How Far We’ve Come:
5-Year Summary of the Reid R. Sacco Adolescent & Young Adult (AYA) Cancer Program

Reid R. Sacco
Adolescent & Young Adult (AYA) Cancer Program
Providing survivorship care to AYAs with a history of cancer.

Clinic

Research
Training
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Director’s Message

Nearly 30 years ago, in the blockbuster motion picture *Field of Dreams*, a farmer standing in a cornfield in Iowa heard an inspiring message:

“If you build it, they will come.”

Five years ago, thanks to the generosity and vision of the Reid R. Sacco Adolescent and Young Adult (AYA) Cancer Alliance and the commitment of the Tufts Medical Center leadership, the Reid R. Sacco AYA Cancer Program was born.

In this report, we share with you the results of the program’s first five years. *We built it; who came?* Since its inception, we have had the privilege of caring for more than 100 cancer survivors, forged key clinical collaborations within our medical center to provide needed specialty and subspecialty expertise, trained more than a dozen sensational future healthcare providers, conducted innovative research targeting AYAs, and have reached hundreds of young adults through our educational outreach initiative.

We hope you enjoy reading about how far we’ve come and where we are going over the next five years. Thank you for your continued support.

Best wishes,

Susan Parsons, MD
Survivorship Care: Program Team

The AYA Cancer Program team is proud to bridge the pediatric- and adult-hematology/oncology divide. Patients benefit from the collective experience of a pediatric-trained oncologist, an adult-trained oncologist, and an adult-trained oncology nurse practitioner. The team also includes our program manager and a pediatric-trained oncology nurse practitioner who serves as a transitions coordinator.

**Susan K. Parsons, MD, MRP, Medical Director**, has more than 25 years of experience as a board certified pediatric hematologist/oncologist. She is a Professor of Medicine and Pediatrics at Tufts University School of Medicine (TUSM), Associate Director of the Tufts Cancer Center and Director of the Center for Health Solutions within the Institute for Clinical Research and Health Policy Studies at Tufts Medical Center (Tufts MC).

**Anita Kumar, MD, MSCE**, is an adult-trained oncologist, with a specialty in hematologic malignancies. Dr. Kumar assists adult patients who are transitioning to survivorship care following active treatment in the Tufts Cancer Center, as well as provides continuous survivorship care to individuals over the age of 39. She is an Assistant Professor at TUSM.

**Nadine Linendoll, PhD, MDiv, GNP**, is the program’s adult-trained nurse practitioner. Dr. Linendoll specialized in neuro-oncology, prior to devoting her time at Tufts MC to the AYA Cancer Program. In addition to seeing AYAs in clinic, Dr. Linendoll prepares the majority of patients’ Treatment Summaries, which serve as the foundation of our Follow-Up Care Plans. She is an Assistant Professor at TUSM.

**Rachel Murphy-Banks, MA**, is the program’s manager. Rachel is the point of contact for scheduling and greets all patients at their clinic appointment. She works with the care team to ensure patients and their other providers receive their most up-to-date Follow-Up Care Plan after each visit. Rachel oversees the program’s social media presence and contributes to outreach efforts.

**Annmarie Conroy, PNP**, serves as the program’s transition coordinator. AYAs who have completed treatment for their cancer at the Floating Hospital for Children are introduced to the AYA Cancer Program by Annmarie who also provides pediatric patients with their Treatment Summary.

**Former Care Team Member Update:**

**Erin Barthel, MD**, continues to work with Dr. Parsons on AYA-related research. She is now at Seattle Children’s Hospital, providing survivorship care.
Survivorship Care: What Is It?

Our aim is to provide age-appropriate, comprehensive survivorship care to AYAs (aged 18-39 years old) who have ever been diagnosed with cancer.

**Survivorship care** – a distinct phase of care

- **Surveillance** for cancer spread, recurrence, or second cancers
- Diagnostic testing

- **Intervention** for consequences of cancer and its treatment
  - Long-term and/or late-effects include:
    - Heart problems
    - Neuro-Cognitive deficits
    - Early menopause/Sexual problems
    - Mental distress-depression, anxiety
    - Neuropathy-numbness or pain
    - Reduced lung function

- **Prevention and detection** of new cancers and recurrent cancer
- Healthy lifestyle behaviors

- **Coordination** among specialists and primary care providers to ensure that all of the survivor’s health needs are met

Traditionally, patients have been followed by their treating oncology team for a set period of time during and after the completion of initial treatment. While some patients remain under their oncologist’s care, others either transition to survivorship care or are lost to follow-up. Our model introduces survivorship earlier on in the process. In collaboration with the primary oncologist, patients learn about the goals and services of survivorship care throughout the surveillance period in a shared care model. Ultimately, the patient transitions to survivorship care when both the patient and care team are ready.
Survivorship Care Plans are utilized to help AYAs and their care team manage initial- and/or late- effects from therapy as well as risks associated with cancer treatments.

The Survivorship Care Plan includes the (1) Treatment Summary (top image) which summarizes the cumulative chemotherapies, radiation and/or surgeries extracted from the patient’s medical records. And (2) the Follow-Up Care Plan (illustrative bottom image) which provides a whole-body view of each (potentially) effected organ system, associated diagnostic test, indication for the test, oncological guidelines suggested time interval between tests, when the test was last completed and which member of the patient’s care team is responsible.

<table>
<thead>
<tr>
<th>Organ System</th>
<th>Test</th>
<th>Indication</th>
<th>Time Interval</th>
<th>Last Completed/Plan</th>
<th>Responsibility</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cardiac</td>
<td>ECHO</td>
<td>Risk of cardiomyopathy from Doxorubicin &amp; radiation</td>
<td>At baseline at entry into clinic, and then every 2 years</td>
<td>7/17/17 Next appt: 2019</td>
<td>Survivorship; Cardiologist</td>
</tr>
<tr>
<td></td>
<td>EKG</td>
<td></td>
<td>At baseline at entry into clinic and then as clinically indicated</td>
<td>7/17/17</td>
<td>Survivorship; Cardiologist; PCP</td>
</tr>
<tr>
<td></td>
<td>BMI</td>
<td>Modifiable risk factors</td>
<td>At every visit</td>
<td>7/17/17</td>
<td>Survivorship; Cardiologist; PCP</td>
</tr>
<tr>
<td></td>
<td>Blood pressure</td>
<td>Modifiable risk factors</td>
<td>At every visit</td>
<td>7/17/17</td>
<td>Survivorship; Cardiologist; PCP</td>
</tr>
<tr>
<td></td>
<td>Fasting lipid profile</td>
<td></td>
<td>Every 2 years</td>
<td>7/17/17</td>
<td>Survivorship; Cardiologist; PCP</td>
</tr>
<tr>
<td>Pulmonary</td>
<td>Pulmonary Function Tests (PFTs)</td>
<td>Surveillance; Asthma</td>
<td>At baseline at entry into clinic and then as clinically indicated</td>
<td>7/17/2017</td>
<td>Survivorship; Pulmonologist</td>
</tr>
<tr>
<td>Musculoskeletal</td>
<td>DEXA Scan</td>
<td>Exposure to radiation</td>
<td>Every two years</td>
<td>7/17/2017</td>
<td>Survivorship</td>
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<tr>
<td>Dermatology</td>
<td>Skin exam of irradiated fields</td>
<td>Exposure to radiation; risk for secondary cancer</td>
<td>Annually</td>
<td>5/16/17</td>
<td>Dermatologist; PCP</td>
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<tr>
<td>Breast Health/Gynecology</td>
<td>Mammogram</td>
<td>Surveillance; Risk of secondary breast cancer</td>
<td>Annually</td>
<td>4/13/17</td>
<td>Breast Health; Gynecologist</td>
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<td>Gynecology Exam</td>
<td>General Wellness</td>
<td>Annually</td>
<td>3/9/17</td>
<td>Gynecologist; PCP</td>
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<td>Dental</td>
<td>Cleaning and Exam</td>
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<td>Every 6 months</td>
<td>2/10/17</td>
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<td>Immunizations</td>
<td>Annual Flu Shot</td>
<td>General Wellness</td>
<td>Annually</td>
<td>10/11/16</td>
<td>PCP</td>
</tr>
</tbody>
</table>
Clinic

The AYA Cancer Program offers clinic appointments on Monday afternoons. The 7th floor clinic in the South Building (referred to as South 7) of Tufts MC has been the program’s base from our first patient’s visit. The dedicated physical space for AYAs is designed to address the disconnect AYA patients report from being surrounded by other patients who are either much younger or much older, if cared for in pediatrics or general adult clinics.

AYA Survivorship & Cardio-Oncology Clinic

Cardio-Oncology is an interdisciplinary specialty for patients who have/had cancer and cardiovascular disease. AYAs who have been treated with anthracyclines and/or alkylator chemotherapy with or without radiation are at increased risk for cardiovascular late effects.

The Cardio-Oncology Program was founded at Tufts MC in the summer of 2016. On select Mondays throughout the year cardio-oncologist, Dr. Jenica Upshaw, is available for clinic appointments. Patients are able to see their survivorship specialist in AYA and then Dr. Upshaw, without changing locations.

The AYA Cancer Program care team works closely with Dr. Upshaw on which patients should be seen in Cardio-Oncology, how frequently a diagnostic testing should be performed, and ongoing medication management. Dr. Upshaw has had 49 visits with patients in our joint clinic to date.
Clinic: Who Came?

Below we share the various methods of how patients learned about the AYA Cancer Program (predominately by other providers), as well as a summary of diagnoses our patients have received.

**Sources of Referrals:**
- **Tufts Cancer Center:** Hematology/Oncology; Radiation Oncology; Neuro-Oncology
- **Floating Hospital for Children:** Pediatric Hematology/Oncology
- **Dr. Parsons:** Patients who had been treated by, or known to, Dr. Parsons prior to the creation of the AYA Cancer Program
- **Self:** Online searches for survivorship care, friends/patients of the program, program outreach efforts, Chronicle tv show

Each person seen in our program receives a Survivorship Care Plan (as outlined on p. 5), regardless of underlying diagnosis or year of treatment. This philosophy has allowed us to welcome patients with a wide range of diagnoses, including:

- Leukemia
- Lymphoma
- Breast
- Sarcoma
- Thyroid
- Neuroblastoma
- Myelodysplastic syndrome
- Lung
- Kidney tumors
- Head and neck
- Brain tumor
- Ovarian
- Testicular
The first AYA Cancer Program patients were welcomed in our clinic on January 7, 2013. Between that time and the end of 2017, 114 individuals who had been diagnosed with cancer under the age of 40 received survivorship care over the course of 427 visits.

90% of the patients who have entered survivorship care with our program have continued within our care. The principal reasons why the remainder of patients no longer receive their care here include changes in insurance eligibility and/or physical distance from Boston.

The frequency of patient visits varies based on need and patient complexity. Some patients return for an annual follow-up visit, while others are seen on a 3- or 6-month basis. At each visit, patients receive an updated Follow-Up Care Plan (illustrative image p.5).
Clinic: Patient Population

The National Cancer Institute defines the Adolescent & Young Adult cancer demographic as individuals diagnosed with cancer between the ages of 15 – 39 years old. Our AYA Cancer Program utilizes this definition by welcoming individuals in the AYA age range who have been diagnosed with cancer either as children, but who have aged into the AYA age range, or who were diagnosed with cancer in the AYA age range.

We work closely with our colleagues in pediatric hematology/oncology, led by our transitions coordinator, Annmarie Conroy, PNP, to facilitate the transitioning of care from pediatric- to adult-based care as younger patients may face a difficult transition into survivorship and/or adult-based care.

Additionally, to continue serving our patients who have aged beyond the AYA demographic, we have established a separate Adult Survivorship Program for patients aged 40 and over.

All of our patients have been diagnosed with cancer under the age of 40 years, of which:

- 67% of patients were diagnosed between 0-14 years old
- 33% of patients were diagnosed between 15-39 years old

In our effort to continually improve the survivorship care provided to our patients, over the last year Dr. Parsons has worked with summer scholars (Lisa Bartucca, Diana Mihalache, and Haylee Rosenblatt) as well as our database manager (Ruth Ann Weidner) to develop a tool to measure our patients’ survivorship risk factors based on disease and treatment, as well as their adherence to Survivorship Care Plan recommendations.

The following is a snapshot of our patients upon entry into our program:

- 66% of patients had been seen in any oncology care over the prior two years
- 34% of patients were receiving psychological care or medication for mental health issue(s)
- 53% of patients had at least ONE known late effect
- Following their introductory AYA Cancer Program appointment, patients were recommended to receive a median of SEVEN diagnostic tests or specialty/subspecialty referrals (range 2-13 tests/referrals)
Clinic: Care Coordination

Care coordination is important throughout the cancer care continuum, including in survivorship. The AYA Cancer Program works with medical and psychosocial providers, primary care physicians, and when applicable the patient’s primary oncologist to ensure follow-up care and testing is timely, comprehensive and streamlined.

We have included here a subset of the specialists/subspecialists to whom the AYA Cancer Program care team routinely partners with in our care of AYAs.

Breast Health/Medical Oncology
Drs. John Erban, Rachel Buchsbaum, Robert Martell

Cardiology
Drs. Gordon Huggins, David Denofrio

Colorectal
Dr. James Yoo

Dermatology
Drs. David Rosmarin, Bichchau Michelle Nguyen, Shiu-Chung Au, Jeffrey Sobell

Endocrinology
Drs. Jacqueline Kung, Ronald Lechan, Lisa Ceglia

Ear, Nose + Throat (ENT)
Drs. Miriam O’Leary, Richard Wein
Research: Ongoing

Research is an integral part of the AYA Cancer Program. Our goal is to continually evaluate how we can improve our care of current survivors, as well as inform the design of upfront cancer care.

Each member of our team has a specific research focus:

- Dr. Parsons’ interests include patients’ quality of life and economics of cancer treatment.
- Dr. Kumar’s focus is on improving care delivered to patients with hematologic cancers, including the decision making process for older adults with these cancers.
- Dr. Linendoll’s work focuses on screening methods to detect neurocognitive and psychological challenges.

National Studies:

Dr. Parsons serves as a member of the Hodgkin Lymphoma (HL) Steering Committee of the Children’s Oncology Group, actively collaborating on ongoing and future trials of children, adolescents and young adults with newly diagnosed HL. She is leading two embedded studies in a Phase III clinical trial to determine the economics of novel cancer treatment and the functional consequences of chemotherapy-induced peripheral neuropathy, a frequent side effect of treatment with chronic sequelae.

With Dr. Kumar, she is also conducting a study of patterns of salvage therapy after HL relapse or progression in a community setting. This study is in collaboration with Kaiser Permanente of Southern California and Seattle Genetics.

With Dr. Upshaw, Dr. Parsons is collaborating with investigators from the Eastern Cooperative Oncology Group (ECOG) to develop a predictive model of cardiac toxicity after chemotherapy for breast cancer.

AYA Cancer Program Generated Studies:

Over the years the research studies generated by the program has sought to share the experiences of AYAs who receive their care within the AYA Cancer Program, in the hopes of other program’s recreating our care model and identifying gaps in the care of AYAs in survivorship. Published outcomes of our work are located on the next page.

Currently in progress:

- Measuring adherence to Survivorship Care Plan recommendations and the impact of:
  - Referral patterns
  - Psychological status
  - Existing late effects
    Initial results are shared on p. 9 of this report.
- Transitions in testing: How pediatric vs. adult ECHOs are interpreted
- Developing screeners for neurocognitive and psychological functioning
Historically, there have been a disparate number of publications dedicated to the AYA oncology demographic. Here are three of the publications published by members of our team. We are currently working on additional publications related to survivorship care planning!

Below is our latest publication, which is not yet in print. This study included both the AYA Cancer Program as well as the University of Chicago’s Childhood and AYA Cancer Survivor Center.
Research: Contributions

Posters, such as the image below presented in 2017, enable wide dissemination of our work to diverse audiences. Presented at the American Society of Clinical Oncology (ASCO) Survivorship Symposium by Dr. Parsons and summer scholar Lauren Boehm, this poster was the result of a collaboration between Tufts Medical Center and the New England Cancer Specialists, in Maine, showing the development and expansion of Survivorship Care Plans, for survivors of breast cancer.

Additional Posters Have Been Presented At:

• Critical Mass: The Young Adult Cancer Alliance (Chicago, IL, 2015)
• 10th International Symposium on Hodgkin Lymphoma (Koln, Germany, 2016)
• 58th American Society of Hematology Annual Meeting (San Diego, CA, 2016)
• 14th Annual American Medical Association Research Symposium (Orlando, Florida, 2016)
• Inaugural & 2nd Annual ASCO Survivorship Symposium (San Francisco, CA, 2016; San Diego, CA, 2017)
A core feature of the AYA Cancer Program is training future healthcare professionals. Young adults interested in helping other young adults, and learning about AYA oncology, have participated in the program since its inception in various roles.

**Peer navigators** have provided patients with age-matched assistance within and outside of appointments.

**Medical school selective/elective interns & Research assistants** have shadowed the AYA care team in clinic appointments as well as contributed to research projects.

**Summer scholars** have joined the program for their summer between 1st and 2nd year of medical school. They are provided with the opportunity to meet patients in clinic to experience first-hand survivorship care as well as participate in research projects.

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**Nathan Bankoff, MD, M17**  
**Ming Lin, MS19**  
**Elizabeth Kiernan, Temple U., M19**  
**Tully Saunders, MBA**  
**Megan Zinsky, TUSM, M19**  
**Sabrina Karim, U. Pittsburgh, M19**  
**Becca Burns, Rush U., M19**  

**Kate Spencer, TUSM, M18**  
**Darcy Banco, TUSM, M18**  

**Tobi Henzer, Washington U., BA18**  
**Lisa Bartucca, TUSM, M19**  
**Emily Anderson, TUSM, M19**  
**Lauren Boehm, TUSM, M19**  

**Haylee Rosenblatt, TUSM, M20**  
**Elise Steinberger, TUSM, M20**  
**Diana Mihalache, TUSM, M20**  

**Not Pictured:**  
**Maggie Connolly**  
**Meghana Prabhu Bantwal**  
**Leigh Johnson**  
**Rebecca Silverman**  
**Brian Pennarola**  
**Connell Studenmund**
Training: Future Providers

We believe incorporating future providers in our program has benefited both our patients and the trainees, who educate and support each other. As expressed by some of our trainees here, the AYA Cancer Program has certainly made an impression! We look forward to following them in their careers!

**It has truly been an honor to be a part of the Reid R. Sacco AYA Cancer Program from its inception. I can distinctly remember our team meetings in the fall of 2012, as we prepared to open the clinic. We all had a vision for what the clinic and more broadly, the program, could be, but it was impossible at that time to predict the growth we have seen over the past five years. I could not be more proud to see the current state of the AYA Cancer Program, from the ever-increasing patient volume, to the continued focus on education through the annual AYA lecture series and the AYA summer scholarships. Dr. Parsons has been an incredible mentor to me, in the way she cares for patients in the clinic, and in the way she gets the most out of everyone on the team, and I have no doubt that the program will continue to thrive under her leadership. I look forward to seeing what the next five years will bring!**

– Nathan Bankoff, Peer navigator, 2013-2014

**Working with the team at the AYA Cancer Program showed me the epitome of multidisciplinary, compassionate care. Patients have numerous needs that need to be met, and the team works together to address them. I will take this team mentality, working with the utmost compassion I have witnessed with me throughout my entire career!**

– Kate Spencer, Summer scholar, 2015

**I have learned so much working with Dr. Kumar. I have enjoyed analyzing data in order to investigate healthcare delivery and utilization. My work has definitely strengthened my interest in medicine and health economics.**

– Tobi Henzer, Summer scholar, 2016, Research assistant, 2017

**The AYA Cancer Program has instilled in me that a cancer survivor’s care doesn’t end when they finish treatment, but is a continuing process throughout their lives. The providers and patients I’ve had the pleasure to interact with have impacted me as a hopeful physician. Whether it be a survivor sharing their story, helping prepare a long term Follow-Up Care Plan, or watching an AYA provider throughout a visit, the small impacts became bigger aspects to incorporate in my future practice.**

– Lisa Bartucca, Selective student, 2015, Summer scholar, 2016

**Meeting patients in the waiting room of the newly-opened AYA Cancer Program in early January 2013 was one of the proudest, but also most daunting moments of my life. I could not have been more proud of how Dr. Parsons, Gene and Lorraine Sacco, Tufts Cancer Center leadership, the Tufts MC community, and patients, friends and family worked together to make the dream of age-appropriate care for AYA cancer patients and survivors a reality. At the same time we had achieved that dream, I was overwhelmed by how our program, just opening its doors, could meet the complex needs of a growing AYA patient population that had been largely ignored by traditional oncology care. Over the past 5 years, the Reid R. Sacco AYA Cancer Program at Tufts MC rose to the occasion to ably meet the needs of AYAs through comprehensive, compassionate care, learning and education, and fostering a community of adolescents and young adults who know they do not have to navigate cancer care alone. Both as a patient and former program coordinator (2012-2016), I am humbled to be part of such an incredible program. I know that in the next five years, and beyond, the AYA Cancer Program at Tufts MC will continue along the frontier of age-appropriate care for AYAs.**

– Tully Saunders

**As a Summer Scholar in the AYA Cancer Program, I collaborated with an incredible team to design and implement survivorship care plans. I then had the opportunity to watch the way in which these care plans are put into practice in clinic, as well as present our work at the ASCO Survivorship Symposium. My experience with the program has inspired me to consider each patient’s long-term health with a broader lens and the value of developing longitudinal relationships.**

– Lauren Boehm, Summer scholar, 2016, Volunteer, 2017

**It has been an amazing experience working with the AYA Cancer Program and participating in its journey to improve outcomes for AYAs. It is truly a privilege to have been a part of a team that is really on the forefront in addressing key issues perpetuating the health disparities among AYAs, improving awareness of those issues, and creating a safe and welcoming community in which AYAs feel comfortable sharing their voices. The work of the Reid R. Sacco AYA Cancer Program creates impact that is tangible, salient, and meaningful, and I cannot wait to see more in the coming years!**

– Ming Lin, Peer navigator, 2014-2017
Working at the AYA Cancer Program truly taught me the importance of continuity of care and long term follow-up for patients with complex medical conditions; with its individualized care plans and never ending support. I learned about the health complexities that follow some cancer patients for life and the importance of providing these patients with team-based care, often involving many specialists. In addition, the program tries to coordinate a patient’s appointments and testing as best as possible to make getting healthcare as easy as possible. I hope in the future to provide my patients with the type of individualized and supportive care that the AYA Cancer Program provides all of their patients.

Through the AYA Cancer Program, I have learned the true meaning of patient centered care. Every paper published, every clinic held, and every event planned is done so because it will improve the care delivered to our patients. The summer I joined the AYA team, I was working on a project about cardiac toxicity. In the clinic we noticed our patients had echocardiogram changes and we thought it correlated to a class of cardio toxic drugs that many of our patients had received. We could have let this inference dissipate but instead, in true AYA Cancer Program fashion, we put together a team to research the topic so that we could better understand the long term effects of these drugs on our patients with the hope that it could help our patients in the future. It has been a true privilege getting to learn from and work with such a talented group of individuals who dedicate their lives to improving the health of our AYAs. Thank you for giving me the opportunity to be a part of such a wonderful program!

–Emily Anderson, Summer scholar, 2016

I found my time as an AYA Summer Scholar to be extremely rewarding and worthwhile. It was an unique experience working with a small group of very talented, dedicated individuals to address the needs of a special population of patients, who have previously been notoriously underrepresented in medicine. Additionally, Dr. Parsons is an amazing mentor, not only because of how knowledgeable she is of the field, but also because of her genuine passion for every aspect of her work.

–Diana Mihalache, Summer scholar, 2017

Warmest congratulations to Dr. Parsons, the Sacco’s, and the whole AYA Cancer Program family on making the Reid R. Sacco AYA Cancer Program such a wonderful home for pediatric and young adult oncology survivors for five years! I’m honored to have witnessed and been a part of the growth of this community. As a third year medical student now, I appreciate what a unique opportunity it was to see how the highest level of care can be given to individuals as they make crucial transitions in their own cancer care. Though it’s been two years since I was a peer navigator, I often think of our patients who made Monday afternoons a source of joy and inspiration-- thank you to our patients and their families for sharing your stories, courage, and motivation to live your fullest lives!


I had a wonderful experience this summer with Dr. Parsons and the entire research team at the Reid R. Sacco AYA Cancer Program. The integration of research and clinic time helped solidify what I was learning about medical oncology through the research, and also demonstrated to me the profound complexity of survivorship care. What I learned in clinic has helped me better understand the science of caring for complex patients, as well as patients’ perspectives on their care. I initially chose to join the team for the summer because of Dr. Parsons’ passion for her work and her clear skill as a leader. After working with her and the rest of the team, I cannot speak highly enough of each and every person on it. Everyone with whom I worked, welcomed the summer scholars and was completely invested in teaching us along the way. I loved the environment and group of people, and look forward to continuing my work on some of the projects!

–Becca Burns, Peer navigator, 2014-2015

–Elise Steinberger, Summer scholar, 2017
Dr. Archie Bleyer considered by many as the “father of AYA cancer care” kicked off the lecture series in 2014. Dr. Bleyer provided a compelling overview of AYA oncology in his talk titled, Cancer in Adolescents and Young Adults: Progress at Last!? How Tufts MC and the Reid R. Sacco Program Can Contribute. His clinical research mission is dedicated to improving the outcome of young adults with cancer who have not fared as well as younger and older patients. Dr. Bleyer invited Dr. Parsons to contribute the chapter, Economic Evaluation in Adolescent and Young Adult Cancer: Methodological Considerations and the State of the Science in the 2015 Cancer in Young Adults publication!

Suleika Jaouad eloquently shared her cancer experience which began at the age of 22 when she was diagnosed with myelodysplastic syndrome and acute myeloid leukemia, with the Tufts MC medical community and fellow AYAs. Suleika is the critically acclaimed author of the New York Times’ Well column *Life, Interrupted*. 

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*Image of the announcement flyer for the lecture series.*

*Image of the audience at the lecture event.*
Dr. Wendy Stock presented her work using pediatric treatment regimens on AYAs diagnosed with leukemia in two talks, *Growing UP: Treatment of Young Adults with ALL & Learning from the Kids!: Making Progress in Treatment of Acute Lymphoblastic Leukemia*. Drs. Parsons and Stock have since begun collaborating on quality-of-life outcomes for patients in their respective clinics.

Dr. Graham Colditz offered a brief history as well as the current status of cancer prevention, with a focus on sun safety, tobacco cessation, obesity and the HPV vaccination. Dr. Colditz underscored the importance of practicing healthy living behaviors as survivors may be at additional risk for chronic conditions due to their treatment.
Education & Outreach: Presentations

Each member of the AYA Cancer Program team has had the opportunity to expand awareness about the program, AYA cancer, and/or survivorship to a variety of audiences over the past five years.

Healthcare Providers:

• Tufts Medical Center
• Community Health Workers & Patient Navigation Conference
• Brockton Hospital
• Bone Marrow Transplant Seminar
• Harrington Hospital
• The George Washington University Cancer Center (webinar)
• Brigham and Women’s Hospital
• Lowell General Hospital
• Roswell Park Cancer Institute
• International Symposium on Childhood, AYA Hodgkin Lymphoma

Patients, Survivors & Caregivers:

• Friends of Mel: Art of Living Conference
• Colorectal Conference
• Stupid Cancer’s Cancer Con
• Lymphoma Research Foundation: North American Educational Forum on Lymphoma

Community Groups:

• Tufts University Relay for Life Event
• North Shore Rotary Clubs

Medical & Nursing Students:

• Tufts University School of Medicine
• Lawrence Memorial/Regis College

We have presented an overview of the cancer experience in AYAs and our program to TUSM Special Interests Groups for the past three years. Medical students have shared that they have learned:

• New awareness of AYA cancers
• Our program is a much needed bridge between pediatric- and adult-based care
• Importance of educating patients on late effects from therapy

Attendees have gone on participate at Summer scholars in the program.

Our program manager, Rachel, presented, “Getting Informed About Long Term Follow-Up Care” to young adult survivors at Cancer Con in 2017. Dr. Parsons looks forward to joining Rachel at Cancer Con in 2018!
Education & Outreach: Raising AYA Awareness

When our program manager, Rachel, was invited to speak at a Boston-area university about her personal experience with cancer and the AYA Cancer Program in 2016 she was pleased to accept. Expanding our outreach efforts to provide the talk, A Young Adult Cancer Experience, to other colleges has led to Rachel presenting to 19 cohorts (over 400 young adults) to date.

Written feedback from the students has shown the effectiveness in raising AYA cancer awareness and we have begun disseminating our findings. An abstract was accepted and presented at the 2nd Global AYA Cancer Congress which took place in Atlanta, GA, in 2017. The poster is shown below:
Education & Outreach: On TV

The AYA Cancer Program and Dr. Parsons were featured on WCVB-TV Channel 5 Boston’s award-winning Chronicle program in May 2017. Thanks to the overwhelming response of viewers, the episode was re-aired over the summer.

The episode, titled, *Beyond the Cure*, introduced the concept of survivorship care to viewers across New England, some of whom have since become patients of our program.

Three AYA patients were interviewed for the segment. Two of the young women had been diagnosed with cancer in childhood, while the third young woman was diagnosed in her 20s. Each survivor shared the impact cancer has had on their lives and the late effects they are experiencing as a result of their successful treatments. We thank these young women for courageously sharing their stories with the public in the effort to help others.

To watch the episode, visit the AYA Cancer Program webpage: www.tuftsmedicalcenter.org/aya.
Education & Outreach: Social Media

We know the importance of connecting with the AYA community. The program has multiple social media accounts that serve as a resource for AYA-related events, programmatic activities and articles for/by AYA peers:

- [facebook.com/AYAcancerProgram](http://facebook.com/AYAcancerProgram)
- [ayacancerprogram.tuftsmedicalcenter.org/blog](http://ayacancerprogram.tuftsmedicalcenter.org/blog)
- [@AYAProgramatTuftsMC](http://twitter.com/AYAProgramatTuftsMC)

Announcements related to the program’s team and new staff introductions are very popular, thanks to our dedicated supporters! Below are some additional types of posts that have resonated with our followers on Facebook:

Members of the AYA community are also able to keep up to date with our e-newsletter, *AYA Community Connection*. The e-newsletter is sent on a quarterly basis with upcoming events, a blog recap and program-related updates. Signing up is easy, simply email ayaprogram@tuftsmedicalcenter.org and request to be added to our mailing list.
Tufts Medical Center &
The Reid R. Sacco AYA Cancer Alliance

Reid R. Sacco AYA Cancer Alliance

The AYA Cancer Program at Tufts MC has been made possible by the collaboration of Dr. Parsons, Tufts MC leadership and the Reid R. Sacco AYA Cancer Alliance.

Our program’s namesake Reid was diagnosed with sarcoma at the age of 18 and passed away two years later. His family (in particular parents Gene and Lorraine, and brother Weston) and community have devoted much of themselves to remembering Reid by doing everything possible to prevent what happened to him from happening to other young adults and adolescents with cancer... spread[ing] awareness of a disease not readily anticipated in young adults and... raising funds.

Learn more at www.cancerinyoungadults.org.

Our program has benefited from a number of organizational supporters throughout our five years of operation. Below is a condensed list of ongoing and previous supporters.

- Tufts Medical Center
- Floating Hospital for Children at Tufts Medical Center
- NEQCA: New England Quality Care Alliance
- YNS Reid Sacco Invitational: U.S.A. North Shore Sharks Swim Meet
- The Jen Di Reeno Foundation, Inc.
- Children’s Cancer Awareness Club, Chelsea High School, Chelsea, MA
- 15-40 Connection
- Conquer Cancer Foundation
- The Y + Livestrong
- The Dunkin Donuts & Baskin-Robbins Community Foundation
Clinic Dedication, 2013
Richard Van Etten,
John Erban,
Susan Parsons,
Bruce Tarr,
Lorraine Sacco,
Gene Sacco,
Weston Sacco

Clinic Dedication, 2013
Frank Sacco, Meredith Nash, Deb Sacco, Lorraine Sacco, Constance Sacco (deceased), Grace Marie Greeno,
Susan Parsons, Stacy Dillon, John Erban, Ladd Greeno, Joe Nash, Gene Sacco, Nathan Bankoff, Bob Sacco (deceased),
Weston Sacco, Kevin Dillon, Scott Neely

Signing, 2012
Weston Sacco,
Scott Neely,
Lorraine Sacco,
Gene Sacco,
Susan Parsons,
Richard Van Etten,
John Erban
Supporting our Supporters

The Reid R. Sacco AYA Cancer Alliance has organized an annual 28-mile bike ride along the North Shore of Massachusetts as part of their efforts to alter the course in AYA cancer, for the past 13 years. The event, Reid’s Ride, supports AYA initiatives including our program at Tufts MC.

Thank You, to all of the “Team Tufts MC” members (many of whom are in the photos below).

2013
Brendan Wills, Ruth Ann Weidner, Angie Mae Rodday,
Pamela Chase, Susan Parsons, Nathan Bankoff,
Mark Bankoff, Tully Saunders, Maggie Connolly,
Becca Burns, Ann Bankoff, Julianne Viola, Sarah Bankoff,
Meridith Braun

2015
Scott Neely, Thomas Armstrong, Tully Saunders,
Ming Lin, Susan Parsons, Liz Kiernan, Kate Spencer,
Darcy Banco, Erin Barthel, Rachel Murphy-Banks,
Nadine Linendoll

2016
Rachel Murphy-Banks, Joseph Riess, Anita Kumar,
Mark Bankoff, Susan Parsons, Ruth Ann Weidner,
Nadine Linendoll, Pamela Chase, Julianne Viola,
Nathan Bankoff, Ming Lin, Lauren Boehm, Sabrina Karim,
Angie Mae Rodday

2017
Rachel Murphy-Banks, Christine Braun, Pamela Chase,
Nicole Linendoll, Haylee Rosenblatt, Annmarie Conroy,
Diana Mihalache, Lauren Boehm, Ming Lin, Nate Bankoff,
Elise Steinberger, Tim Montgomery, Susan Parsons,
Tully Saunders, Meridith Braun, Angie Mae Rodday,
Kate Spencer, Darcy Banco
Squares decorated by AYA Cancer Program patients and team members.

Reid R. Sacco Adolescent & Young Adult (AYA) Cancer Program

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