DEVELOPMENT

Elizabeth Saylor is an important part of the multidisciplinary care team that young adult patients receive at UMGCC. She has access to young adult cancer patients anywhere in the medical center and receives referrals from staff at all levels – from unit secretaries and coders to established faculty members.

- Participates unit rounds and is frequently an active member in family end of life/palliative care meetings.
- Continues to reach young adults who are living with cancer and HIV by working closely with the Jacques Institute at UMMC as well as the attending Infectious disease physician who to provide the most appropriate list of resources and information.
- Facilitates several supportive peer-mentoring relationships with young men impacted by HIV and blood cancer who also identify as gay.
- Active member of the Patient Education Workgroup.

PROGRAM HIGHLIGHTS

- Partnered with the outpatient social worker and the ACS Patient Navigator to hold weekly “mini cluster” meetings to discuss challenges and strategies for young adults being seen in the outpatient center.
- Has built a successful working relationship with the new inpatient leukemia social worker and collaborates often on young adult cases.
- Presented at APOS (American Psycho -Social Oncology Society) Annual Conference on the Comprehensive Cancer Wellness Program at Towson University.
- Participated in the Ulman Cancer Fund’s Cancer to 5K Coaches Symposium, offering a brief training on psychosocial realities young adults face after an experience with cancer.

TESTIMONIALS

Diana is a Caucasian patient that was diagnosed with Hodgkins Lymphoma in her late 30s. Diana is married, has a young daughter and teenaged daughter and significant support from extended family, with grandparents often caring for the children during Diana's treatment.

Suffering from a complicated form of Hodgkins Lymphoma, which has not responded completely to first or second line therapies, she is now undergoing a bone marrow transplant with stem cells secured from a matched, unrelated donor.

Diana's main concerns center around helping her two daughters cope with her illness and scheduling chemotherapy treatments around significant events such as her elder daughter's choral performances. She acknowledges that the commute to and from the hospital is expensive and greatly appreciates the support UCF has provided through gas cards.

Elizabeth has been able to provide resources to Diana and her family to assist in their children's coping and offer strategies that have been successful for other families – such as a "cleaning party" to prepare for mom's return from hospital – which allows girls to feel part of mom's experience and control over what is happening. In addition, Elizabeth worked with the medical team and medical oncologists to ensure that Diana's employer received the appropriate paperwork during her treatment.

Tinisha is African-American women from Baltimore. She is in her mid-20s and has metastatic cervical cancer. She does not have health insurance. She presented to the UMMC emergency room with extensive bleeding which required immediate surgery.

Tinisha has moderate family support from her mother and her boyfriend, but is often alone during her appointments.

Tinisha introduced to Elizabeth by the medical, surgical and oncology teams caring for her. Team members were very concerned about her compliance with treatment. Over the past few months Elizabeth and Tinisha have nurtured a relationship build on trust and respect. Elizabeth provides support to Tinisha by driving her to and from appointments and have staying with her during painful procedures and treatments. Without Elizabeth's support, Tinisha would be alone in her cancer fight.

GOALS FOR NEXT QUARTER

- 1** Work with more faculty who would endorse psychosocial and behavioral research that would lift up best practices for reducing mortality rates in young adult patients.
- 2** Identify residents and fellows who could be trained in young adult cancer care and provide further education on young adult cancer issues and realities.
- 3** Convene a workgroup of clinicians and administrators to develop a hospital protocol for young adult fertility preservation.