

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

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**2020**  
**Annual Report**

**Tufts** Medical  
Center

# Messages from the AYA Cancer Program Team

*“To quote my beloved grandmother, ‘such a year!!’ 2020 has challenged us in ways we could not have imagined—a pandemic, economic misfortune, and cries of injustice. Through all of this, we are grateful that the AYA Cancer Program has survived—indeed, thrived—thanks to the advent of telemedicine, dedicated team members, inspiring clinical partners, and loyal patients. Much has been written about the year and how it has tested our resolve. For me, the most inspiring message came from an AYA survivor, who reminds us all, ‘when there is no wind, we row.’ We wish you health, hope, and strength in the 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



**Anita Kumar, MD, MSCE, PhD(c)**

Adult-trained  
Hematologist/Oncologist,  
specialized in hematologic  
malignancies,  
Assistant Professor at TUSM

*“I am incredibly grateful for the wonderful community we have in our program. I am also grateful for the opportunity to connect with patients via telehealth (p.3). I believe that telehealth will help keep AYA patients engaged in the future! I am most looking forward to ‘normal days’ where we can be back in person together!”*



**Nadine Linendoll, PhD, MDiv, NP**

Adult-trained Nurse Practitioner,  
specialized in neuro-oncology,  
Assistant Professor at TUSM

*“When the struggles and hardships experienced by so many felt overwhelming this year—I tried to focus on what we can do, to bring some light back into the world. One surprising advancement over this difficult period has been telehealth. Launching telehealth (p.3) has helped me to realize that despite the challenges of the past year we are all deeply connected. I look forward to walking together into 2021 with renewed hope and optimism for the future.”*



**Rachel Murphy-Banks, MA**

Program Manager

*“Despite the challenges of 2020, it has been a year filled with opportunities to impact the lives of AYAs—evidenced by new additions to our website (p.6) and partnership with Teen Cancer America (p.9), and sharing the impact of the young adult cancer experience at the American Society of Clinical Oncology annual meeting (p.5).”*

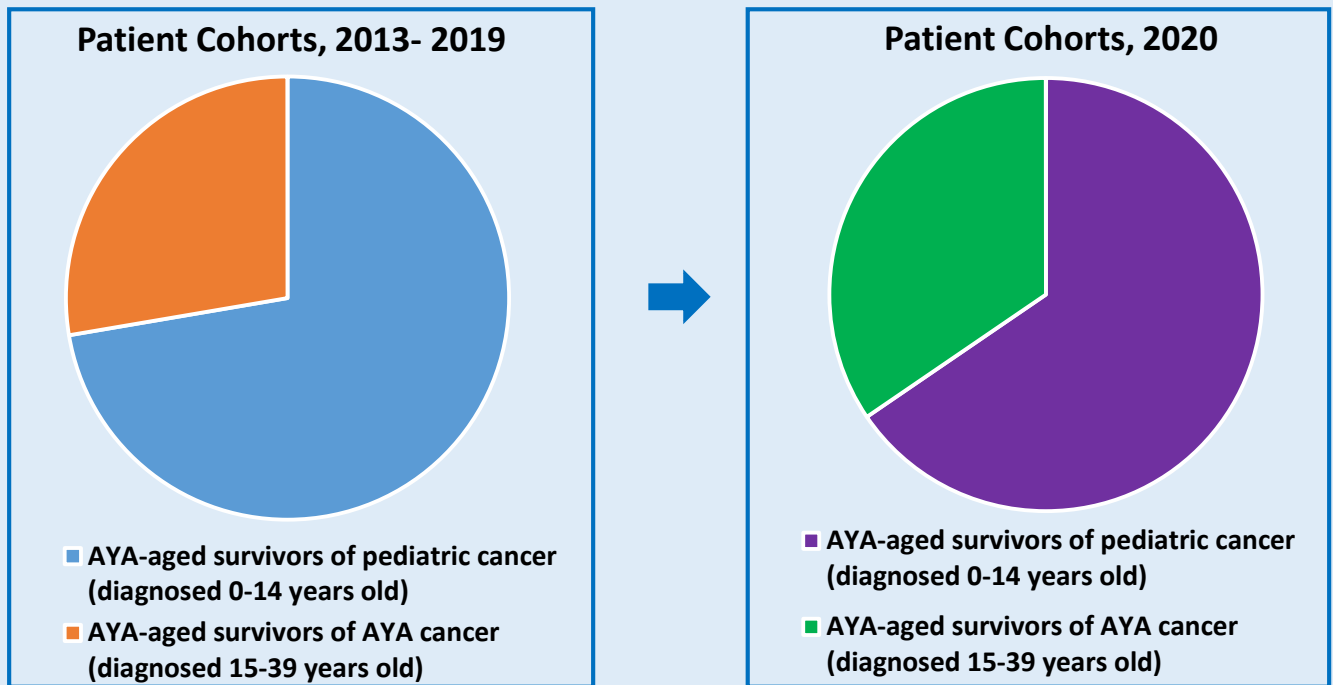
# Survivorship Clinical Care

In 2020 the estimated annual number of individuals diagnosed with cancer between the ages of 15-39 in the United States increased to 89,000 young people (from 70,000 per year).<sup>1,2</sup> With advances in treatment options and modalities, dedicated survivorship care is essential for the long term health of these patients. Of the estimated 16.9 million<sup>3</sup> Americans who have a cancer history, there are ~2 million who were diagnosed as AYAs.<sup>4</sup>

**The AYA Cancer Program incorporates the tenets of survivorship care<sup>5</sup> into our care model:**

- 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.

AYA-aged patients who receive their survivorship care are composed of two patient cohorts (i.e., survivors diagnosed under the age of 15 years old and survivors diagnosed between the ages of 15-39). Both groups deserve comprehensive survivorship care designed to address the myriad issues younger survivors may face.<sup>2</sup> In 2020, the proportion of AYA-aged survivors increased slightly, from the program's historic majority of pediatric cancer survivors.



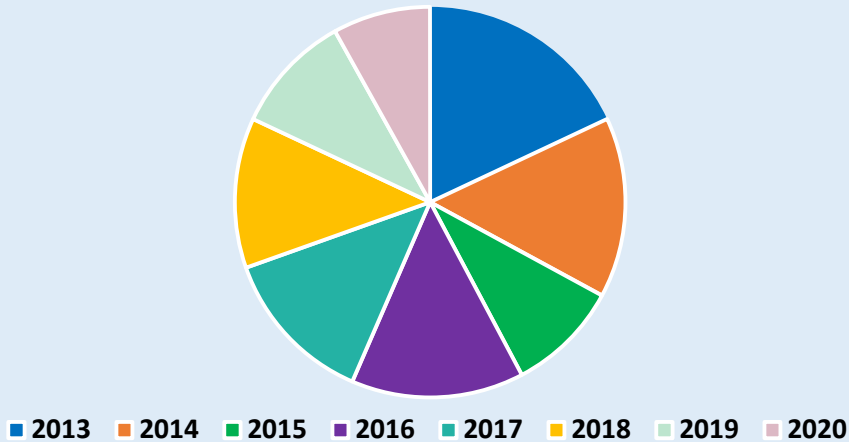
References

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2. Miller et al. Cancer statistics for adolescent and young adults, 2020. CA: A Cancer Journal for Clinicians. 2020;70(6):443-459
3. American Cancer Society. Cancer Facts & Figures 2020. Atlanta: American Cancer Society; 2020.
4. Bleyer et al. Global assessment of cancer incidence and survival in adolescents and young adults. Pediatric Blood Cancer. 2017;64:e26497
5. 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.

# Survivorship Clinical Care

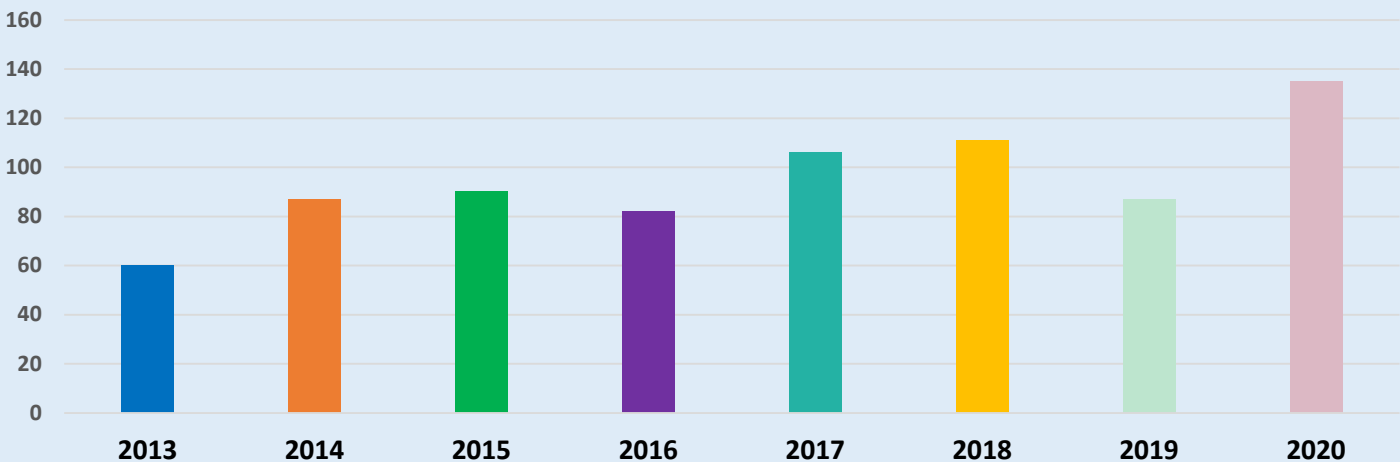
Patients receive a cumulative Treatment Summary and oncological guideline-based Care Plan (i.e., Survivorship Care Plan) at their initial visit in the AYA Cancer Program. The Care Plan is updated after each subsequent appointment, to help keep track of recommended testing/specialty referrals. In 2020 we welcomed a new cohort of patients whom we look forward to caring for in the years ahead.

### New Patients, 2013-2020



As the pandemic evolved in the United States, Tufts Medical Center paused in person visits in the early spring to meet the needs of patients with Covid-19 as well as to ensure the safety of the community. During this time we transitioned from in person visits in the clinic to offering telehealth appointments. The flexibility in how the AYA Cancer Program's care team was able to provide care and address the needs of our patients led to our largest number of visits conducted, since the inception of the program. Of the 2020 visits, 70% were conducted as telehealth appointments. We plan to continue to offer the telehealth option for the foreseeable future.

### Visits, 2013-2020



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## The Creation of a Comprehensive Adolescent and Young Adult Cancer Survivorship Program: “Lost in Transition” No More

Nadine Linendoll, PhD, MDiv, GNP,<sup>1-3</sup> Rachel Murphy-Banks, MA,<sup>1,3</sup> Erin Barthel, MD,<sup>1,\*</sup>  
Lisa Bartucca, MD,<sup>1,†</sup> Lauren Boehm, MD,<sup>1,‡</sup> Madison Welch, BS,<sup>1</sup>  
Ruth Ann Weidner, MBA, MRP,<sup>3</sup> and Susan K. Parsons, MD, MRP<sup>1-3</sup>

**Purpose:** The Reid R. Sacco AYA Cancer Program set out to improve survivorship care for AYA-aged patients (15–39 years) of pediatric or AYA cancer. This article discusses the steps in establishing the clinic, including the creation of a database on cancer history, exposures, and attendant risks of late effects. Results from the database tell the broader story of AYAs who seek care within a dedicated survivorship clinic.

**Methods:** The database was created with REDCap<sup>®</sup> (Research Electronic Data Capture), a secure web-based, HIPAA compliant application for research and clinical study data. Data were abstracted and analyzed by trained members of the program team.

**Results:** A total of 144 patients were seen for their initial survivorship visit between January 2013 and September 2019. Regarding physical health, two-thirds of the patients presented with an established late effect, one third with an established medical comorbidity, and 11% ( $n=16$ ) with secondary cancer related to their oncologic treatment. In assessing mental health, a significant cohort reported a known affective disorder (32%,  $n=46$ ) with one quarter already taking a psychotropic medication. Despite the transient nature of AYAs, 85% of patients remained in care within the long-term follow-up clinical model.

**Conclusions:** Data presented illustrate how multilayered and complex survivorship care needs can be, as patients enter the clinic with complicated pre-existing psychosocial issues, significant late effects, and comorbidities. This study reinforces the value of a clinical database to better understand AYA survivors with the ultimate goal of optimizing and coordinating care.

As part of an internationally respected academic medical center, the AYA Cancer Program team contributes to peer-reviewed journals with the aim to contribute to knowledge building and improve the care of AYAs with a history of cancer. This year a comprehensive overview of the program was published in the [Journal of Adolescent & Young Adult Oncology](#) (image of abstract, above).

The paper summarizes:

- The development of a unique model of care that can be applied to AYA programs around the world
- A detailed breakdown of our patient population, highlighting the importance of long term follow-up care for AYA cancer survivors

In other publication news, Dr. Parsons was invited to write two editorials in the Journal of Clinical Oncology: [Longitudinal assessment of health-related quality of life among survivors of Hodgkin Lymphoma: It is about time!](#) and [Continuum of care for Hodgkin Lymphoma: Impact of modern therapy on postacute morbidity and mortality.](#)

## Expanding our Education and (Out)Reach

The AYA Cancer Program team has embraced 2020's expanded virtual opportunities to continue our education and outreach efforts.

**Dr. Parsons** spoke at the 10<sup>th</sup> annual **Texas AYA Oncology Conference** which took place in February, in San Antonio, Texas. The presentation titled, "Financial challenges faced by AYAs with cancer" is part of her ongoing contribution to the national dialogue on the financial impact of cancer. She has also been working with **Teen Cancer America (TCA)** (p. 9) on a report of the economic impact of cancer on AYAs and on society. Dr. Parsons also led panel discussions during the virtual **Children's Oncology Group** meeting in her role as scientific chair of the Cancer Care Delivery Research discipline.

**Nadine**, our Oncology Nurse Practitioner, provided an overview of AYA cancer and our survivorship care to incoming Tufts MC **Hematology/Oncology Fellows**. This presentation helped increase the number of referrals to our program. She also expanded her own education in the topic of oncofertility, completing the **ECHO** Training Program (Enriching Communication Skills for Health Professionals in Oncofertility).

**Dr. Kumar** delivered a presentation on survivorship care to **Tufts MC's rehabilitation medicine residents and internal medicine residents**, and moderated a health services research session at the virtual **American Society of Hematology** annual conference. As a selected member of the **National Academy of Sciences Committee on Diagnosing and Treating Cancer** she worked on a report to help aid in disability assessments for cancer patients and survivors.

**Rachel**, our Program Manager, was a virtual lecture speaker at **Tufts University** and **Northeastern University**. She presented, "Life Interrupted: Cancer as a Young Adult," at the **American Society of Clinical Oncology (ASCO)** annual meeting, educational program. In an interview by the ASCO Daily News, [Tools for Discussing Difficult Topics with Adolescent and Young Adults with Cancer](#), Rachel shared: *"There are so many unmet needs in the sense of peer-to-peer connection and talking to somebody who has been through a similar experience, knowing that you are not alone in this, knowing that other people your age have paused work or had to stop school."* She also provided an overview of the AYA Cancer Program to **TCA's AYA program network** which is made up of AYA programs located across the United States.

# Expanding our Education and (Out)Reach

In alignment with the shift to relying on virtual connections more than ever, we have expanded the information available on the AYA Cancer Program's [Tufts Medical Center webpages](#). Updates include a new Education + Outreach tab, an enhanced list of curated resources for the AYA cancer community, a comprehensive list of our supporters who help make our model of care possible, and a new Training tab to showcase the many talented (future) medical providers who have taken the initiative to include AYA cancer survivorship in their medical training.



**New features of the AYA Cancer Program website include:**

**1. Education + Outreach Tab**

- Publications
- Annual Reports
- Conferences + Events
  - Includes links to our AYA Community Connection e-newsletter, and snapshots of conferences at which the AYA Cancer Program team has presented or attended

**2. Enhanced Resource Links** (selected topics include:)

- Connect with AYA Cancer Community
- Employment
- Fertility & Family Planning
- Finances + Insurance
- Fitness + Adventure Retreats

**3. Training Tab**

As part of creating an all-in-one location for AYA Cancer Program information and resources we have closed our blog site. Previously posted blog pieces are in the process of being transferred to the Tufts MC site. We hope you enjoy these updates.

## Training

Despite the challenges posed by the pandemic, the AYA Cancer Program remained committed to one of our foundational principles: training (future) providers in the care of AYAs. This year we welcomed three young adults interested in learning more about the impact of AYA cancer. **Annika Jain**, a previous research volunteer, is working with Dr. Parsons on a multi-site financial navigation study. **Neena Patel**, a candidate at Tufts University for a master of biomedical science degree, has contributed to outreach and clinical projects. **David Posawatz** has committed to volunteering his time while also pursuing a dual Tufts University School of Medicine (TUSM) medical degree/Brandeis University master of business administration degree.

**Dr. Danai Dima** and **Emma Livne** began their participation in the program in 2019 and extended their time through 2020. They shared how their experience will impact their future careers:



**Danai Dima, MD,**  
**Internal Medicine Resident, Tufts MC**

*"Working at the AYA Cancer Program has been one of my most unique and rewarding experiences from my Internal Medicine residency. Not only did I gain valuable insight into the complexities of caring for cancer survivors, but I also learned to appreciate the importance of an excellent patient-physician relationship. Furthermore, I have come to appreciate that the best patient care is achieved through team effort and long-term coordination. It was immensely gratifying to see patients thrive in their lives many years after their cancer diagnosis, and this satisfaction is one of the many reasons I have chosen Hematology-Oncology for fellowship training. I hope to be able to apply and expand all this knowledge in my future career, with the goal to always provide the highest standard of care for my patients."*



**Emma Livne,**  
**4<sup>th</sup> year Medical Student, TUSM**

*"As a future medical provider, I pursued work with the Reid R. Sacco AYA Cancer Program because of their clear dedication to compassionate, comprehensive care, and translational research. My experience taught me the importance of collaboration while working with a multidisciplinary team, and strengthened my skills in research and care coordination. As a future pediatrician, I will bring my knowledge of patient-oriented research, and passion for AYA advocacy into practice."*



## Tribute to Dr. Erban



**Dr. John (Jack) Erban**

In September 2020, we lost a great friend and supporter of AYA oncology. **Dr. John (Jack) Erban** died after a one-year history of brain cancer. Since the inception of our program in 2012, Jack was at our sides, cheering us on, and supporting our collective and individual growth. One of our cherished memories of Jack was the evening we shared with him in November 2019 at the Reid R. Sacco AYA Alliance gala, along with his sister Barbara. Jack spent his career building bridges rather than walls and tried whenever or however possible to see potential and the best in others. We are inspired by his legacy.



### **AYA Cancer Program Signing, 2012**

*Dr. Weston Sacco, Scott Neely, Lorraine Sacco, Gene Sacco, Dr. Parsons, Dr. Richard Van Etten, Dr. Erban*



### **15<sup>th</sup> Annual Reid's Ride, 2019**

*(Back row-left to right) Todd Stanganelli, Pamela Chase, Angie Mae Rodday, PhD. (Front row-left to right) Nadine Linendoll, PhD, Drs. Kumar, Parsons and Erban, Ruth Ann Weidner, Drs. Lauren Boehm and Nathan Bankoff, Rachel Murphy-Banks, and Dr. Mark Bankoff.*



### **AYA Cancer Program Annual Meeting**

*Dr. Erban and Nadine Linendoll, PhD*

### The Reid R. Sacco AYA Cancer Alliance

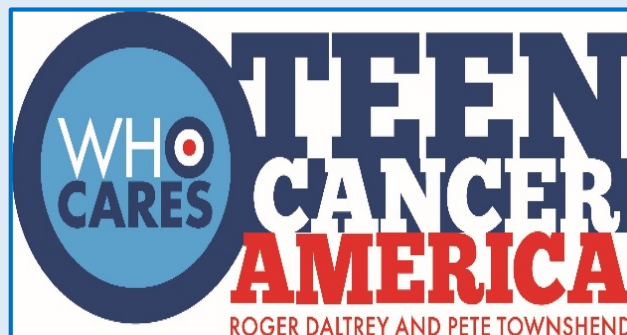
The AYA Cancer Program's ardent supporters, [The Reid R. Sacco AYA Cancer Alliance](#) have contributed more than \$1.3 million to Tufts MC – helping us transform AYA cancer survivorship care. Featured in the [Tufts MC Development Office October 2020 e-newsletter](#), the Alliance co-founders Lorraine, Gene and Weston Sacco shared how their “inspiration continues to be our son, Reid” who passed away from cancer at the age of 20. For 16 years the Alliance has led a relentless effort to ensure progress and to improve care and awareness of AYAs with cancer.



Mark your calendars for April 9, 2021. The Alliance will host the inaugural [Northeast Adolescent & Young Adult \(AYA\) Cancer Conference](#): Impact of the AYA Movement on Clinical Practice and Clinical Research. The planned virtual event will feature members of the AYA Cancer Program as well as AYA experts across the country.

### Teen Cancer America

[Teen Cancer America](#) (TCA) partners with hospitals across the United States to develop specialized services and facilities for teens and young adults affected by cancer. The AYA Cancer Program and TCA formalized a partnership in 2020.



In addition to the benefits of joining a network of AYA programs across the country to share best practices and resources, with TCA support, our AYA Cancer Program aims to enhance its outreach efforts to better serve AYAs throughout the medical center.

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

T: (617) 636-5168

F: (617) 636-6280

E: [ayaprogram@tuftsmedicalcenter.org](mailto:ayaprogram@tuftsmedicalcenter.org)

W: [www.tuftsmedicalcenter.org/aya](http://www.tuftsmedicalcenter.org/aya)

f: [facebook.com/AYAcancerprogram](https://www.facebook.com/AYAcancerprogram)

### Tufts Medical Center

800 Washington St., #345

Boston, MA 02111

Clinic Location: South 7



World Cancer Day, February 4, 2020

**Tufts** Medical Center