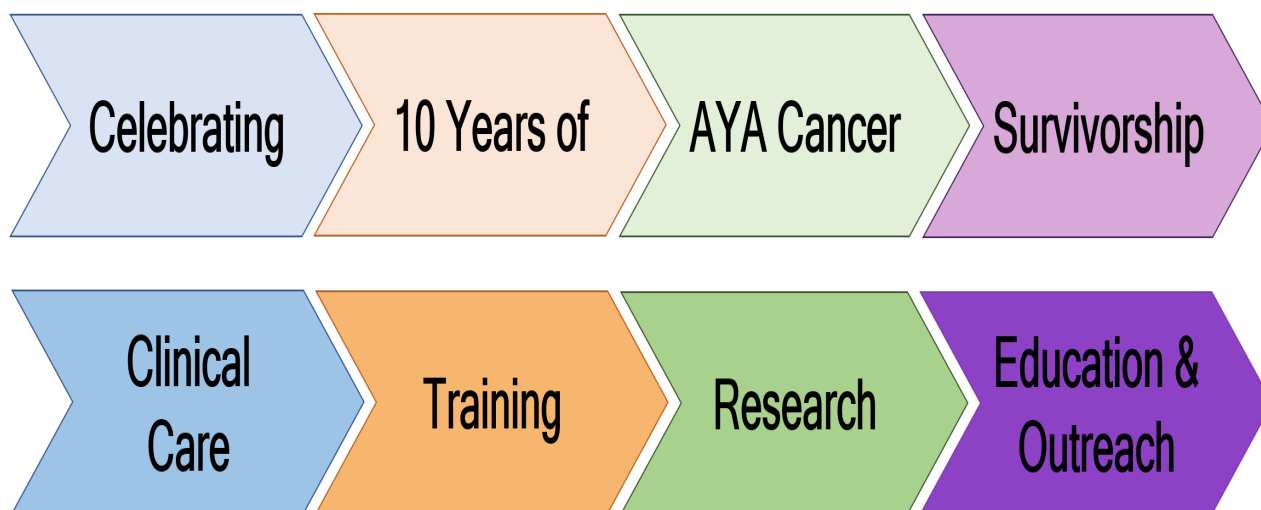


Reid R. Sacco

Adolescent & Young Adult (AYA) Cancer Program

2022 Annual Report



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AYA CANCER PROGRAM TEAM MESSAGE

Susan Parsons, MD, MRP, Medical Director's Message:

It has been said that time passes more quickly as one gets older. While I would be reluctant to endorse any association with advancing age, I certainly can attest to the rapid passage of time. And here we are at the end of another year.

In this report you will read about how the program has grown—indeed, thrived—over the past year and over the past decade, thanks to our generous donors, dedicated staff, and wonderful patients. While we remain still steeped in the COVID pandemic, we have been able to continue clinical visits, resume our summer scholars program and fellows' training, and flourish in extramurally funded AYA research. Locally, nationally, and internationally, the AYA community is strong and getting stronger. Collaborations are plentiful and impactful.

Thank you for your support and encouragement over the past 10 years, as we have realized the dream of better care for AYAs.

Nadine Linendoll, PhD, MDiv, NP's Message:

For me, assessing the breadth of the AYA Cancer Program's clinical work, outreach and scholarship over the last ten years is similar to the experience of being a parent, not realizing how much my child is growing day-by-day, until I compare their school photos over time. Providing survivorship care and participating in clinical research requires immense dedication, focus and presence in the moment. When completing important daily tasks, it can be difficult to fully recognize their larger impact. The annual report provides a wonderful opportunity to step back from daily life and zoom out for a wider perspective. I realize that each interaction, engagement and task of our clinic team, trainees, research partners and wonderful patients contributes to the larger, global advancement of AYA cancer care as a whole. In that spirit, I celebrate the last ten years of growth, development and progress and am inspired to enthusiastically launch into the next decade.

Rachel Murphy-Banks, MA, Program Manager's Message:

"I've considered it a privilege to be a part of the program, from the moment I joined the team in 2015. Whether greeting a patient in clinic, connecting with another AYA program manager across the country on what we can be doing better for our AYAs, or supporting our care team, there is intrinsic value to me, for contributing even on the smallest level to the improvement in the lives our AYA patients and survivors."

AYA PROGRAM OVERVIEW

10 years of highlights of the four foundational AYA Cancer Program tenets: clinical care, training, research, and education & outreach, are shown on the following pages.



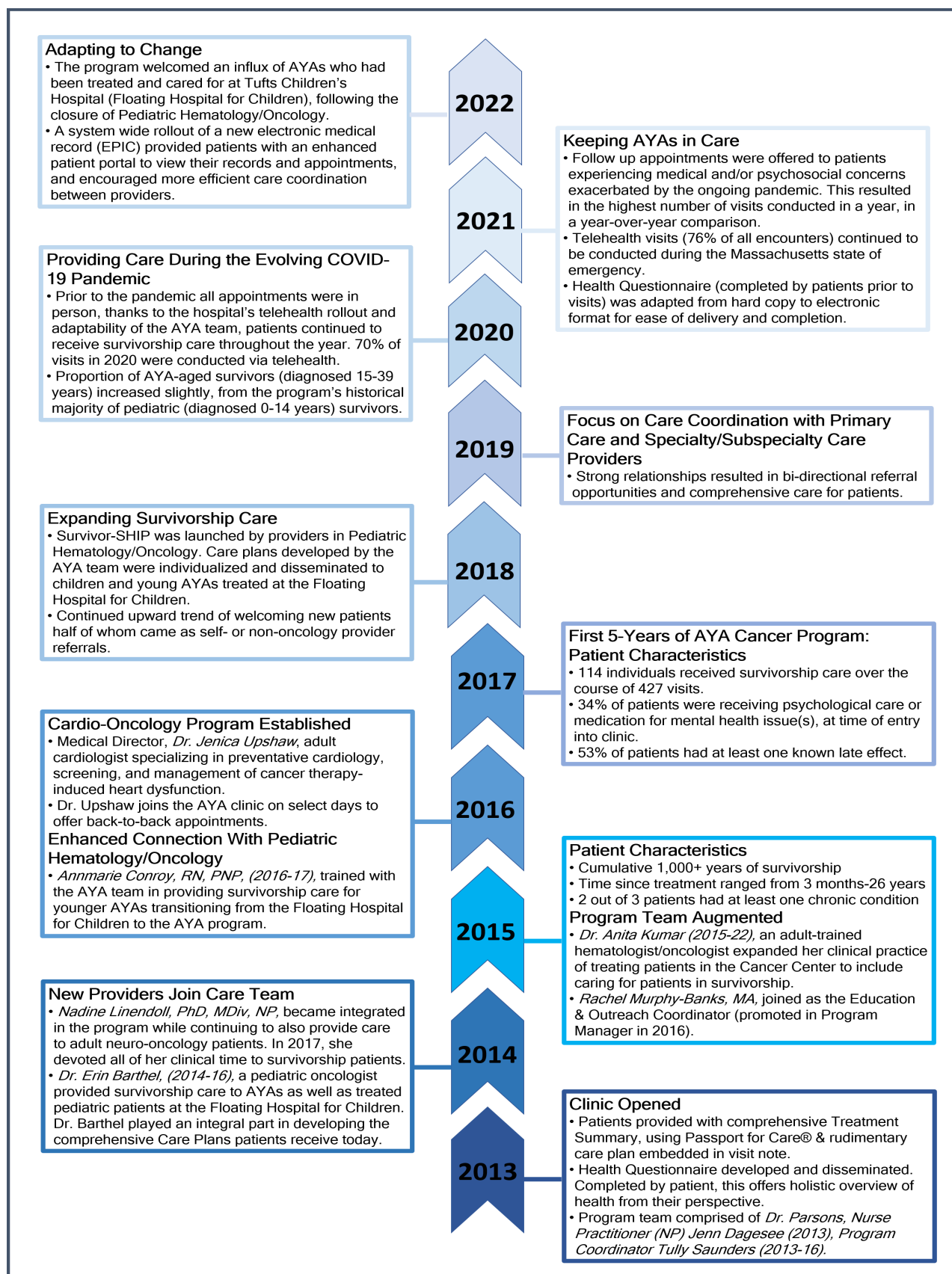
AYA-dedicated Survivorship Clinical Care is based on individualized Survivorship Care Plans:

- Treatment Summary, comprehensive cumulative treatment information including type of chemotherapies, radiation, and/or transplant, with dates, locations, and doses.
- Follow-Up Care Plan, includes suggested specialty and/or test recommendations (e.g., ECHO, Dermatology skin exam); reasons and frequency for the recommendation; when the visit or test was completed; and by which provider.

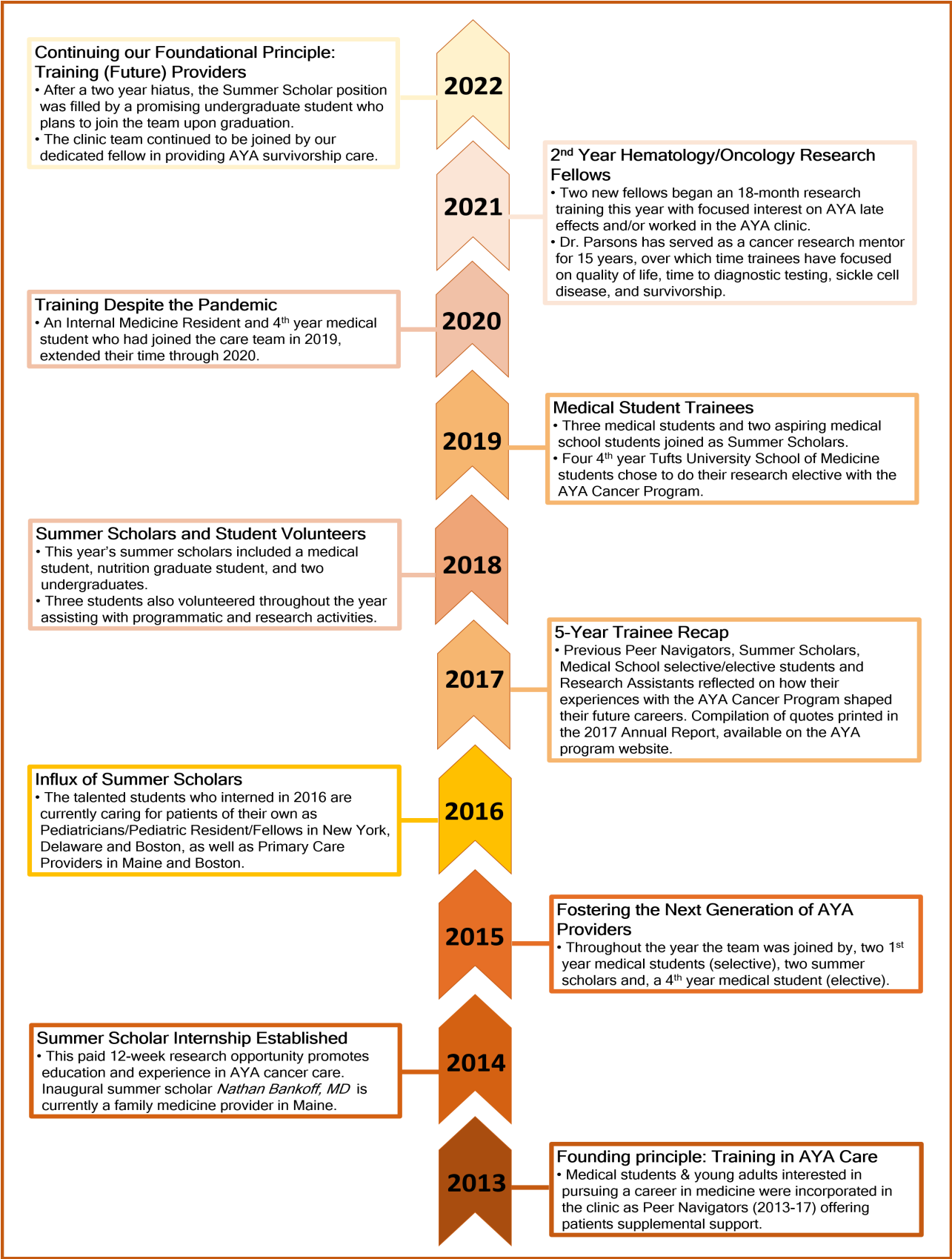
To reach the broader AYA Community, the AYA Cancer Program team is also invested in:

- **Training Providers** to ensure that AYA cancer is on the trainees' radar when they provide care to patients in the future.
- **Conducting AYA-focused Research and Disseminating Results**, which is vitally important to improve the care and outcomes for AYAs. The team has collaborated with external research partners and generated studies including sharing our care model in hopes of providing an example to other AYA programs. All research conducted has been reviewed and approved by the Tufts Health Sciences Institutional Review Board (IRB).
- **Connecting with the AYA Community via Education & Outreach** has linked patients/survivors with psychosocial resources, as well as educated young adults and medical professionals about AYA cancer diagnoses and survivorship care.

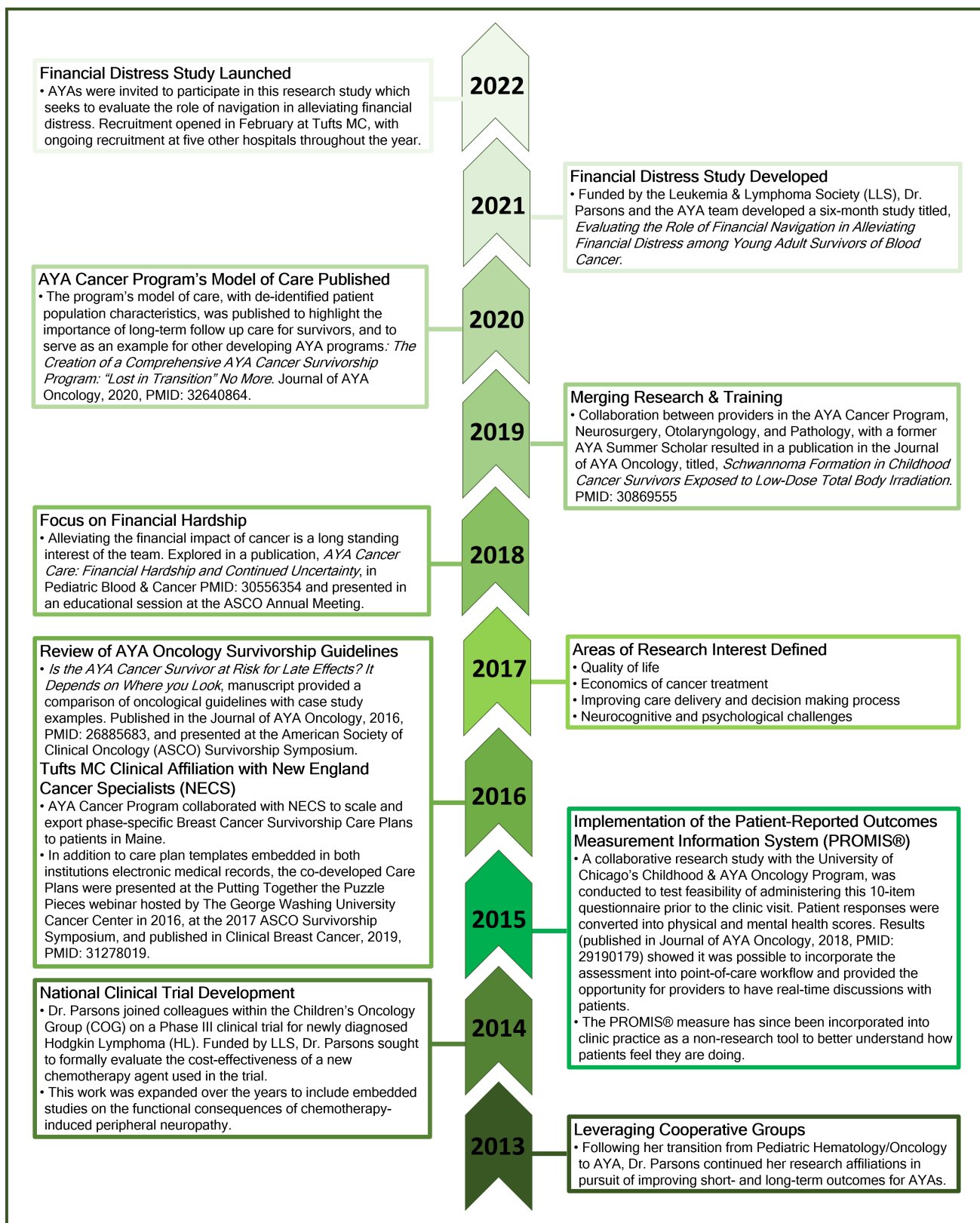
10 Years of Clinical Survivorship Care



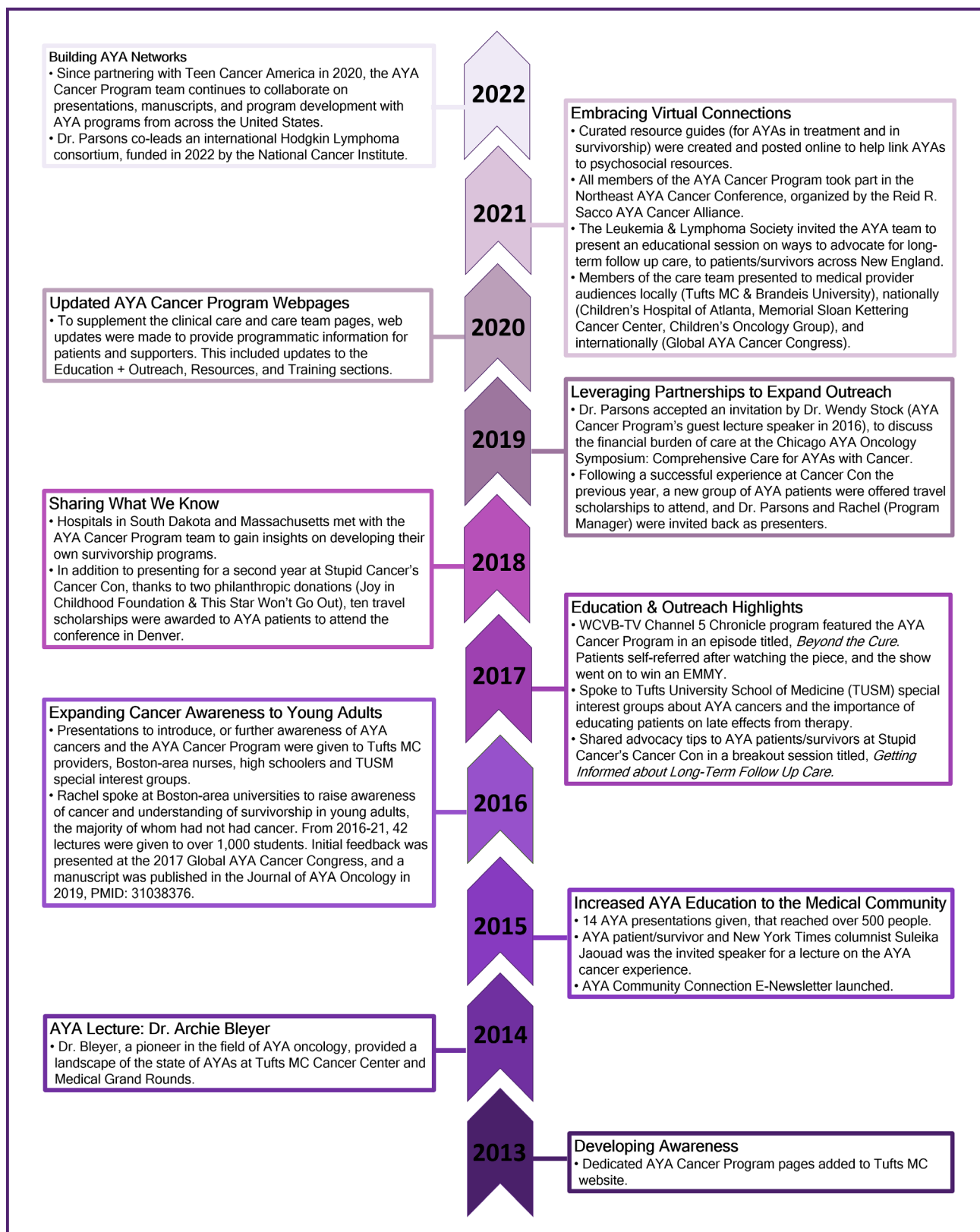
10 Years of Training (Future) Providers



10 Years of AYA-focused Research



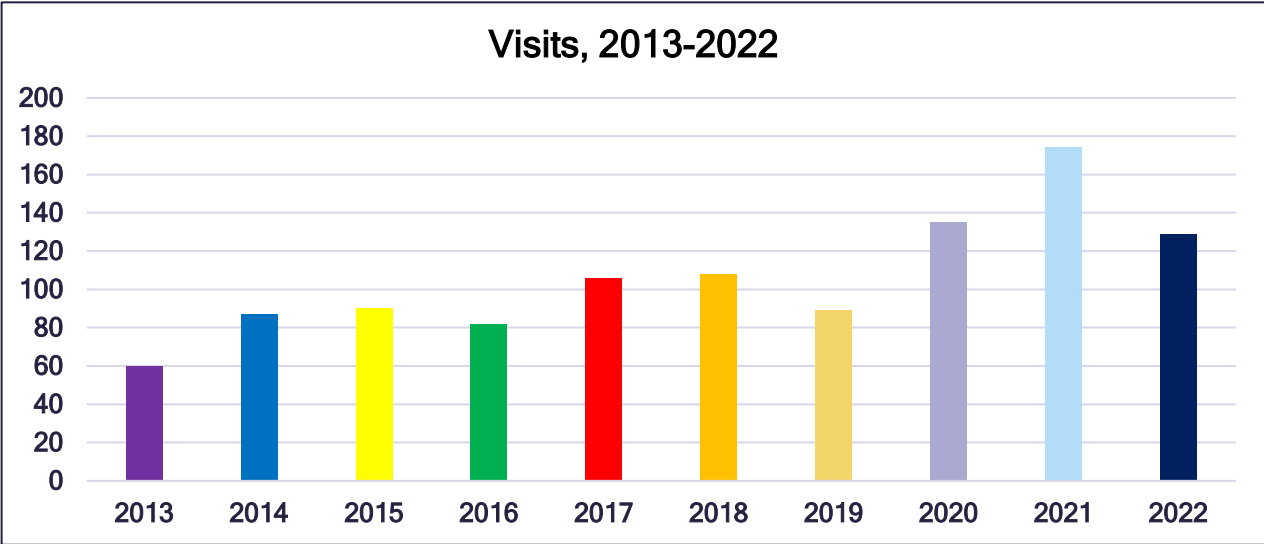
10 Years of AYA Education & Outreach



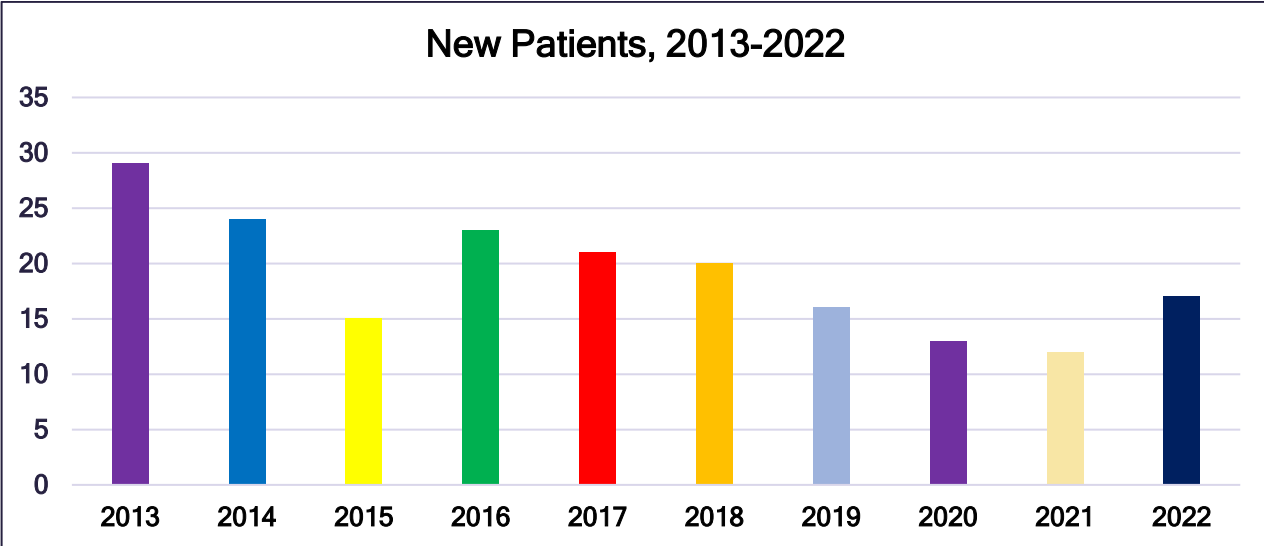
PATIENTS & VISITS

Patients, who are not on active therapy and were diagnosed with cancer as an AYA, are eligible for the AYA Cancer Program, regardless of, when and where they were treated, or their diagnosis. On trend with the program’s history, the majority (67%) of the patients seen in 2022 were diagnosed in childhood (age 0-14y), with the remaining (33%) patients diagnosed between 15-39y. Of patients seen this year, 66% had received an initial blood cancer diagnosis.

Each patient’s guidelines-based Care Plan is updated after each survivorship visit.



Most new patients seen in 2022 were young AYAs transitioning from Pediatric Hematology/Oncology (see next page).



CLINICAL CARE

Welcoming Pediatric Hematology/Oncology Patients to AYA

In January 2022 hospital leadership announced that Tufts Children's Hospital would close inpatient services, including Pediatric Hematology/Oncology. Like so many patients we heard from, the AYA Cancer Program team was incredibly sad to hear this news.

Working closely with pediatric-based colleagues, the clinic team identified patients eligible for survivorship care. Understanding that the transition in care (e.g., pediatric- to adult-based providers, treating oncologist/nurses to survivorship specialists) could be difficult, the clinic team contacted each referred patient to provide an introduction to the AYA Cancer Program. It has been a gratifying experience to welcome these new patients into the program.

New Electronic Medical Record System

In April, Tufts Medical Center underwent a system-wide update to the electronic medical record (EMR). Prior to this change each department had their own system, making care coordination challenging.

Benefits to Patients and the Care team include:

- Patients can now directly access their Survivorship Care Plan, doctors' notes, and test results through the 'My Tufts Med' patient portal
- Patients can see upcoming appointments, check-in and/or cancel their appointments, throughout the medical center, via the portal
- If patients have providers at other offices/hospitals with the same EMR (EPIC), the Care team can access those doctor's notes for enhanced care coordination. This also eliminates the need for patients to formally request medical records, which can be time intensive.

Transition from Telehealth to In Person Appointments

The end of the COVID-19 Massachusetts State of Emergency in late 2021 led to restrictions on the ability to offer telehealth appointments. To document the success and acceptance of telehealth among AYA survivors, the AYA Care team submitted a publication to the Journal of Adolescent & Young Adult Oncology. The manuscript, titled *Adolescent and Young Adult Survivorship Care: Emerging from the COVID-19 Pandemic Stronger through Teleoncology* is now available online.

[> J Adolesc Young Adult Oncol. 2022 May 27. doi: 10.1089/jayao.2022.0027. Online ahead of print.](#)

Adolescent and Young Adult Survivorship Care: Emerging from the COVID-19 Pandemic Stronger Through Teleoncology

Nadine Linendoll ^{1 2 3}, Rachel Murphy-Banks ^{1 3}, Annika Jain ³, Susan Parsons ^{1 2 3}

Affiliations [+ expand](#)

PMID: 35639104 DOI: [10.1089/jayao.2022.0027](#)

Financial Support for AYA Patients

Cancer survivors may experience ongoing medical care needs that are expensive. Thanks to a very generous two-year gift by Mr. Gerald Allman, discretionary funds were available for a second year to assist AYA patients, who disclosed a financial need to pay for medical-related bills.

Financial support included payment for:

- Parking passes
- Hearing aids
- Medical co-pays
- Talk therapy (not covered by insurance)
- Dental care

One grateful patient shared: “*With all the craziness in this world, it is heartwarming to know that there are so many good people who are there to help each other in times of need.*”

-The Lewis Family, March 2022

FINANCIAL DISTRESS IN AYAS

Insurance & Financial Navigation

Responding to the needs of patients, the AYA Cancer Program team continued to provide non-clinical support to AYAs through:

- Updating insurance plans in patient records
- Coaching on how to request referrals for specialty care visits
- Connecting patients with Financial Coordination to supplement insurance plans
- Working with the Billing and Patient Access departments to understand bills

Financial Navigation Study

Multi-site, randomized research study building on clinical care experience.

Background

This study seeks to understand and mitigate financial challenges faced by YA survivors. Included in this six-month intervention are repeat assessments to look for change over time and, depending on study arm, access to a study-based financial navigator. Following approval from the Tufts IRB, eligible AYA Cancer Program patients were invited to join the study in early 2022.

Partners

Funded by the Leukemia & Lymphoma Society (LLS), 2020-present, participants of this study are blood cancer survivors.

In addition to Tufts MC, five other hospitals (based in Texas, South Carolina, and California) are involved in recruiting AYA survivors.

Initial Publication

A manuscript that describes the study design and protocol, titled, *Evaluating the Role of Financial Navigation in Alleviating Financial Distress Among Young Adults with a History of Blood Cancer: A Hybrid Type 2 Randomized Effectiveness-Implementation Design*, was published in Contemporary Clinical Trials in November.

Next Steps

Qualitative interviews and quantitative analysis of participant-reported measures are planned in 2023. The study team looks forward to disseminating results with the aim of identifying the most effective methods of supporting AYA cancer survivors with financial distress.

TRAINING

Incorporating AYA Survivorship into Clinical Care and Research Training

Over the last ten years the AYA Cancer Program has welcomed ~30 undergraduate, graduate, and medical school students, who were interested in learning about AYAs. The majority of former trainees are now caring for patients of their own, many within the fields of pediatrics and internal medicine!

Graduate Student Trainees

Neena Patel, MS, completed her tenure with the AYA Cancer Program in early 2022. Under the formal mentorship of Dr. Parsons and Rachel, Neena's final project was the completion of her thesis titled, *Lynch Syndrome in Women*. The thesis explored the impact of cancer predispositions (specifically Lynch Syndrome) on AYAs, including fertility, mental health and health equity challenges. Neena is currently attending Tufts University School of Medicine.

Megan Catalano, MS, a 2018 AYA Summer Scholar, returned to the AYA Cancer Program this spring. Her contributions included assisting Drs. Parsons and Wismer on the clinic's late effects database. Megan is now in medical school in New Jersey.

Project Coordinator

Alissah Sillah, MPH, joined as Project Coordinator in the spring of 2022. In the AYA Community Connection E-Newsletter, she shared: *"I am looking forward to contributing to a team that is dedicated to providing meaningful and specialized care to AYA cancer survivors. I am also excited to develop more skills and knowledge related to public health and health services research."*



2022 Summer Scholar

After a hiatus due to the COVID 19 pandemic, the Summer Scholar initiative, an AYA-focused 12-week internship, was reinstated. The team welcomed **Katelin Isakoff**, a rising senior at Tufts University, who shadowed the care team in clinic and contributed as a research assistant on the Financial Navigation Study. Following her December graduation, we are thrilled to welcome Katelin back as a full-time member of our team.



Research Hematology/Oncology Fellows

Each year Dr. Parsons has served as research mentor, to Hematology/Oncology Fellows who sought to enhance their understanding of vulnerable patient populations.

“The AYA Cancer Program is unique in its ability to provide individualized survivorship care for its patients and I have gained invaluable experience working alongside the team. My time with the program has become a foundational aspect of my training. I plan to incorporate the AYA team's guiding principles and holistic approach to the care of cancer survivors into my clinical practice after fellowship.” - Dr. John Melson

Dr. Melson has worked with Drs. Parsons and Upshaw to examine prevalent and incident heart disease among women with breast cancer, based on treatment exposure (e.g., anthracycline, trastuzumab, radiation) along with the use of cardioprotection to mitigate the risk.

“I had the privilege of working with the AYA team during my hematology/oncology fellowship. My time was focused on clinical research investigating the late treatment effects experienced by many in the AYA survivorship population. Being able to work with this unique patient population allowed me to gain insight and knowledge into the many facets of providing high quality survivorship care. I am grateful for this experience and will be able to apply the lessons I learned to my patients in the future.” - Dr. Michael Wismer

Dr. Wismer is evaluating adherence to current recommendations for colorectal cancer screening among our AYA survivors, based on treatment exposure (e.g., radiation) and genetic predisposition.

Dr. Xiao Hu began her two-year research period in the summer. Her research will examine the expanding indications for immune checkpoint inhibitors, as well as the growing awareness and management of immune-related adverse events.

EXTERNAL RESEARCH COLLOBORATIONS

In addition to the Financial Navigation Study (p.12), conducted by the AYA Cancer Program team, Dr. Parsons is collaborating on a number of research projects to improve AYA care.

Hodgkin Lymphoma International Study for Individual Care (HoLISTIC) Consortium

Dr. Parsons co-founded the international, 70+ member HoLISTIC Consortium, with Dr. Andrew Evens (formerly of Tufts Medical Center, currently at Rutgers Cancer Institute). In 2022 they were awarded a multi-million dollar grant from the National Cancer Institute (R01CA262265-01A1). The grant aims to use de-identified clinical trial and registry data to create decision models to assist patients and their providers in determining best treatment options for newly diagnosed Hodgkin lymphoma (HL) patients.

Illustration of Recent HL AYA Related Work:

Ongoing Clinical Trial Collaborations, with the Children's Oncology Group (COG):

- Cost of Therapy
- Peripheral Neuropathy
- Patient Reported Outcomes

National & International Presentations

- American Society of Hematology (ASH), 2016, 2018-22
- American Society of Clinical Oncology, (ASCO), 2018-20
- International Symposium on HL, 2016, 2018, 2022
- International Symposium on Childhood, Adolescent & Young Adult HL, 2020-21
- Congress of the European Hematology Association, 2020

Publications

- Health and Quality of Life Outcomes, 2016, PMID: 27473596
- Leukemia & Lymphoma, 2017, PMID: 29214876
- Journal of Clinical Oncology, 2020, PMIDs: 32650684; 33030980
- Chapter in Hodgkin Lymphoma, Springer, 2021
- Clinical Lymphoma, Myeloma & Leukemia, 2021, PMID: 34452864
- Supportive Care in Cancer, 2021, PMID: 34524526

Social Genomic Mechanisms of Health Disparities among AYA Survivors.

(Brad Zebrack, PhD, U. of Michigan, PI)

Dr. Parsons is collaborating on a 5-year study that seeks to better understand how external social factors, such as isolation, could impact certain cancers. Rachel contributed to survey pilot testing in preparation of the launch of this study.

Systematic Review to Support the Development of ASH Clinical Practice Guidelines on Acute Lymphoblastic Leukemia in AYAs

This in-depth evidence synthesis for the American Society of Hematology (ASH) focuses on the care for AYAs with acute lymphoblastic leukemia. Dr. Parsons is a co-Investigator on the project and a member of the methods team, led by investigators at Brown University.

EDUCATION & OUTREACH

Bringing healthcare professionals together is an excellent way to share the amazing work being done for AYAs who have or have had cancer. In addition to the presentations listed below, Dr. Parsons was invited back to the Lymphoma Research Foundation conference to discuss shared decision making when talking to your healthcare team about treatment plan.

AYA Cancer Program at Tufts MC

<u>Audience</u>	<u>Information Disseminated</u>
Hematology/Oncology Fellows at Tufts MC	<ul style="list-style-type: none"> • Financial Toxicity in AYAs • Genetic Predisposition Syndromes • AYA Cancer Survivorship

Health-Related Quality of Life (HRQoL) of AYAs in Cancer Clinical Trials

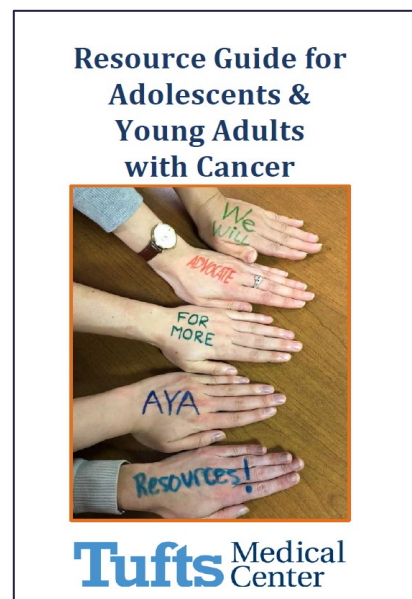
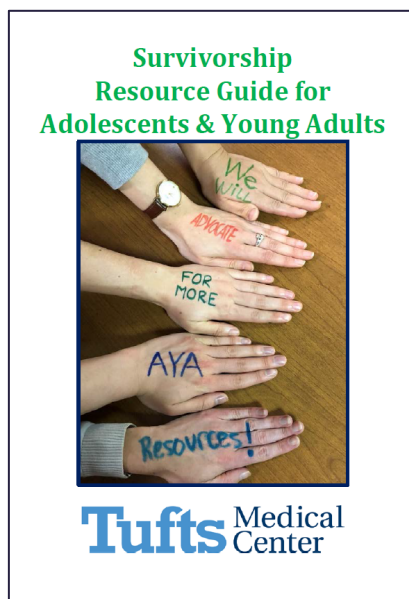
<u>Audience</u>	<u>Information Disseminated</u>
Healthcare providers: <ul style="list-style-type: none"> • Teen Cancer America Monthly Drip webinar • National Cancer Institute (NCI) Community Oncology Research Program (NCORP) Annual meeting • Children's Oncology Group (COG) Fall meeting • International Symposium on Hodgkin Lymphoma (ISHL) 	Dr. Parsons and Dr. Michael Roth (MD Anderson) have worked closely over the past two years on a Childhood Cancer Data Initiative grant to incorporate and analyze the impact of cancer treatment on AYA HRQoL. They have been sharing findings of patient reported outcomes incorporated on several clinical trials (B cell Lymphoma; Osteosarcoma; Acute Lymphoblastic Leukemia; Hodgkin Lymphoma) to national and international audiences.
<u>Results were published in the Journal of the National Cancer Institute:</u> Roth ME, Parsons SK, Ganz PA, et al. Inclusion of a core patient-reported outcomes battery in adolescent and young adult cancer clinical trials. J Natl Cancer Inst. 2022 Oct 21:djac166. doi: 10.1093/jnci/djac166. Epub ahead of print. PMID: 36266760.	

AYA Resource Guides

Created for the purpose of linking AYAs with supportive resources, curated AYA resource guides were given to patients at their appointments and are available on the AYA Cancer Program website. In addition to a guide for AYAs off treatment, there is a guide dedicated to resources that support patients in treatment.

Topics covered include:

- Fertility - Sexual Health
- Costs - Insurance
- Financial Grants
- School - Work
- Social Connections (e.g., conferences, virtual meet ups)



World Cancer Day Contribution

Celebrated in February each year, World Cancer Day is an international day of awareness of cancer and encouragement of its prevention, detection, and treatment. Shared on social media, the AYA Cancer Program contributed our aim to:



PARTNERS & SUPPORTERS

Philanthropic partners and supporters enable the AYA Cancer Program team to broaden the scope of AYA-focused contributions, outside of the clinical care provided. The program is incredibly grateful to our generous supporters, some of whom have been with us from the beginning and other more recent relationships formed this year.

Reid R. Sacco AYA Cancer Alliance

This all-volunteer alliance was founded to celebrate the life of Reid R. Sacco (photo at right courtesy of the alliance), and to improve the lives of other AYAs impacted by cancer. Led by Gene, Lorraine and Weston Sacco, the alliance has continued to be steadfast in their motto to ‘alter the course of adolescent & young adult cancer.’ Our program is a clear beneficiary of their dedication.



Teen Cancer America

The AYA Cancer Program and Teen Cancer America (TCA) entered a formal partnership in 2020. Over the last three years this has resulted in an enhanced network of AYA champions to collaborate with across the country.

Some outcomes of this partnership to date include:

- AYA patient referrals
- Manuscript and/or Poster Abstract submissions
- Invited speaking engagements to AYA professionals across the United States

Generous Supporters

Over the past ten years dozens of individuals, clubs, and organizations have donated and/or contributed to positively impact the program and its patients. Recent gifts from **Golf Fights Cancer** and **Mr. Gerald Allman** have directly benefited patients through funds supporting navigation services and medical-related reimbursements.

Dr. Anita Kumar, transitioned out of Tufts Medical Center in the summer of 2022 to pursue other opportunities. We are thankful for her time with the AYA Cancer Program.

Lastly, we wish to thank the patients who have entrusted us with their survivorship care over the last ten years.