

Reid R. Sacco Adolescent & Young Adult Cancer Program Annual Report 2018

*“Even when treatment
is successful,
cancer can have lifetime effects.
Our clinic is here to help young
survivors manage them.”*

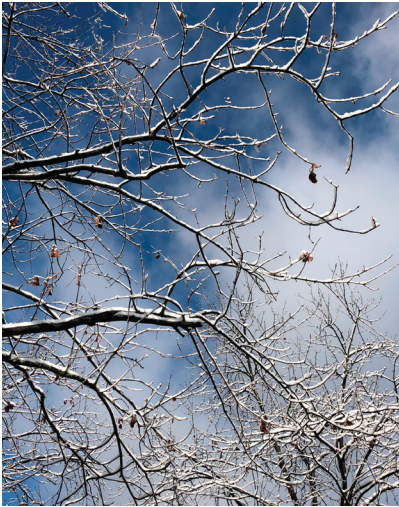
Dr. Susan Parsons, Medical Director,
2013

*“Few years ago I was in a
bad place and without AYA
[Program] who knows
where I’d be.”*

AYA Survivor,
2018

Table of Contents

Director's Message	2
Survivorship Care	3
Survivorship Overview	4
Survivorship Care Coordination	5
Patients Served	7
Sharing What We Know	9
Summer Scholars 2018	12
Cancer Con 2018	13
Thank You.....	15



Director's Message

Dear Colleagues, Supporters, and Friends,

On behalf of the entire program team, I am pleased to share with you the sixth annual report of the Reid R. Sacco Adolescent and Young Adult (AYA) Cancer Program. Established in 2012 with the generosity of the **Reid R. Sacco AYA Cancer Alliance** and the shared vision of Tufts Medical Center, our program provides integrated and coordinated clinical care to AYA survivors of cancer. Each year we have welcomed many new patients to the clinic through provider- and self-referrals. In addition, we provide educational and training opportunities to college, graduate, and medical students through our AYA Summer Scholars initiative. Special thanks to each of this year's scholars for the contributions they have made to the program.



Clinical care and training are only part of the story. Each of us also is involved in ongoing research about AYA cancer and the impact this disease has on patients' lives. In addition to our commitment to survivorship care, our team has worked on the design of new clinical trials for newly diagnosed patients, building on a growing awareness nationally of the need for an AYA focus in trial design.

In this year's report we highlight an exciting trip several of us took to Cancer Con, a weekend-long conference for young adults, sponsored by Stupid Cancer. We are so grateful for the support of the **Joy in Childhood Foundation** and **This Star Won't Go Out**, enabling us to provide travel for conference participants from our program in 2018 and 2019!

We look forward to the new year and where it will take us. We hope you all have a peaceful and joyous holiday season and a new year filled with health and happiness.

Susan Parsons, MD

Medical Director, Reid R. Sacco AYA Cancer Program
Professor of Medicine and Pediatrics at Tufts University School of Medicine
Director of the Center for Health Solutions, Institute for Clinical Research and Health Policy Studies at Tufts Medical Center

Survivorship Care

AYAs who seek their survivorship care with the AYA Cancer Program benefit from a team-based approach which combines the expertise of pediatric- and adult-trained oncology providers. The team is supported by a program manager.



**Susan K. Parsons,
MD, MRP,**
Medical Director,
Pediatric-trained
hematologist/oncologist,
Professor of Medicine & Pediatrics at
Tufts University School of Medicine
(TUSM)



**Anita Kumar,
MD, MSCE,**
Adult-trained
hematologist/oncologist,
specialty in
hematologic malignancies,
Assistant Professor at TUSM



**Nadine Linendoll,
PhD, MDiv, NP,**
Adult-trained
nurse practitioner,
specialty in neuro-oncology,
Assistant Professor at TUSM



**Rachel Murphy-Banks,
MA,**
Program Manager

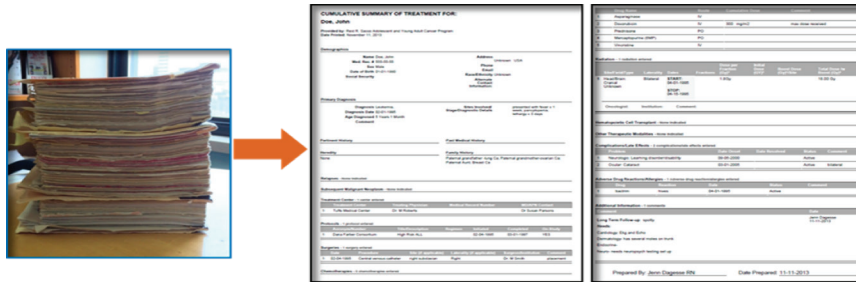


The designated AYA clinic space is located in the South Building on the 7th Floor.

Survivorship Overview

Each patient receives a Survivorship Care Plan, regardless of whether he or she has recently finished treatment or if they were diagnosed many years ago. The Survivorship Care Plan includes a cumulative Treatment Summary and a long term Follow-Up Care Plan.

Treatment Summary
Used to help educate AYAs on the treatment they received and a useful tool to share with other providers.



Follow-Up Care Plan
The illustrative example shows the individualized plan discussed and provided at each survivorship visit. The plan incorporates:

- Treatment-based risks
- Late effects management
- Oncological guidelines
- General wellness

Jane Smith: MRN 123456, DOB 11/19/1988 Health History: Diagnosed at age 23 with Hodgkin Lymphoma. Treated with Doxorubicin (300MG/M2), Bleomycin, Vinblastine, Dacarbazine and mediastinal radiation 30Gy. Current Diagnosis: Hypothyroidism (E03.9), Asthma (J45.9)					
Organ System	Test	Indication	Time Interval	Last Completed	Responsibility
Cardiac	ECHO	Risk of cardiomyopathy from Doxorubicin & radiation	At baseline at entry into clinic and then every 2 years	8/13/2018	Survivorship; Cardiologist, PCP
	EKG		At baseline at entry into clinic and then as clinically indicated	8/7/2017	Survivorship; Cardiologist; PCP
	BMI	Modifiable risk factors	At every visit	8/13/2018	Survivorship; Cardiologist; PCP
	Blood pressure		At every visit	8/13/2018	Survivorship; Cardiologist; PCP
	Fasting lipid profile		Yearly	8/13/2018	Survivorship; Cardiologist; PCP
Endocrine	Thyroid exam, Thyroid function tests	Exposure to radiation; History of hypothyroidism	Annually	3/9/2018	Endocrinologist
Breast Health; Gynecology	Mammogram/Breast MRI	Surveillance; Risk of secondary breast cancer	Yearly beginning at age 25	4/12/18	Breast Health
	Gynecology Exam	General Wellness	Annually	3/9/18	Breast Health; Gynecologist
Dermatology	Skin exam with special attention to radiation fields	Exposure to radiation; Risk of secondary skin cancer	Annually	8/13/2018	Dermatology
Musculoskeletal	DEXA Scan	Exposure to radiation	Every 2 years	8/13/2018	Survivorship
Pulmonary	Pulmonary Function Tests	Surveillance; Asthma	Baseline and then as clinically indicated	8/7/2017	Survivorship
Dental	Cleaning and Exam	General Wellness	Every 6 months	5/16/2018	Dentist
Immunizations	Annual Flu Shot	General Wellness	Annually	10/10/2017	PCP

Survivorship Care Coordination

We are happy to share exciting news from two programs we work closely with: The Cardio-Oncology Program and the Pediatric Hematology/Oncology Department.



Jenica Upshaw, MD,

The Cardio-Oncology Program's Medical Director, Dr. Upshaw, joins us in clinic on select Mondays to offer back-to-back AYA survivorship and Cardio-Oncology visits for patients under her care.

We are thrilled to share that Dr. Upshaw was selected as the Zaniboni Scholar for her project, *Personalized Shared Decision Making in Breast Cancer Therapy—Balancing the Risks of Cardiotoxicity with the Benefits of Adjuvant Chemotherapy*.

This research will create tools to help patients and providers balance the risks and benefits of breast cancer therapies, some of which can be toxic to the heart.

Survivor-SHIP

at the

Floating Hospital
for Children

at **Tufts** Medical
Center

The Pediatric Hematology/Oncology team at the Floating Hospital for Children formally began providing children and young teens with Survivorship Care Plans in 2018.

The initiative led by Drs. Michael Kelly & Tishi Shah, with Annmarie Conroy, PNP, will use Care Plans created by the AYA providers. Dr. Shah and Annmarie have both trained in the AYA clinic.

We congratulate the team and look forward to working with them when patients are ready to transition to the AYA Program.

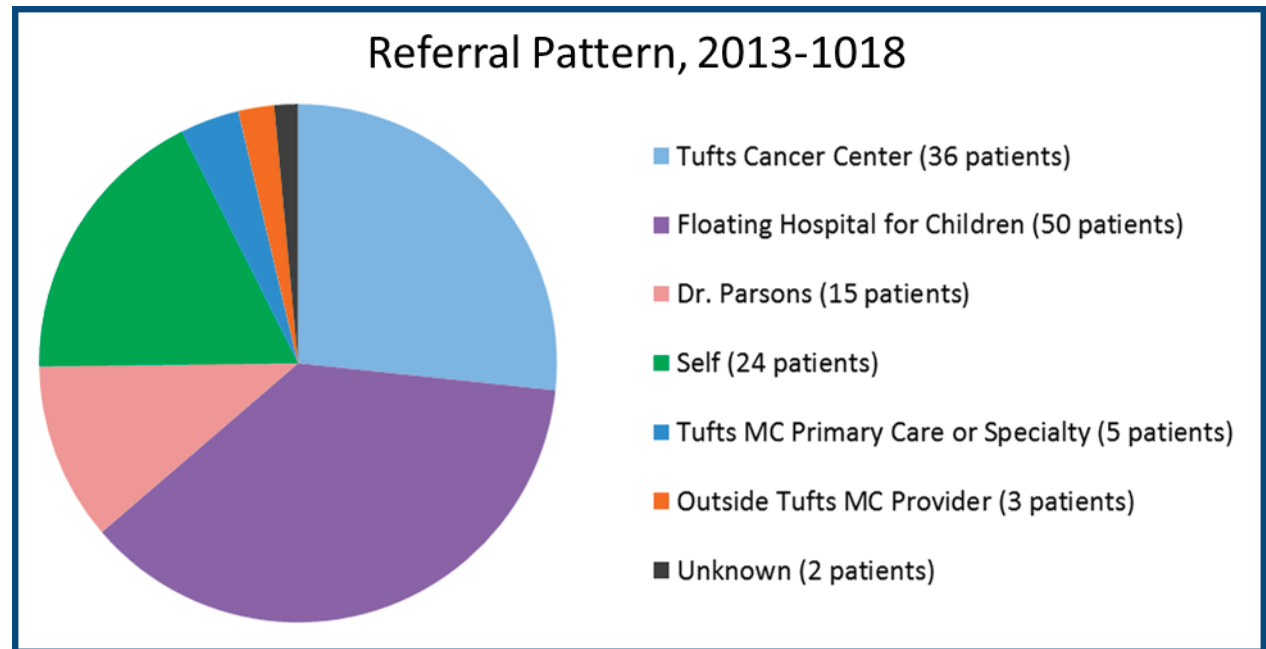
Survivorship Care Coordination

Survivorship is a distinct phase of care which focuses on providing comprehensive, follow-up care to individuals who have completed cancer treatment.

The National Academy of Medicine (formerly named the Institute of Medicine) emphasizes four tenets of survivorship: **Surveillance** for cancer spread, recurrence or second cancers; **Intervention** for consequences of cancer and its treatment; **Prevention and Detection** of new cancers and recurrent cancer; and **Coordination** among specialists and primary care providers to ensure that all the survivor's health needs are met.

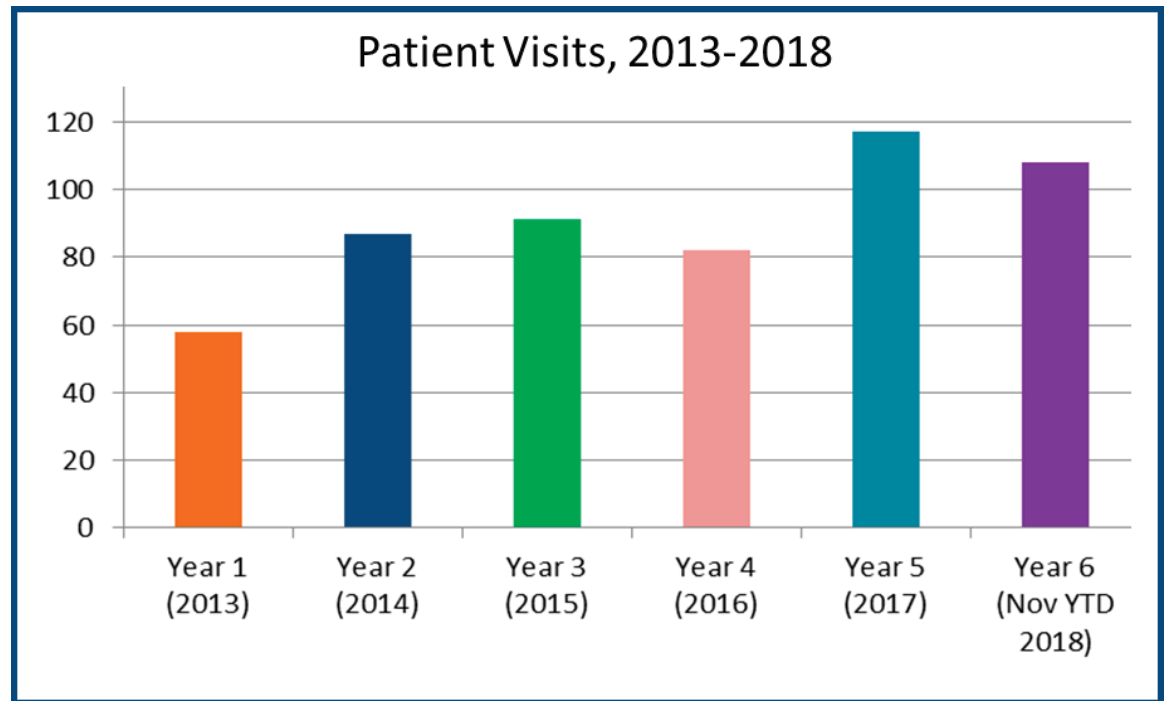
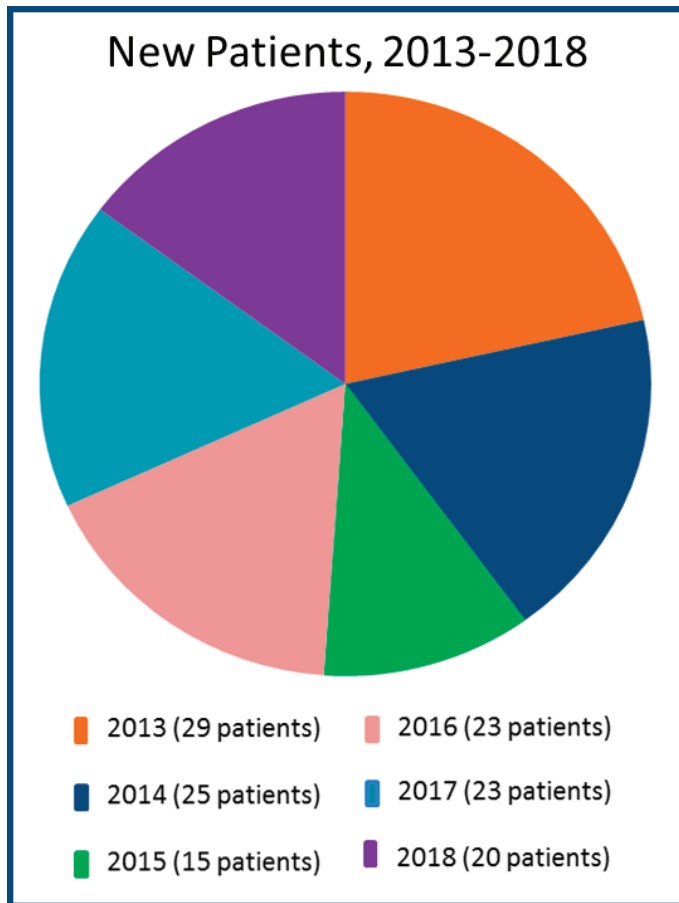
We would like to extend our gratitude for the coordinated care and referrals provided by the following departments at Tufts Medical Center:

- Audiology
- Breast Health
- Cardiology
- Colorectal
- Dermatology
- Ear, Nose & Throat
- Endocrinology
- Gastroenterology
- Medical/Radiation Oncology
- Nephrology
- Neurology
- Neuropsychology
- Obstetrics/Gynecology
- Ophthalmology
- Physical Therapy/Rehab Medicine
- Primary Care
- Psychiatry
- Pulmonary
- Social Work
- Urology



Patients Served

We are genuinely pleased to welcome new individuals who have a history of cancer to our survivorship program. While our model strives to introduce survivorship care at the end of completion of initial treatment, some of our new patients had been lost to long term follow-up care. In 2018, we continued to experience an upward trend in new patients, half of whom came as self- or non-oncology provider-related referrals.



Patients Served

The AYA Cancer Program provides care to a diverse group of patients.

Patients served include AYAs who were diagnosed as children as well as individuals who were diagnosed in their adolescence or young adulthood (aged 15-39 years old).

Of our current patient cohort, diagnosed under the age of 40 years old:

- 61% of patients were diagnosed between 0-14 years old
- 39% of patients were diagnosed between 15-39 years old

Diagnoses have included:

- Leukemia
- Lymphoma
- Breast
- Sarcoma
- Thyroid
- Neuroblastoma
- Lung
- Kidney tumors
- Head and neck
- Brain tumor
- Ovarian

In last year's report we shared a snapshot of our patients upon entry into the AYA Cancer Program. This information was made possible from a tool we developed as part of our programmatic aim to continually improve survivorship care.

We've updated this snapshot here:

- 30% of patients had not received oncology care within two years of their AYA Cancer Program appointment
- 37% of patients were receiving psychological care or medication for mental health issue(s)
- 73% of patients had at least ONE known late effect

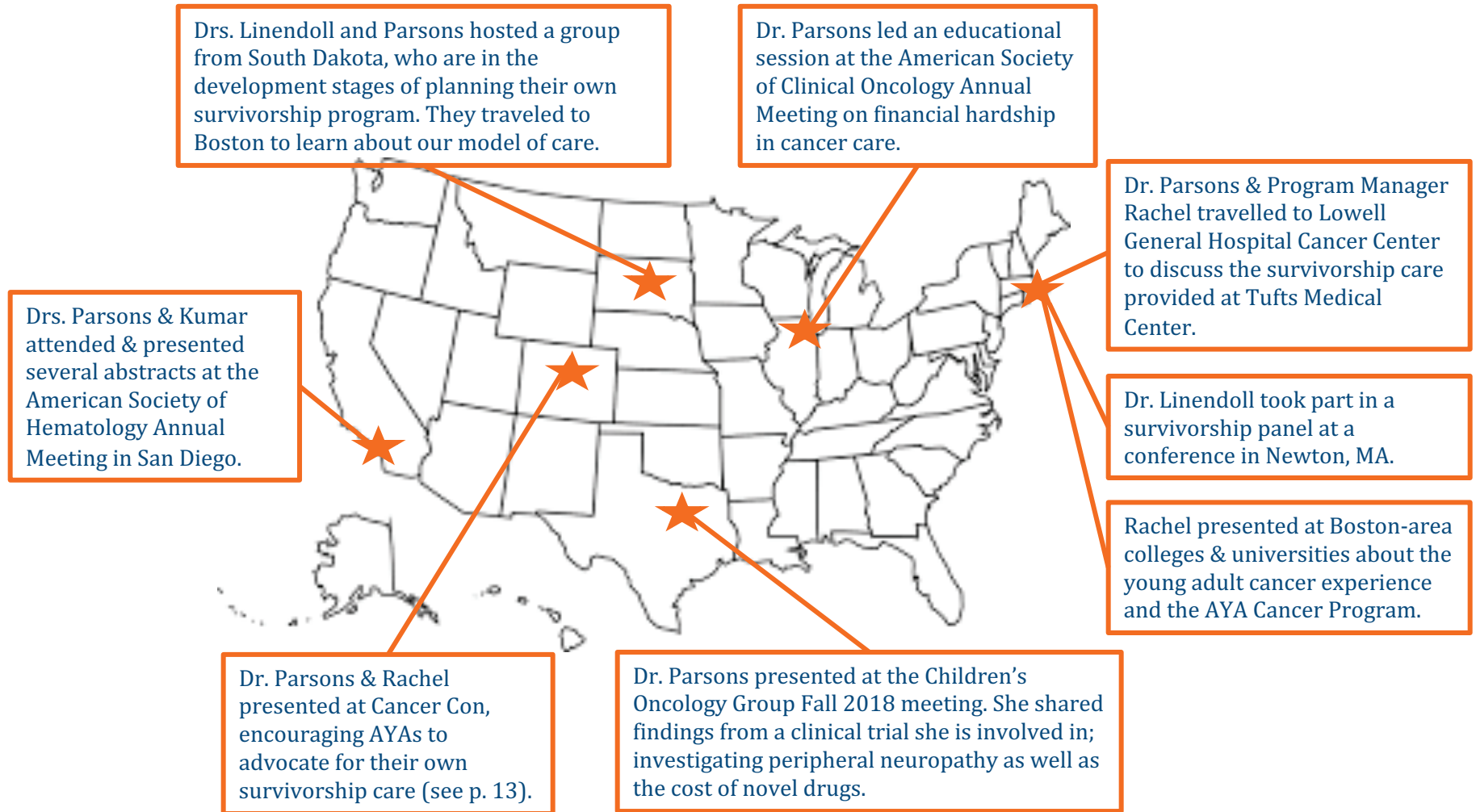
Sharing What We Know

In the pursuit of advancing awareness and care of AYAs who have been diagnosed with cancer the AYA Cancer Program team has contributed to multiple manuscripts. Here we provide a look at some of this work.

- *Adolescent and Young Adult Cancer Care: Financial Hardship and Continued Uncertainty*
 - Authors: Drs. Parsons & Kumar
 - *In press:* Pediatric Blood Cancer Journal
- *Development of phase-specific breast cancer survivorship care plans*
 - Authors: Lauren Boehm, former AYA Summer Scholar, Dr. Tracey Weisberg of New England Cancer Specialists (NECS), Dr. Linendoll, Arlene Damon, NP of NECS, Dr. John Erban & Dr. Parsons
 - Under review
- *Optimizing Decision Making in Hodgkin Lymphoma*
 - Authors: Dr. Parsons, Joshua Cohen, PhD & Dr. Andrew Evens of Rutgers Cancer Institute of New Jersey
 - Chapter in forthcoming Springer book titled Hodgkin Lymphoma
- *Schwannoma Formation in Childhood Cancer Survivors Exposed to Low-Dose Total Body Irradiation*
 - Authors: Emily Anderson, former AYA Summer Scholar, Dr. Linendoll, Dr. Carl Heilman, Dr. Ron Riesenburger, Dr. Miriam O'Leary, Dr. Knarik Arkun, Dr. Tara Nail, Dr. Martin Goodman & Dr. Parsons
 - Under review
- *Updated: Health-related quality of life in Hodgkin lymphoma: a systematic review*
 - Authors: Dr. Linendoll, Dr. Margaret Byrne, Dr. Anem Waheed, Rachel Murphy-Banks, Nawal Wasif & Dr. Parsons
 - Drs. Parsons & Linendoll were invited to update their 2016 article titled *Health-related quality of life in Hodgkin lymphoma: a systematic review* which was published in the Health and Quality of Life Outcomes Journal
- *Personal narrative: Raising awareness of AYA cancer and survivorship in age-related peers*
 - Authors: Rachel Murphy-Banks, Danielle Blanch-Hartigan, PhD of Bentley University, Pauline Hamel, EdD, PT of Northeastern University & Dr. Parsons
 - Under review

Sharing What We Know

In addition to manuscripts, members of our team have traveled near and far to deliver talks on topics related to the AYA cancer experience, our program's model of survivorship care and health-related quality of life in young cancer patients. We also had the pleasure of welcoming oncology providers from the Midwest who were eager to learn about our best practices as they were in the process of developing their own survivorship program.

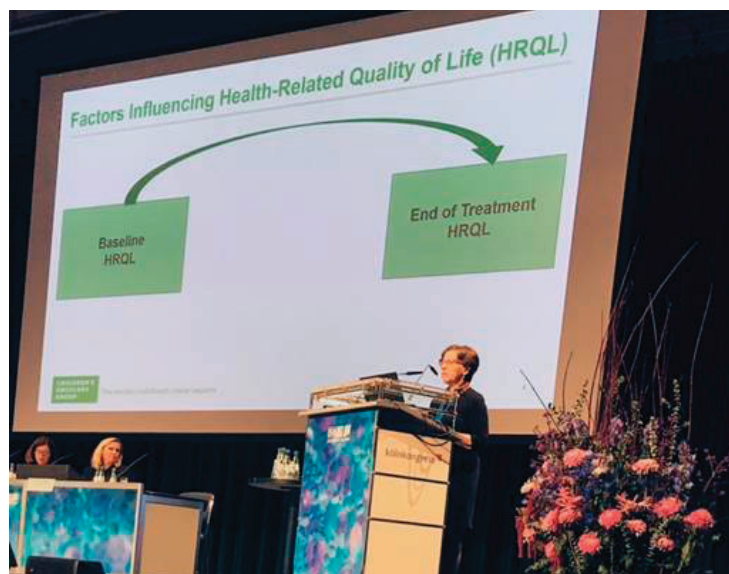


Sharing What We Know

Drs. Parsons and Kumar attended the 11th annual International Symposium on Hodgkin Lymphoma in Cologne, Germany. Dr. Parsons shared her work, on behalf of the Children's Oncology Group, about health-related quality of life. Dr. Parsons is a strong believer that health-related quality life should be assessed throughout the cancer care continuum; from diagnosis, through treatment, as well as at the end of treatment.



Drs. Parsons and Kumar



Dr. Parsons presenting at the conference.

Summer Scholars 2018

Throughout the year students who are interested in learning about AYA cancer and survivorship care are invited to shadow the care team in clinic and/or participate in research. This year, projects ranged from a literature review on financial hardships experienced by AYAs diagnosed with cancer to helping the care team better understand the impact of late effects from treatment. We are glad of their interest and appreciate knowing they will take their newfound awareness of the AYA demographic with them in their future careers.

Four students joined us for eight weeks over the summer as Summer Scholars:



Owen Bennion
Medical student at
Tufts University
School of Medicine



Megan Catalano
Undergraduate student at
Brandeis University



Raisa Masood
Graduate student at
Tufts University
Friedman School of Nutrition
Science and Policy



Mary Cate Sullivan
Undergraduate student at
Emory University

Volunteers included Meghana Prabhu Bantwal who is in her final year at Northeastern University and joined us in May 2017, Sarah Reis who graduated from Northeastern University in May 2018, and Nawal Wasif who is an undergraduate student at Boston University.

Cancer Con 2018



Cancer Con (produced by Stupid Cancer, the largest psychosocial young adult cancer advocacy group in the United States), brings together 600 young adults who were diagnosed with cancer as children, teenagers or young adults.

Over a long weekend in Denver, Colorado hundreds of young adults connect with others they are able to relate to: “who get it,” form bonds and get informed on topics ranging from how to navigate college after cancer to how to practice self care.

In 2018, ten young adults received a travel scholarship to attend the conference. This was made possible by the **Reid R. Sacco AYA Cancer Alliance** which was awarded a grant, on behalf of the AYA Cancer Program, from the **Joy in Childhood Foundation** as well as a grant from the **This Star Won't Go Out** organization. Each attendee shared the impact the conference had on them (selective quotes on next page).

We look forward to supporting a second group of attendees next year!



For a second year in a row, we presented a breakout session titled: ***Advocating for your Long Term Follow-Up Care!***

Participants were encouraged to:

- Seek out a Survivorship Care Plan (i.e., Treatment Summary & Follow-Up Care Plan)
- Expand their knowledge of survivorship care: Surveillance alone is not enough
- Embrace healthy living behaviors because cancer prevention is important for survivors too

Dr. Parsons and Rachel have been invited back to present in 2019!

Cancer Con 2018 Scholarship Attendee's Feedback



2018 Scholarship attendees with Dr. Parsons and Program Manager Rachel

"They told us to be careful in Denver, that the altitude sneaks up on you and that its going to be harder to breath. But I felt quite the opposite. I feel like I had been holding my breathe my whole life, and finally, I could let go."

"I learned so much about myself. For the longest time I was allowing the cancer to define me. But I finally came to the conclusion that it doesn't. I am a survivor and continue to live life to the best of my ability. I can't let it stop me from pursuing my goals."

"I shared my fears with others. As it turned out, most of what I was feeling was not uncommon. The answers to the fears were so simple though. With my main fear being loss of friends, new and old. It was answered so simply, over a casual meal of pizza. I explained it to a new friend and all she said in return was 'you just have to take the good with the bad, enjoy it while it's there.'"

"I am so grateful that I had the opportunity to attend Cancer Con. I left on the last day with a clearer sense of my own story and who I am as a cancer survivor. I also left with a sense of HOPE."

"Meeting the wonderful people attending Cancer Con allowed me to feel not so alone. It has given me young adult peers who are dealing with the same things I am from the long-lasting side effects from chemotherapy and radiation and the anxiety doctor's appointments and tests can bring, while balancing day to day life such as working and having a family."

Thank You AYA Cancer Program Supporters!

Ongoing support from Tufts Medical Center (MC), the Floating Hospital for Children at Tufts MC and the Reid R. Sacco AYA Cancer Alliance (AYA Cancer Alliance) have made the model of care we provide possible.

Donations made by AYA patients and their families to the AYA Cancer Program have funded a social gathering and assisted individuals with paying medical bills.



Left to right: Timothy Montgomery (rider), Angie Mae Rodday (rider), former AYA Summer Scholar Dr. Nate Bankoff (rider), Nicole Savidge, Pamela Chase (rider), former AYA program coordinator Tully Saunders (rider), Dr. Parsons, Weston Sacco (rider), Christine Braun (rider), Ruth Ann Weidner, Dr. Linendoll, former AYA Summer Scholar Lauren Boehm & Rachel Murphy-Banks. Not pictured: Dr. Mark Bankoff (rider).

The partnership between Dr. Parsons, Tufts MC leadership and the AYA Cancer Alliance led to the clinic welcoming its first patients in January 2013.

Years before, just after the passing of Reid Sacco in 2005, the AYA Cancer Alliance began an annual 28-mile bike ride, **Reid's Ride**, along the North Shore to honor Reid and raise funds to fight AYA cancer.

In July 2018, at the 14th annual ride, members of "Team Tufts AYA Program," and program members past and present participated in the event to support our supporters (picture at left).



Reid R. Sacco
AYA Cancer Alliance

Tufts Medical
Center

Floating Hospital
for Children
at **Tufts** Medical
Center

Reid R. Sacco Adolescent & Young Adult Cancer Program

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Tufts Medical Center

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Boston, MA 02111

Clinic Location: South 7



We Can Impact the Lives of AYA Survivors
World Cancer Day 2018

We encourage you to connect with us online!

To sign up for our quarterly *AYA Community Connection* e-newsletter simply send us an email.



[facebook.com/AYAcancerProgram](https://www.facebook.com/AYAcancerProgram)



ayacancerprogram.tuftsmedicalcenter.org/blog



[@AYAProgramatTuftsMC](https://www.instagram.com/AYAProgramatTuftsMC)

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