

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

Caring For and Empowering Survivors of Cancer



**Tufts** Medical  
Center

## MESSAGE FROM OUR DIRECTOR

On behalf of the Reid R. Sacco Adolescent and Young Adult (AYA) Cancer Program at Tufts Medical Center, I am delighted to share with you a brief overview of the status of our program. Over the past year we have continued to pursue our programmatic goals in four key areas: patient care (p. 3); research (p. 6); training (p. 8); and AYA awareness & outreach (p. 9). In response to our patients' needs, we have focused on two principal themes: care coordination with primary care and specialty/subspecialty care; and the financial burdens of cancer. Our goal over 2020 will be to develop programmatic enhancements in these targeted areas, which we will then share with other AYA programs nationally.



We remain indebted to our philanthropic sponsors, principally the Reid R. Sacco AYA Alliance (p. 10), and the numerous gifts we have received to directly help patients navigate survivorship care. We are grateful to colleagues with whom we have shared the care of our patients (see p. 5) and to the institution for providing us with the support we need to thrive.

We wish you all a healthy, happy, and productive new year.

*Susan Parsons, MD*

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

## AYA CANCER PROGRAM TEAM



**Anita Kumar, MD, MSCE, PhDc**  
Adult-trained Hematologist/Oncologist  
specialized in hematologic malignancies,  
Assistant Professor at TUSM



**Nadine Linendoll, PhD, MDiv, NP**  
Adult-trained Nurse Practitioner  
specialized in neuro-oncology,  
Assistant Professor at TUSM



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

# SURVIVORSHIP CARE

There are over 16.9 million cancer survivors in the United States,<sup>1</sup> of which nearly 2 million were diagnosed between the ages of 15-39 years.<sup>2</sup> These survivors need long-term care, provided by health care providers with expertise on the consequences of cancer and its treatment. The report, *From Cancer Patient to Cancer Survivor*,<sup>3</sup> identified four essential components of survivorship care:

- 1) Prevention of recurrent and new cancers, and of other late effects;
- 2) Surveillance for cancer recurrence or second cancers;
- 3) Intervention for consequences of cancer and its treatment (e.g., cardiac problems, psychological distress, financial burden); and
- 4) Coordination between specialists and primary care providers.

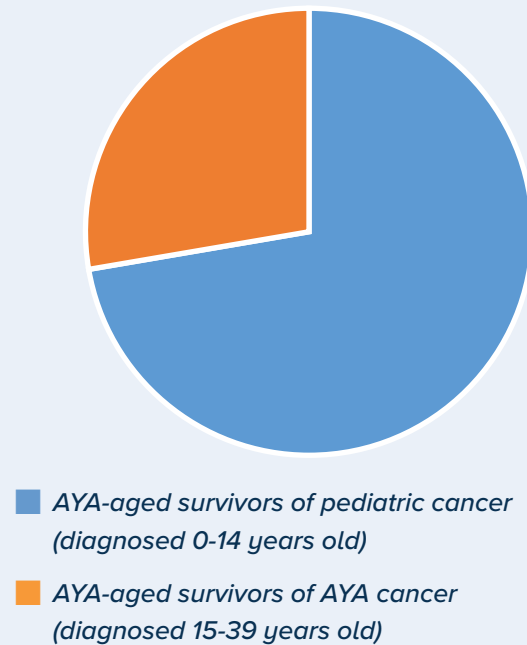
The AYA Cancer Program fulfills a unique niche in providing survivorship care, including all the above named aspects, to adolescents and young adults (aged 18-39 years).

References:

1. American Cancer Society. Cancer Treatment & Survivorship Facts & Figures 2019-2021. Atlanta: American Cancer Society; 2019.
2. Bleyer et al. Global assessment of cancer incidence and survival in adolescents and young adults. *Pediatric Blood Cancer*. 2017;64:e26497
3. Institute of Medicine and National Research Council. 2006 *From Cancer Patient to Cancer Survivor: Lost in Transition: An American Society of Clinical Oncology and Institute of Medicine Symposium*. Washington, DC: The National Academies Press.

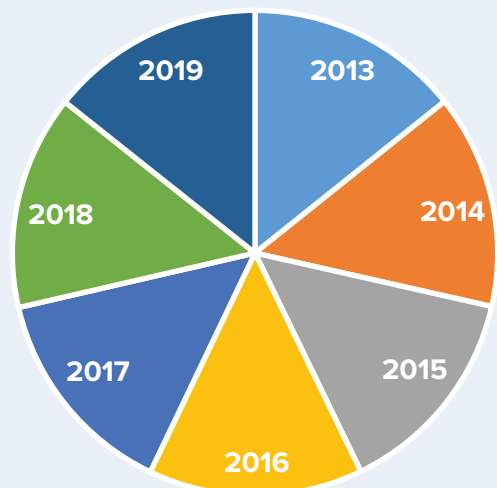
Our dedication to providing care to AYAs with a history of cancer has fostered two patient cohorts, based on age at initial diagnosis:

### Patient Cohorts



Patients have shown their appreciation for the care provided; 80% remain in active care. In 2019, we welcomed a new group of patients, on par with the yearly growth seen since the clinics inception:

### New Patients



# LONG-TERM FOLLOW-UP CARE PLAN

The foundation of each clinic visit is the patient’s individualized Survivorship Care Plan (SCP), comprised of a Treatment Summary (TS) and a long-term follow-up Care Plan (*illustrative sample below*). To create the TS, the Care Team reviews medical records to ascertain the individual’s cumulative chemotherapy, radiation, applicable surgeries and/or transplants. For patients who were treated as children, or who were treated outside of Tufts Medical Center, paper medical charts are requested and carefully reviewed to determine the exact treatment that each patient received. Reviewing the TS at the initial visit provides an opportunity for patients to further understand the specific oncology treatment that they received.

A Care Plan is created based on the TS and oncology guidelines (e.g., Children’s Oncology Group, National Comprehensive Cancer Network Clinical Practice, American Society of Clinical Oncology). This Care Plan is arranged by body system and consists of recommended testing/specialty referrals, indication, time interval, last completed date and the provider responsible. At each visit, the Care Plan is reviewed, updated and saved in the patient’s electronic medical record.

Jane Smith: MRN 123456, DOB 11/19/1981  
 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)

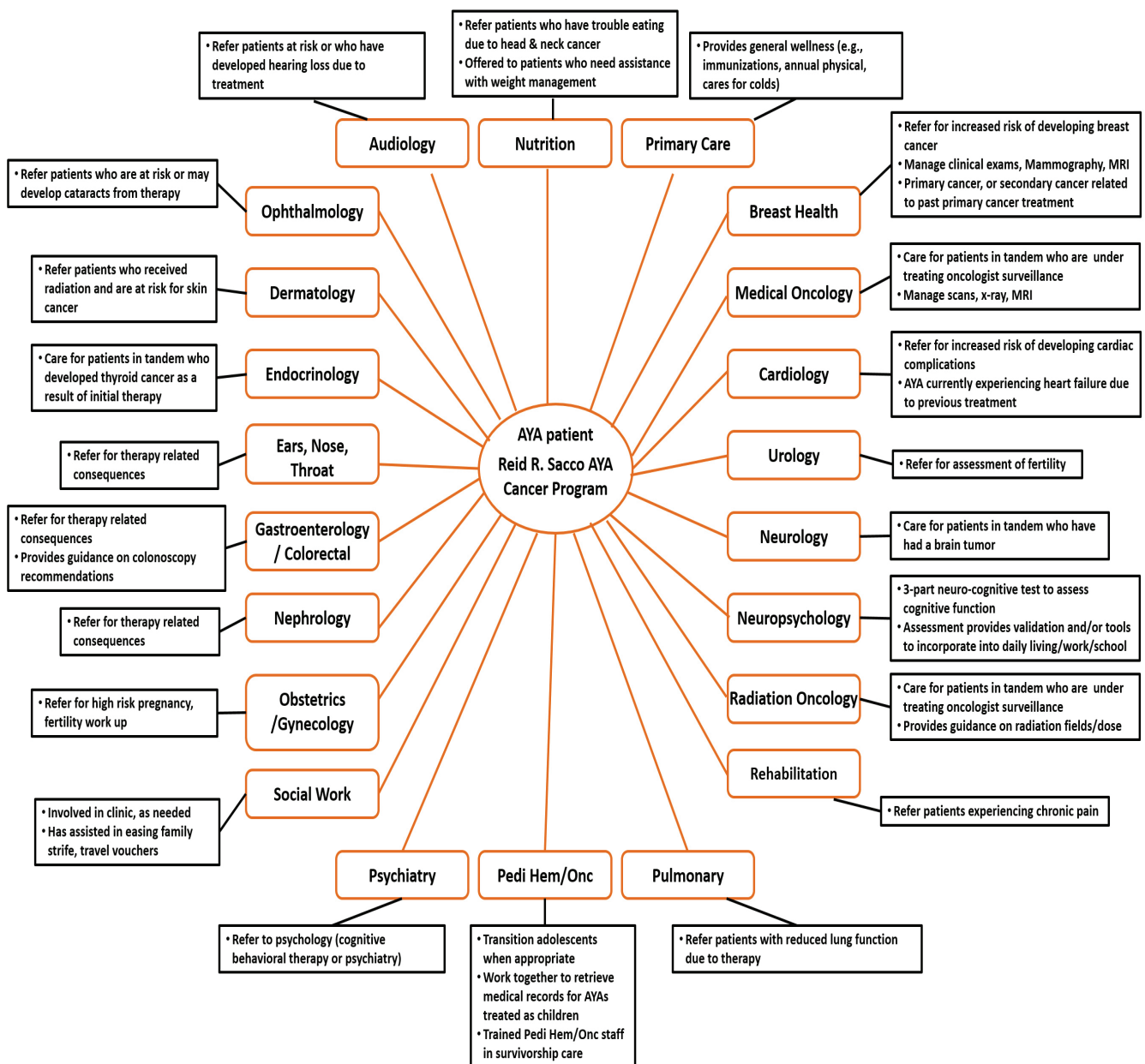
Organ System	Test	Indication	Time Interval	Last Completed/Plan	Responsibility
Cardiac	ECHO	Doxorubicin (300 mg/m2) with mediastinal radiation; risk of cardiomyopathy, coronary artery disease	Every Other Year	7/17/2019	Survivorship; Cardiologist, PCP
	EKG		At baseline at entry into clinic and then as clinically indicated	7/17/2019	Survivorship; Cardiologist; PCP
	BMI	Cardiac modifiable risk factors	At every visit	7/17/2019	Survivorship; Cardiologist; PCP
	Blood pressure		At every visit	7/17/2019	Survivorship; Cardiologist; PCP
	Fasting lipid profile		Every Other Year	7/17/2019	Survivorship; Cardiologist; PCP
Endocrine	Thyroid exam, Thyroid function tests	Mediastinal radiation; History of hypothyroidism	Annually	6/30/2019	Endocrinologist
Breast Health	Breast Exam	Mediastinal radiation; Risk of secondary breast cancer	Every six months	11/13/2019	Breast Health
	Mammogram/Breast MRI	Mediastinal radiation; Risk of secondary breast cancer	Yearly beginning at age 25	11/13/2019	Breast Health
Pulmonary	Pulmonary Function Tests	Bleomycin, mediastinal radiation, and history of asthma	Baseline and then as clinically indicated	6/30/2019	Survivorship
Dermatology	Skin exam with special attention to radiation fields	Mediastinal radiation; Risk of secondary skin cancer	Annually	6/30/2019	Dermatology
Neurologic	Neurologic Exam	Vinblastine; at risk for peripheral neuropathy	Baseline and then as clinically indicated	7/17/2019	Survivorship/PCP
Psychosocial	Psychosocial assessment: attention to depression, PTSD, anxiety	Cancer diagnosis and treatment	Assess at each visit and make referrals as needed	7/17/2019	Survivorship, Psychology

\*Sample of a Long-Term Follow-Up Care Plan ©

# COMPREHENSIVE CARE COORDINATION

Many cancer survivors have complex medical needs, which require multiple specialty and sub-specialty providers. Patients benefit from our multidisciplinary care network composed of specialists, primary care physicians and psychosocial providers. Building these strong relationships has allowed for bi-directional referral opportunities and the comprehensive care of our patients.

The AYA Cancer Program's Care Team works closely with Dr. Jenica Upshaw, Medical Director of the Cardio-Oncology Program, offering real-time care coordination and the convenience of back-to-back appointments to reduce the number of trips to the medical center. Dr. Upshaw cares for patients who are at increased risk of developing, or have developed, cardiomyopathy from chemotherapy or radiation treatment.



## BROADENING OUR REACH

A goal of our program is to continually evaluate and improve the care of our patients, as well as to share the best practices of survivorship care. Below are two 2019 publications, both of which were first authored by former AYA Cancer Program Summer Scholars, who are now resident physicians.

### Development of Phase-Specific Breast Cancer Survivorship Care Plans

Lauren Boehm,<sup>1</sup> Tracey Weisberg,<sup>2</sup> Nadine Linendoll,<sup>1,3</sup> A. Circe Damon,<sup>2</sup>  
John K. Erban,<sup>1,3</sup> Susan K. Parsons<sup>1,3,4</sup>

#### Abstract

Survivorship care plans (SCPs) have the potential to be powerful tools in providing individualized, comprehensive survivorship care over time, particularly if these documents are used in a dynamic fashion and updated throughout the survivorship course. We propose the addition of the phase-specific SCP at key care junctures to capture time-specific risks and updates, as well as to prepare for transitions of care. We detail the development and integration of the phase-specific SCP into the electronic medical record and clinical work flow at two, diverse practice settings.

**Introduction:** Phase-specific survivorship care plans (SCPs) have the potential to be powerful tools in providing individualized, comprehensive survivorship care, particularly in terms of care coordination and transition, if used as dynamic documents. **Materials and Methods:** We designed an initial follow-up care plan (FCP) to be used at the conclusion of curative therapy, as well as distinct, phase-specific FCPs for periodic use at 5-year and 10-year time points in the survivorship course. These FCPs incorporate the 4 essential components of survivorship care outlined by the Institute of Medicine: prevention, surveillance, intervention for consequences of cancer treatment, and coordination among health care providers. **Results:** Phase-specific SCPs were designed by a multidisciplinary team with expertise in breast health, survivorship, and cancer care delivery across diverse practice settings. The FCPs were formulated to align with national guidelines and emergent, peer-reviewed literature, and reflect evolving recommendations regarding the duration of adjuvant hormone therapy. The SCPs were pilot-tested and successfully integrated into the existing work flow of the electronic medical records at each practice site. **Conclusion:** Phase-specific SCPs were developed to incorporate new knowledge about evolving treatment recommendations, screening guidelines, and updated genetic information to encourage timely discussions relevant to the specific stage of survivorship.

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**Keywords:** Care coordination, Electronic medical record integration, Hormone therapy, Implementation, Late effects

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### Schwannoma Formation in Childhood Cancer Survivors Exposed to Total Body Irradiation: Case Series

Emily Anderson, MSPH,<sup>1</sup> Nadine Linendoll, PhD, GNP,<sup>1</sup> Carl B. Heilman, MD,<sup>2</sup> Ron I. Riesenburger, MD,<sup>2</sup>,  
Miriam A. O'Leary, MD,<sup>3</sup> Knarik Arkun, MD,<sup>4</sup> Tara J. Nail, MD,<sup>2</sup>  
Martin Goodman, MD,<sup>5</sup> and Susan K. Parsons, MD, MRP<sup>1</sup>

Childhood cancer survivors are at risk for ongoing health risks related to their initial treatment. One potential long-term complication following radiation is the development of secondary tumors, including peripheral nerve tumors, such as schwannomas. We present three adolescent and young adult (AYA)-aged survivors of pediatric cancer (22–40 years), followed in our AYA survivorship clinic. Each was found to have a schwannoma many years following total body irradiation for a childhood primary malignancy. We highlight a late effect of low-dose total body irradiation as well as the importance of long-term monitoring in this population.

**Keywords:** schwannoma, peripheral nerve tumor, late effects, total body irradiation, low-dose irradiation



Patients both on- and off-treatment for cancer face many financial concerns related to their medical care. Leveraging her graduate degree in health planning/economic development, Dr. Parsons contributed to a chapter titled *Principles and Practice of Pediatric Oncology* in the text book, *Economic Issues in Pediatric Cancer*, 8th edition, as well as presented on this topic across the country.

Dr. Parsons (*above center*) was an invited guest speaker at The Chicago AYA Oncology Symposium: Comprehensive Care for AYAs with Cancer in May 2019. Her talk was titled *Health Economics and AYA Oncology: Financial Burden of Care*. She is pictured with the University of Chicago Medicine's Dr. Tara Henderson, Director of Childhood Cancer Survivors Center (*above left*) and Dr. Wendy Stock, co-Director of their AYA Cancer Program. Dr. Stock was the Reid. R. Sacco AYA Cancer Program's 2016 guest lecturer (*above right*).

Dr. Parsons also spoke about the *Financial Challenges Faced by AYAs with Cancer* at the Innovators in AYA Cancer: Driving Science and Policy toward a Brighter Future for Teens and Young Adult with Cancer in Cleveland, Ohio in November 2019.

Dr. Kumar extended her reach from direct patient care to education, acting as co-chair to a Leukemia & Lymphoma Society Chronic Leukemia Rounds education program, as well as presenting to a group of Hematology/Oncology Fellows at Tufts Medical Center.

# STUDENT SCHOLARS

More than 20 medical and undergraduate school students have participated in the AYA Cancer Program over the last seven years. These young adults have expressed enthusiastic interest in learning about AYA cancers and survivorship care. These students take their clinical and research experience, along with their newfound awareness of the AYA demographic, into their future medical careers.

This year five students joined us for eight weeks as endowed Summer Scholars. Throughout the year four 4th year Tufts University School of Medicine (TUSM) students also joined the program to fulfill research electives by contributing in ongoing research projects (*not pictured: Lisa Bartucca and Lauren Boehm*). Additionally, two students Madison Welch and Samantha Smith (*not pictured*) volunteered as part of their undergraduate capstone project.

We thank them for their interest and contributions!



**Aram Bedrosian**  
Summer Scholar  
Medical Student  
TUSM



**Megan Catalano**  
Summer Scholar  
Undergraduate Student  
Brandeis University



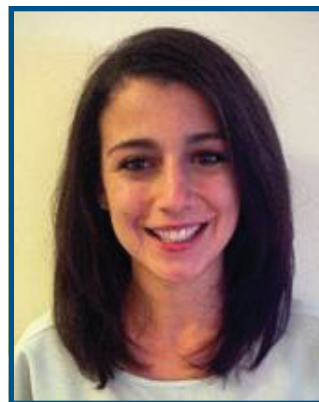
**Rabiah Fresco**  
Summer Scholar  
Medical Student  
St. Louis University School of Medicine



**Mathew Lucas**  
Summer Scholar  
Medical Student  
TUSM



**Emma Livne**  
Research Elective  
Medical Student  
TUSM



**Diana Mihalache**  
Research Elective  
Medical Student  
TUSM



**Ben York**  
Summer Scholar  
Medical Student  
TUSM



# BUILDING COMMUNITY & RAISING AWARENESS

The AYA cancer community is strong, resilient, motivated to help others, but sometimes is hard to find. Thanks to travel grants from the Reid R. Sacco AYA Cancer Alliance & The Joy in Childhood Foundation, a group of AYAs travelled to Denver to attend Stupid Cancer’s 2019 Cancer Con, a conference dedicated to young adults who have experienced cancer. Additionally, Dr. Parsons and Rachel presented (for the third year in a row) tips and tools on how to advocate for long-term follow-up care to AYAs who might live in areas where survivorship programs are not available.



**AYA Cancer Program attendees at Cancer Con**



**Presenters: Dr. Parsons and Rachel**

Our Program Manager Rachel was named one of the 40-under-40 in Cancer for her work in supporting the AYA Cancer Program and numerous presentations at local universities regarding the young adult cancer experience. Student responses were summarized in a published manuscript (*below right*).



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**Personal Narrative:  
 Raising Awareness of Adolescent and Young Adult Cancer  
 Survivors in Similarly Aged University Students**

Rachel Murphy-Banks, MA,<sup>1</sup> Danielle Blanch-Hartigan, PhD, MPH,<sup>2</sup> Lauren Boehm, BS,<sup>1</sup>  
 Pauline C. Hamel, EdD, PT,<sup>3</sup> and Susan K. Parsons, MD, MRP<sup>1</sup>

**Purpose:** As part of a programmatic educational initiative, we developed a personal narrative presentation, embedded with evidence-based data, to raise awareness of adolescents and young adults (AYAs) who have been diagnosed with cancer between the ages of 15 and 39 years among similarly aged university students. The narrative encompassed the cancer care continuum from signs of the disease through survivorship and incorporated psychosocial aspects of the experience.

**Methods:** The presenter, diagnosed with lymphoma at the age of 25 years in 2007, interwove AYA data with her narrative in a series of 26 invited lectures given over 2 academic years, 2016–2017 and 2017–2018. Students were asked to provide anonymous open-ended feedback. Six hundred thirteen forms were collected and retrospectively dually coded and analyzed.

**Results:** The majority of students (97%) referenced at least one of the presentation’s three objectives: (1) build awareness of the AYA demographic; (2) encourage a personal health care focus; and (3) expand awareness of the far-reaching impact of cancer (i.e., psychological, social, and medical) both during and beyond the treatment phase. Format- and/or content-related suggestions and potential benefits of hearing the narrative also were reported.

**As part of the AYA Cancer Program’s education and outreach, events and AYA perspectives were shared on our online portals: on Facebook, our AYA Community Connection e-newsletter and blog (*information on back cover*).**

# THE REID R. SACCO AYA CANCER ALLIANCE

The Reid R. Sacco AYA Cancer Alliance was founded by Lorraine, Gene and Weston Sacco in honor of Reid, in 2005. Reid, by all accounts, was kind, smart, outgoing, and had many plans for his life which was cut too short when he was diagnosed with cancer as a young adult. Inspired by Reid to improve the lives of AYAs diagnosed with cancer, the amazing, dedicated network of Alliance members has supported the development of programs dedicated to the care of AYAs, including our program at Tufts Medical Center. To celebrate 15 years of raising awareness of AYAs with cancer and improving their care, the Alliance held two events: Reid's Ride, the annual fundraising 28-mile bike ride along the North Shore in July, and a holiday Gala at the Fairmont Copley in November. Members of the AYA Cancer Program, Tufts Medical Center leadership, medical trainees and supporters of the AYA Cancer Program were honored to participate in these two events.



## 15th Annual Reid's Ride

### *Back Row – Left to Right*

Todd Stanganelli, Executive Director Tufts Medical Center Cancer Center; Pamela Chase; Dr. Rodday

### *Front Row – Left to Right*

Drs. Linendoll, Kumar, Parsons, and Erban; Ruth Ann Weidner; Drs. Boehm and N. Bankoff; Rachel Murphy-Banks; and Dr. M. Bankoff

### *Riders missing from photo:*

Jonathan McEuen, Timothy Montgomery, Sarah and Rabiah Fresco

To learn more about Reid's

Ride, July 19, 2020, please contact the AYA Cancer Program Team.



## AYA Red Carpet Holiday Gala

### *Back Row – Left to Right*

Drs. N. Bankoff, Anderson, and Boehm; Emma Livne; Walter Armstrong; Rachel Murphy-Banks;  
Drs. Rodday, Linendoll, Kumar, Upshaw, Scharman, and Hachem

### *Front Row – Left to Right*

Drs. Parsons and Waheed; Diana Mihalache; Dr. Karim

### *Missing from photo:*

Dr. Apkon, CEO and President of Tufts Medical Center and his spouse Michelle; Dr. Buchsbaum, Director of Tufts Medical Center Cancer Center and her spouse Michael Arwe; Maura Lynch; Susan Harrington; Dr. Erban and his sister Barbara; Ted Schwartzberg; Drs. M. Byrne, J. Byrne, and Andujar Vazquez; Christina Graham; Thomas Armstrong; and Elizabeth Peabody

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

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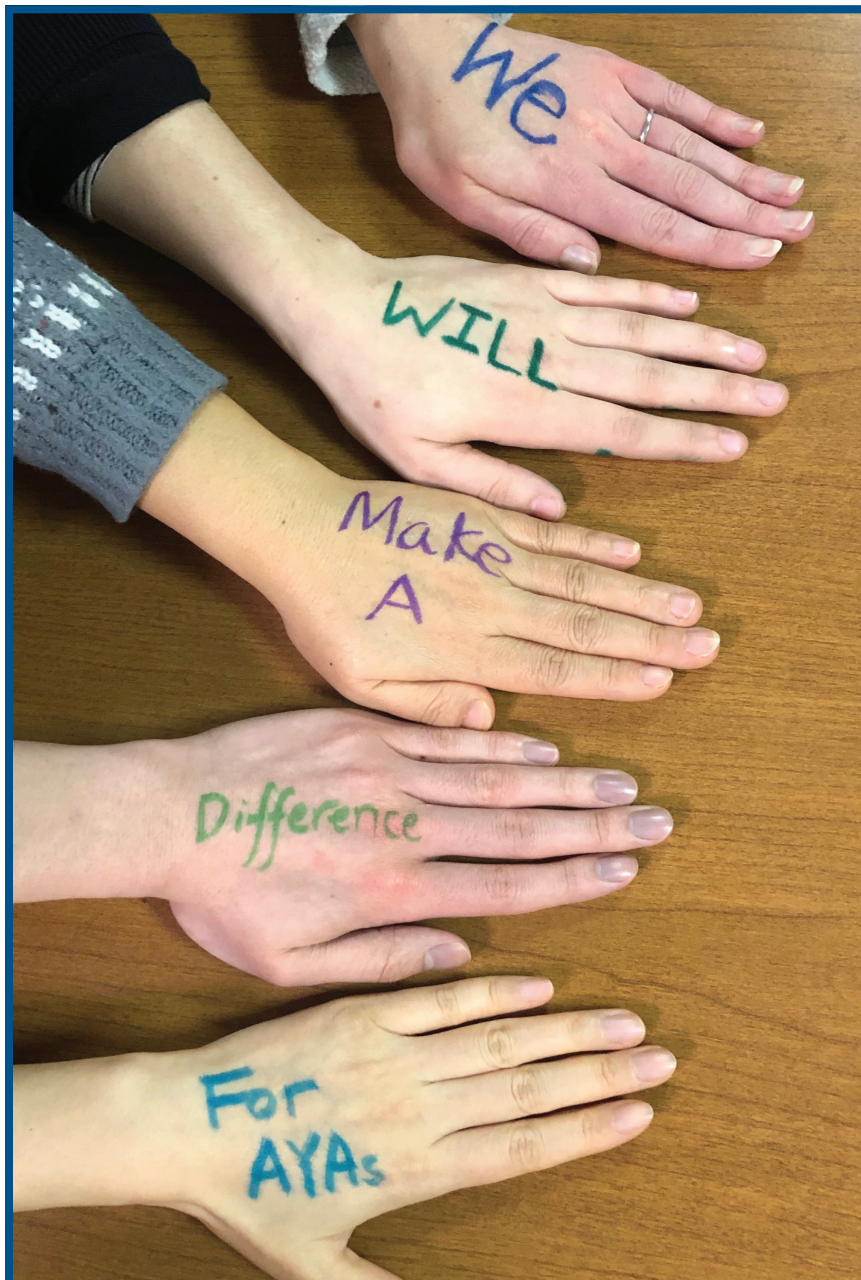
**Tufts** Medical Center

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Clinic Location: South 7



*World Cancer Day, February 4, 2019*