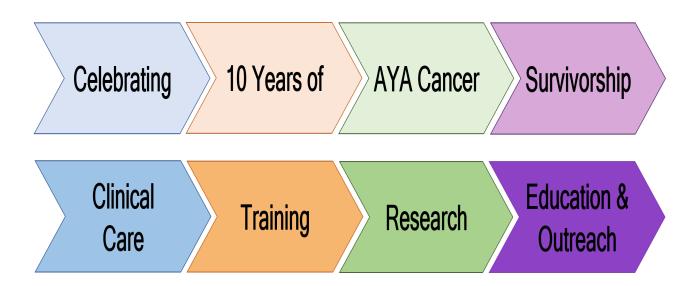
# Reid R. Sacco

# Adolescent & Young Adult (AYA) Cancer Program 2022 Annual Report



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# **TABLE OF CONTENTS**

AYA Cancer Program Team Message	_ 3
AYA Program Overview	4
10 Years of Clinical Survivorship Care	
10 Years of Training (Future) Providers	6
10 Years of AYA-focused Research	
10 Years of AYA Education & Outreach	8
Patients & Visits	9
Clinical Care	
Welcoming Pediatric Hematology/Oncology Patients to AYA	10
New Electronic Medical Record System	1(
Transition from Telehealth to In Person Appointments	1
Financial Support for AYA Patients	1
Financial Distress in AYAs	_ 12
Insurance & Financial Navigation	
Financial Navigation Study	12
Training	_ 13
Incorporating AYA Survivorship into Clinical Care and Research Training_	13
External Research Colloborations	15
Education & Outreach	
AYA Resource Guides	17
Partners & Supporters	_ 18
Reid R. Sacco AYA Cancer Alliance	18
Teen Cancer America	18
Generous Supporters	18

# 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:

- <u>Treatment Summary</u>, 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.

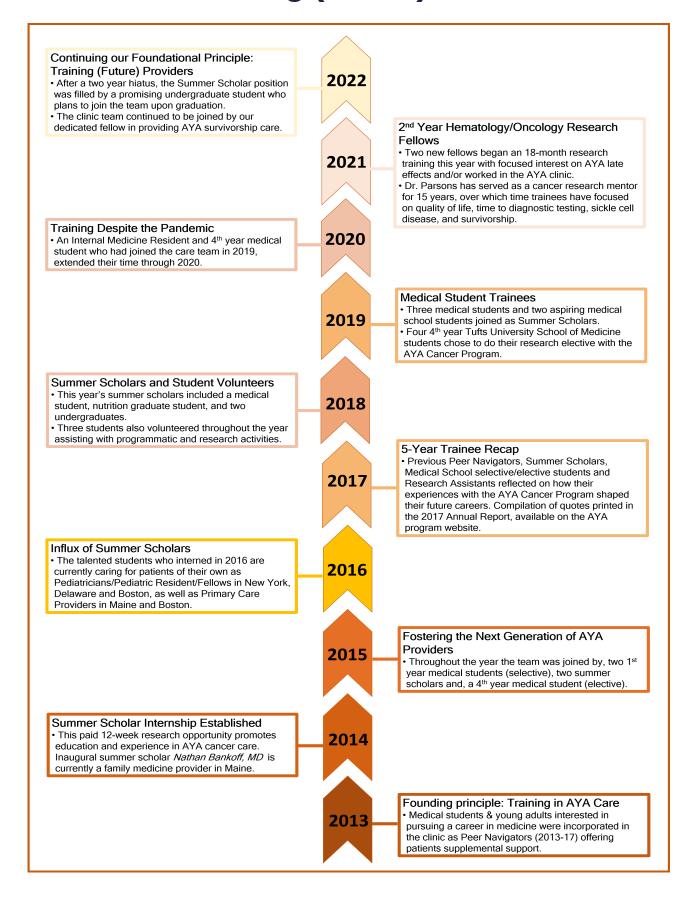
To reach the broader AYA Community, the AYA Cancer Program team is also invested in:

- **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

#### Adapting to Change The program welcomed an influx of AYAs who had been treated and cared for at Tufts Children's Hospital (Floating Hospital for Children), following the 2022 closure of Pediatric Hematology/Oncology. A system wide rollout of a new electronic medical Keeping AYAs in Care record (EPIC) provided patients with an enhanced Follow up appointments were offered to patients patient portal to view their records and appointments, experiencing medical and/or psychosocial concerns and encouraged more efficient care coordination exacerbated by the ongoing pandemic. This resulted between providers. in the highest number of visits conducted in a year, in 2021 a year-over-year comparison. Telehealth visits (76% of all encounters) continued to be conducted during the Massachusetts state of Providing Care During the Evolving COVID-19 Pandemic Health Questionnaire (completed by patients prior to · Prior to the pandemic all appointments were in visits) was adapted from hard copy to electronic person, thanks to the hospital's telehealth rollout and format for ease of delivery and completion. adaptability of the AYA team, patients continued to 2020 receive survivorship care throughout the year. 70% of visits in 2020 were conducted via telehealth. Proportion of AYA-aged survivors (diagnosed 15-39 years) increased slightly, from the program's historical majority of pediatric (diagnosed 0-14 years) survivors. Focus on Care Coordination with Primary Care and Specialty/Subspecialty Care 2019 **Providers** · Strong relationships resulted in bi-directional referral opportunities and comprehensive care for patients. **Expanding Survivorship Care** Survivor-SHIP was launched by providers in Pediatric Hematology/Oncology. Care plans developed by the AYA team were individualized and disseminated to 2018 children and young AYAs treated at the Floating Hospital for Children Continued upward trend of welcoming new patients half of whom came as self- or non-oncology provider First 5-Years of AYA Cancer Program: referrals. **Patient Characteristics** 114 individuals received survivorship care over the 2017 course of 427 visits. · 34% of patients were receiving psychological care or medication for mental health issue(s), at time of entry Cardio-Oncology Program Established Medical Director, Dr. Jenica Upshaw, adult 53% of patients had at least one known late effect. cardiologist specializing in preventative cardiology, screening, and management of cancer therapyinduced heart dysfunction. Dr. Upshaw joins the AYA clinic on select days to 2016 offer back-to-back appointments. **Enhanced Connection With Pediatric** Patient Characteristics Hematology/Oncology Cumulative 1.000+ years of survivorship Annmarie Conroy, RN, PNP, (2016-17), trained with • Time since treatment ranged from 3 months-26 years the AYA team in providing survivorship care for • 2 out of 3 patients had at least one chronic condition younger AYAs transitioning from the Floating Hospital **Program Team Augmented** for Children to the AYA program. 2015 · Dr. Anita Kumar (2015-22), an adult-trained hematologist/oncologist expanded her clinical practice of treating patients in the Cancer Center to include caring for patients in survivorship. New Providers Join Care Team Rachel Murphy-Banks, MA, joined as the Education · Nadine Linendoll, PhD, MDiv, NP, became integrated & Outreach Coordinator (promoted in Program in the program while continuing to also provide care Manager in 2016). to adult neuro-oncology patients. In 2017, she 2014 devoted all of her clinical time to survivorship patients. Dr. Erin Barthel, (2014-16), a pediatric oncologist provided survivorship care to AYAs as well as treated Clinic Opened pediatric patients at the Floating Hospital for Children. Dr. Barthel played an integral part in developing the Patients provided with comprehensive Treatment comprehensive Care Plans patients receive today. Summary, using Passport for Care® & rudimentary care plan embedded in visit note. 2013 Health Questionnaire developed and disseminated. Completed by patient, this offers holistic overview of health from their perspective. Program team comprised of Dr. Parsons, Nurse Practitioner (NP) Jenn Dagesee (2013), Program Coordinator Tully Saunders (2013-16).

# 10 Years of Training (Future) Providers



# 10 Years of AYA-focused Research

#### Financial Distress Study Launched 2022 · AYAs were invited to participate in this research study which seeks to evaluate the role of navigation in alleviating financial distress. Recruitment opened in February at Tufts MC, with ongoing recruitment at five other hospitals throughout the year. Financial Distress Study Developed Funded by the Leukemia & Lymphoma Society (LLS), Dr. 2021 Parsons and the AYA team developed a six-month study titled, Evaluating the Role of Financial Navigation in Alleviating Financial Distress among Young Adult Survivors of Blood AYA Cancer Program's Model of Care Published • The program's model of care, with de-identified patient population characteristics, was published to highlight the 2020 importance of long-term follow up care for survivors, and to serve as an example for other developing AYA programs: The Creation of a Comprehensive AYA Cancer Survivorship Program: "Lost in Transition" No More. Journal of AYA Oncology, 2020, PMID: 32640864. Merging Research & Training Collaboration between providers in the AYA Cancer Program, 2019 Neurosurgery, Otolaryngology, and Pathology, with a former AYA Summer Scholar resulted in a publication in the Journal of AYA Oncology, titled, Schwannoma Formation in Childhood Cancer Survivors Exposed to Low-Dose Total Body Irradiation. PMID: 30869555 Focus on Financial Hardship · Alleviating the financial impact of cancer is a long standing 2018 interest of the team. Explored in a publication, AYA Cancel Care: Financial Hardship and Continued Uncertainty, in Pediatric Blood & Cancer PMID: 30556354 and presented in an educational session at the ASCO Annual Meeting. Areas of Research Interest Defined Review of AYA Oncology Survivorship Guidelines 2017 Quality of life Is the AYA Cancer Survivor at Risk for Late Effects? It Depends on Where you Look, manuscript provided a · Economics of cancer treatment · Improving care delivery and decision making process comparison of oncological guidelines with case study Neurocognitive and psychological challenges examples. Published in the Journal of AYA Oncology, 2016, PMID: 26885683, and presented at the American Society of Clinical Oncology (ASCO) Survivorship Symposium. Tufts MC Clinical Affiliation with New England Cancer Specialists (NECS) 2016 · AYA Cancer Program collaborated with NECS to scale and Implementation of the Patient-Reported Outcomes export phase-specific Breast Cancer Survivorship Care Plans to patients in Maine. Measurement Information System (PROMIS®) In addition to care plan templates embedded in both A collaborative research study with the University of institutions electronic medical records, the co-developed Care Chicago's Childhood & AYA Oncology Program, was Plans were presented at the Putting Together the Puzzle conducted to test feasibility of administering this 10-item Pieces webinar hosted by The George Washing University questionnaire prior to the clinic visit. Patient responses were 2015 Cancer Center in 2016, at the 2017 ASCO Survivorship converted into physical and mental health scores. Results Symposium, and published in Clinical Breast Cancer, 2019, (published in Journal of AYA Oncology, 2018, PMID: PMID: 31278019. 29190179) showed it was possible to incorporate the assessment into point-of-care workflow and provided the opportunity for providers to have real-time discussions with National Clinical Trial Development patients Dr. Parsons joined colleagues within the Children's Oncology The PROMIS® measure has since been incorporated into Group (COG) on a Phase III clinical trial for newly diagnosed 2014 clinic practice as a non-research tool to better understand how Hodgkin Lymphoma (HL). Funded by LLS, Dr. Parsons sought patients feel they are doing. to formally evaluate the cost-effectiveness of a new chemotherapy agent used in the trial. This work was expanded over the years to include embedded studies on the functional consequences of chemotherapyinduced peripheral neuropathy. Leveraging Cooperative Groups 2013 Following her transition from Pediatric Hematology/Oncology to AYA, Dr. Parsons continued her research affiliations in pursuit of improving short- and long-term outcomes for AYAs.

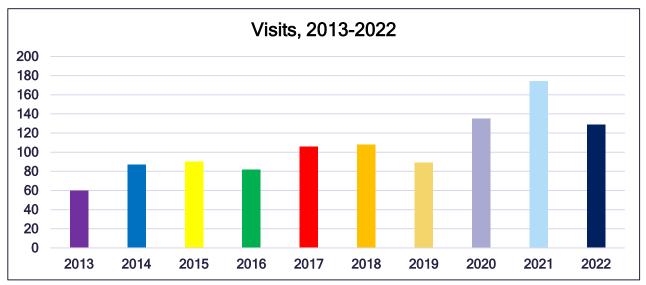
# 10 Years of AYA Education & Outreach

#### **Building AYA Networks** · Since partnering with Teen Cancer America in 2020, the AYA Cancer Program team continues to collaborate on 2022 presentations, manuscripts, and program development with **Embracing Virtual Connections** AYA programs from across the United States. · Curated resource guides (for AYAs in treatment and in • Dr. Parsons co-leads an international Hodgkin Lymphoma survivorship) were created and posted online to help link AYAs consortium, funded in 2022 by the National Cancer Institute. to psychosocial resources · All members of the AYA Cancer Program took part in the Northeast AYA Cancer Conference, organized by the Reid R. 2021 Sacco AYA Cancer Alliance. The Leukemia & Lymphoma Society invited the AYA team to present an educational session on ways to advocate for longterm follow up care, to patients/survivors across New England. Members of the care team presented to medical provider audiences locally (Tufts MC & Brandeis University), nationally **Updated AYA Cancer Program Webpages** (Children's Hospital of Atlanta, Memorial Sloan Kettering · To supplement the clinical care and care team pages, web 2020 Cancer Center, Children's Oncology Group), and updates were made to provide programmatic information for internationally (Global AYA Cancer Congress). patients and supporters. This included updates to the Education + Outreach, Resources, and Training sections Leveraging Partnerships to Expand Outreach Dr. Parsons accepted an invitation by Dr. Wendy Stock (AYA Cancer Program's guest lecture speaker in 2016), to discuss 2019 the financial burden of care at the Chicago AYA Oncology Symposium: Comprehensive Care for AYAs with Cancer. · Following a successful experience at Cancer Con the previous year, a new group of AYA patients were offered travel Sharing What We Know scholarships to attend, and Dr. Parsons and Rachel (Program Hospitals in South Dakota and Massachusetts met with the Manager) were invited back as presenters. AYA Cancer Program team to gain insights on developing their own survivorship programs. 2018 In addition to presenting for a second year at Stupid Cancer's Cancer Con, thanks to two philanthropic donations (Joy in Childhood Foundation & This Star Won't Go Out), ten travel Education & Outreach Highlights scholarships were awarded to AYA patients to attend the WCVB-TV Channel 5 Chronicle program featured the AYA conference in Denver Cancer Program in an episode titled, Beyond the Cure. Patients self-referred after watching the piece, and the show 2017 went on to win an EMMY. Spoke to Tufts University School of Medicine (TUSM) special interest groups about AYA cancers and the importance of **Expanding Cancer Awareness to Young Adults** educating patients on late effects from therapy Presentations to introduce, or further awareness of AYA Shared advocacy tips to AYA patients/survivors at Stupid cancers and the AYA Cancer Program were given to Tufts $\ensuremath{\mathsf{MC}}$ Cancer's Cancer Con in a breakout session titled. Getting. providers, Boston-area nurses, high schoolers and TUSM Informed about Long-Term Follow Up Care. special interest groups. Rachel spoke at Boston-area universities to raise awareness 2016 of cancer and understanding of survivorship in young adults, the majority of whom had not had cancer. From 2016-21, 42 lectures were given to over 1,000 students. Initial feedback was presented at the 2017 Global AYA Cancer Congress, and a manuscript was published in the Journal of AYA Oncology in 2019, PMID: 31038376. Increased AYA Education to the Medical Community 14 AYA presentations given, that reached over 500 people. 2015 AYA patient/survivor and New York Times columnist Suleika Jaouad was the invited speaker for a lecture on the AYA cancer experience AYA Community Connection E-Newsletter launched. AYA Lecture: Dr. Archie Bleyer 2014 Dr. Bleyer, a pioneer in the field of AYA oncology, provided a landscape of the state of AYAs at Tufts MC Cancer Center and Medical Grand Rounds **Developing Awareness** 2013 Dedicated AYA Cancer Program pages added to Tufts MC website

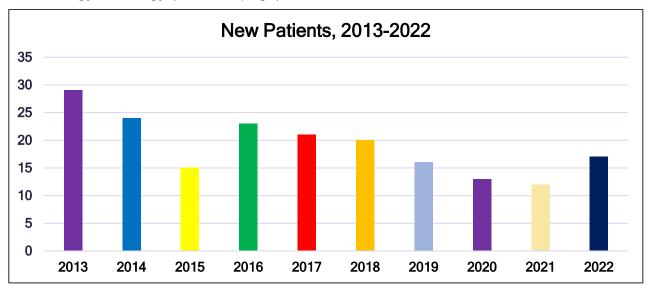
# **PATIENTS & VISITS**

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.





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

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Nadine Linendoll <sup>1 2 3</sup>, Rachel Murphy-Banks <sup>1 3</sup>, Annika Jain <sup>3</sup>, Susan Parsons <sup>1 2 3</sup>

Affiliations + expand

PMID: 35639104 DOI: 10.1089/jayao.2022.0027
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#### 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 interest 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.

# <u>Ho</u>dgkin <u>Lymphoma International St</u>udy for <u>Individual Care</u> (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>	Information Disseminated
Hematology/Oncology Fellows at Tufts MC	Financial Toxicity in AYAs
	Genetic Predisposition Syndromes
	AYA Cancer Survivorship

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

Audience	Information Disseminated
<ul><li>Healthcare providers:</li><li>Teen Cancer America Monthly Drip webinar</li></ul>	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
<ul> <li>National Cancer Institute (NCI)</li> <li>Community Oncology Research Program (NCORP) Annual meeting</li> </ul>	analyze the impact of cancer treatment on AYA HRQoL. They have been sharing findings of patient reported outcomes
<ul> <li>Children's Oncology Group (COG) Fall meeting</li> <li>International Symposium on Hodgkin Lymphoma (ISHL)</li> </ul>	incorporated on several clinical trials (B cell Lymphoma; Osteosarcoma; Acute Lymphoblastic Leukemia; Hodgkin Lymphoma) to national and international audiences.

Results were published in the Journal of the National Cancer Institute:

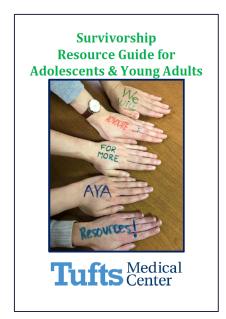
Roth ME, Parsons SK, Ganz PA, et al. <u>Inclusion of a core patient-reported outcomes</u> <u>battery in adolescent and young adult cancer clinical trials.</u> J Natl Cancer Inst. 2022 Oct 21:djac166. doi: 10.1093/jnci/djac166. Epub ahead of print. PMID: 36266760.

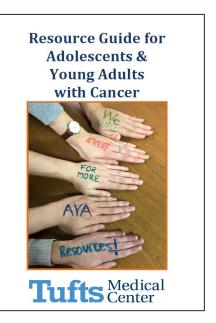
## **AYA Resource Guides**

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.