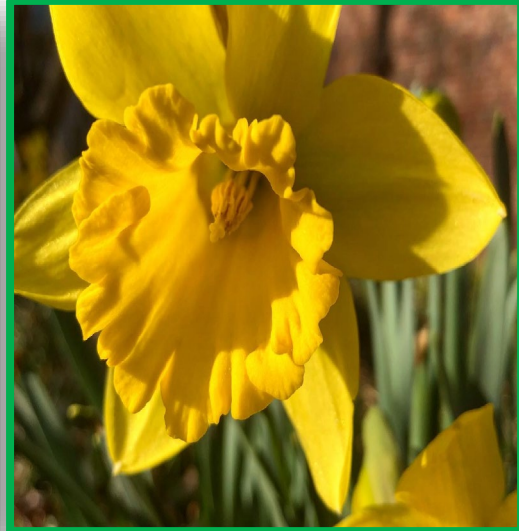
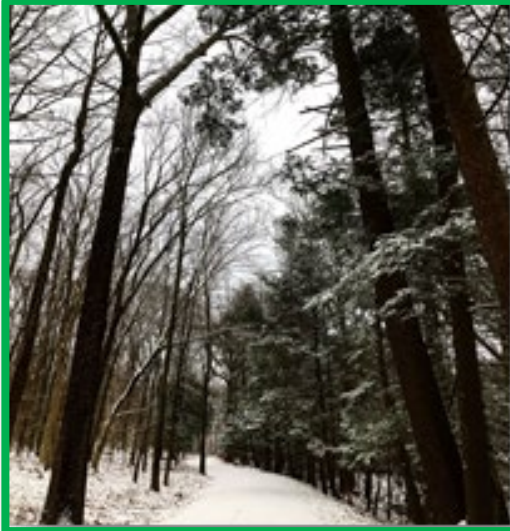


REID R. SACCO ADOLESCENT & YOUNG ADULT (AYA) CANCER PROGRAM ANNUAL REPORT 2021



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DIRECTOR'S MESSAGE

Dear Friends, Colleagues, and Sponsors,

When we closed out the year at the end of 2020, we'd held onto the promise that the new year would be easier than the prior one. Instead, we found ourselves continuing to grapple with the effects of the global pandemic on many aspects of our lives.

Despite the challenges, several bright spots emerged. The availability of vaccines allowed us to resume in-person care, supplemented where necessary, by telehealth. Slowly, we returned to in-person work—mostly in a hybrid model to minimize risk and exposure, while optimizing team work and support.

Key collaborations with research partners across town, across the country, and indeed, across the globe, coupled with critical funding, have allowed us to take on new work in many different directions on behalf of AYAs with cancer. We highlight some of these projects in the pages that follow, along with a review of our clinic volume, growth, and focus.

This year we've shared celebrations that reminded us of the richness in our lives from our friends and loved ones. We mourned loss of beloved family members and friends. We soldiered through uncertainty about actual and perceived risk.

Through all of this, we thank our patients for authentic conversations and trust during very difficult times. We thank colleagues and sponsors for unwavering support. So, as we turn the page on 2021, may 2022 be easier, fulfilling, and filled with good health for all.

Sincerely,



Susan K. Parsons, MD, MRP

Professor of Medicine and Pediatrics, Tufts University School of Medicine

Medical Director, Reid R. Sacco AYA Cancer Program

Director, Center for Health Solutions, Institute for Clinical Research and Health Policy Studies,
Tufts Medical Center



AYA CANCER PROGRAM OVERVIEW

Program Team



**Dr. Anita Kumar,
MD, MSCE, PhD©**
Adult-trained
Hematologist/Oncologist



**Nadine Linendoll,
PhD, MDiv, NP**
Adult-trained
Oncology Nurse Practitioner



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

Program Aim

The Reid R. Sacco Adolescent & Young Adult (AYA) Cancer Program at Tufts Medical Center provides survivorship care to 18-39 year olds with a history of cancer.

The program has four main components:

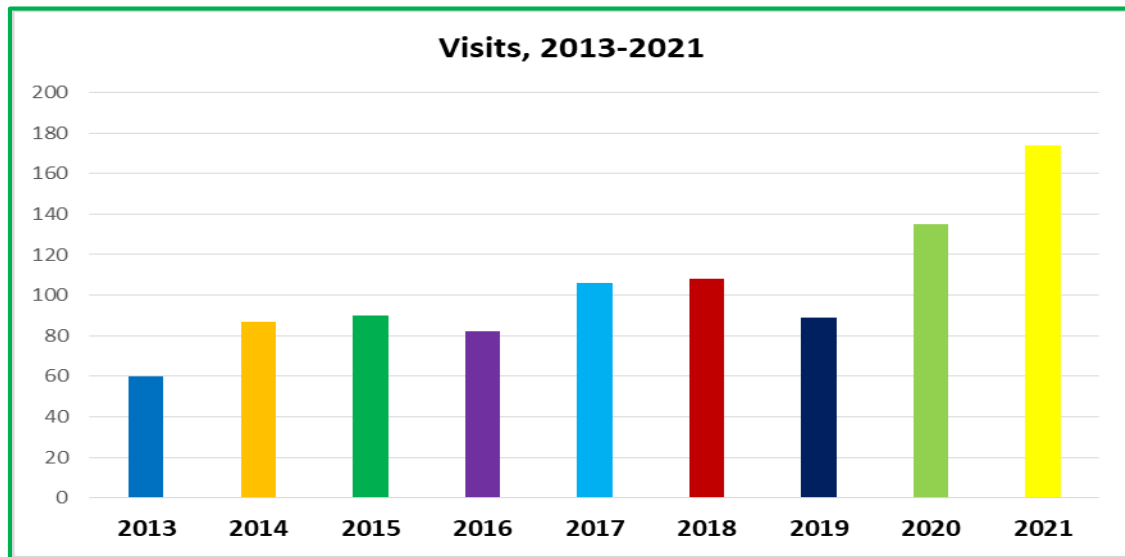
1. Clinical care (described below)
2. Research that seeks to improve the care and/or health-related quality of life for AYAs
3. Training of medical providers in the care of AYAs/survivorship
4. Education & outreach to connect with the AYA cancer community

The long-term follow up clinical care provided is based on a **Survivorship Care Plan**. Each patient receives a cumulative Treatment Summary (at their introductory appointment) and a detailed Care Plan which outlines recommended specialty referrals/testing to monitor and/or manage health effects that may result from cancer or cancer treatment (updated at each visit).

PATIENTS & VISITS

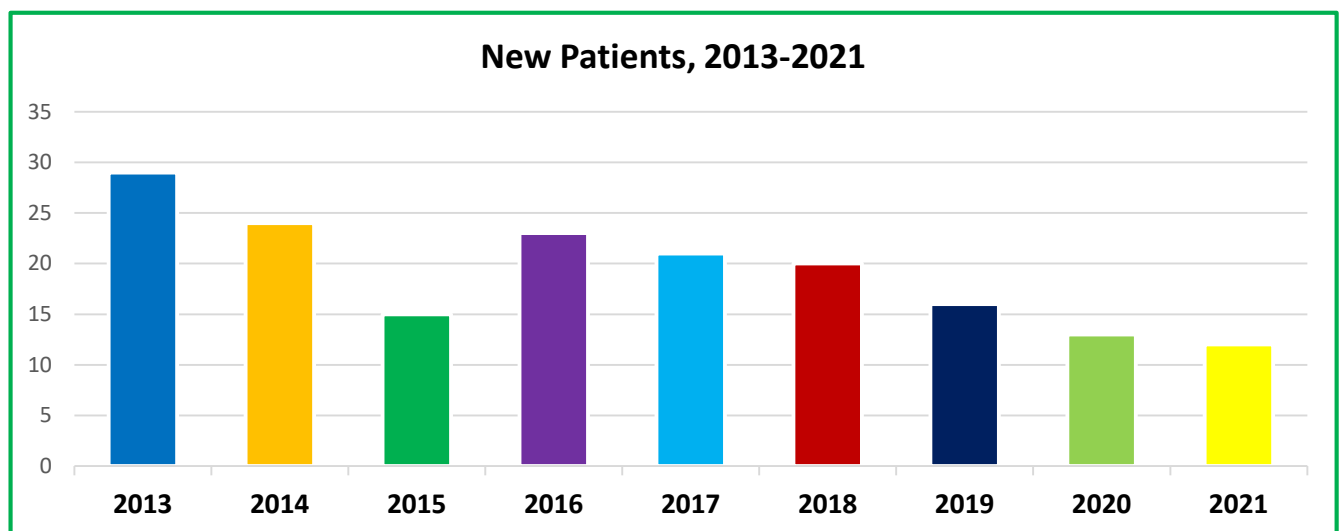
Care Provided as Needed

Many patients are seen on an annual basis to review and receive an updated Care Plan (page 3). Over the last two years we have experienced an increase in visits, and patients seen in our clinic. The Care Team continues to offer more frequent appointments to patients with complex medical and psychosocial concerns exacerbated by the ongoing pandemic, as well as emerging medical issues.



Welcoming New Patients

The AYA Cancer Program team enjoys building long-term relationships with patients who trust us with their survivorship care, year after year. The team also looks forward to welcoming new patients; validating that survivorship can be difficult; and providing Survivorship Care Plans and care coordination for their next phase of cancer-related care.



PATIENTS & VISITS

Telehealth

The AYA Cancer Program's team continued to offer telehealth survivorship visits through most of 2021. This mode of connection was popular with our patients, with 76% of visits that took place during the Massachusetts state of emergency conducted via telehealth.



The AYA Cancer Program's contribution to the World Cancer Day (2/4/2021) awareness campaign (#iwill; #wewill message) reflected our use of telehealth this year.

Due to changing parameters and restrictions on telehealth implemented with the end of the state of emergency, the ability to offer telehealth appointments became more limited. To encourage policy makers to consider expansion of telehealth services and to highlight the successful use of connecting with patients virtually the team has submitted a manuscript titled: *AYA Survivorship Care: Emerging from the COVID-19 Pandemic Stronger through Teleoncology*.

Electronic Health Questionnaire (HQ)

Prior to appointments, patients are asked to fill out a HQ, developed by the AYA Program Care Team. This document helps identify any concerns the patient may be experiencing. In 2020 we successfully piloted sending a web-link that would collect responses directly in our secure REDCap® HQ database. This year the HQ was sent electronically whenever an email was available. This process saved time as the HQ was filled out and reviewed by providers prior to the appointment time.

TUFTS MC COLLABORATIONS

Financial/Insurance Coordination

AYA Cancer Program financial navigation:

As the pandemic continued to impact the financial wellbeing of our patients, the AYA Cancer Program team provided navigation services whenever possible. Patients were counseled or provided support on topics ranging from:

- Billing/cost of medical care
- Food assistance
- Insurance plan options
- FMLA paperwork
- Transportation costs
- Housing

Thanks to a recurring and generous donation from a grateful family, funds were available to offset selected medical expenses (page 13).

AYA Cancer Program team & Tufts MC Cancer Center Financial Navigator partnership:

Loss of employment, exacerbated during the pandemic, can have far reaching impacts, and potentially devastating effects for cancer survivors, particularly when employment is linked to the survivor's health insurance. Dr. Linendoll took the lead role in establishing a connection with the Cancer Center's financial navigator. The navigator helps link patients to the best insurance plan, based on their eligibility.

This partnership led to patients:

- Enrolling in secondary insurance plans to expand coverage
- Reducing deductible/co-pays through change of insurance plan
- Establishing a new insurance plan when their employer's plan ended coverage

Nutrition Referral Improvement Project

Nutrition, Ear, Nose, Throat (ENT) & AYA Survivorship:

The Tufts MC's Cancer Committee identified a need to improve nutrition referrals for patients with head & neck cancers. Dr. Parsons connected members of the AYA Cancer Program, who had previously developed referral tracking databases, with members of ENT and the Nutrition departments to provide this database support. This initiative has resulted in a streamlined referral process for ENT patients to Nutrition, and increased ENT patient referrals to survivorship care.

Cardio-Oncology embedded in Survivorship

Back-to-Back appointment scheduling: Patients benefit from the close partnership between the AYA Cancer Program team and Dr. Jenica Upshaw, Director of the Cardio-Oncology Program. We continue to offer back-to-back appointments, on select Monday afternoons for ease of care coordination and scheduling.

TRAINING

Dedicated training in AYA and/or survivorship care is rare for most medical providers. For this reason, including providers and future providers in the AYA Cancer Program is essential to advancing awareness and interest in these specialized areas of care.



Dr. Emily Anderson (a former AYA Summer Scholar and current pediatric intern at Massachusetts General Hospital) worked with Dr. Linendoll to expand survivorship's reach. She created Breast Health Care Plans, for patients who recently completed treatment. She also has closely partnered with Dr. Parsons on the clinic's late effects database.



Neena Patel, MS(c) continued to volunteer in 2021, assisting with quality improvement projects. She will work closely with the team through early 2022 as she composes her master's thesis titled 'Women's Health in Lynch Syndrome.' We congratulate Neena on her recent acceptance to Tufts University School of Medicine!



Dr. Michael Wismer is a 2nd year Hematology/Oncology Fellow. He will be spending his dedicated 18-month research training under the mentorship of Dr. Parsons.



Dr. John (Jack) Melson is a 2nd year Hematology/Oncology Fellow. He will be spending his dedicated research training period under the co-mentorship of Drs. Parsons and Upshaw (Cardio-Oncologist).

RESEARCH

Evaluating the Role of Financial Navigation in Alleviating Financial Distress among Young Adult Survivors of Blood Cancer (Financial Navigation Study)

Dr. Parsons is the Principal Investigator for a multi-site hybrid type 2 intervention study, supported by the Leukemia & Lymphoma Society (LLS). The study aims to evaluate whether access and support from dedicated financial navigators reduces financial distress in AYA survivors of blood cancer. This study will be conducting entirely *remotely from recruitment to consent and assessment*.

The study team includes members of the AYA Cancer Program team, Research Assistants, Navigators and a Statistician. The study will be open to AYA patients in six hospitals located across the United States, including Tufts MC in 2022.

Michigan-Genome Social Stress impacts AYAs

In September 2021, the National Cancer Institute (NCI) awarded a five-year grant to Dr. Brad Zebrack of the University of Michigan, who is leading a study on the extent to which social isolation, socio-economic disadvantage, and social determinants of health alter the patient's genome, changing susceptibility to late effects and disease outcomes. Dr. Parsons is delighted to be one of the co-investigators on this highly innovative new study among survivors of lymphoma.

Patient Reported Outcomes (PROs) on studies

In September 2020, the NCI awarded a two-year grant to Drs. Parsons and Michael Roth (MD Anderson Cancer Center) as part of the Childhood Cancer Data Initiative. The co-PIs sought to develop consensus about the capture of PROs in AYA cancer clinical trials, standardize the collection of socio-demographic and social determinants of health, and begin the transition to electronic data capture for PROs. Thus far, the duo have worked successfully on the design of four studies (osteosarcoma, Hodgkin lymphoma, non-Hodgkin lymphoma, and ALL) under this initiative. In the remaining 18 months, the team plans to formally evaluate the functionality of electronic data capture.

Thank You & Happy Retirement, Ruth Ann!

Ruth Ann Weidner, MBA, MRP, has worked with Dr. Parsons on and off for more than 20 years. Ruth Ann supported the AYA Cancer Program as the database manager, building numerous databases and serving as the Institutional Review Board liaison for all research studies. We wish her well in retirement!

PUBLICATIONS

Survivors' Perspectives on Treatment Decision-Making and Understanding of Late Effects

Members of the AYA Cancer Program were awarded a Leukemia & Lymphoma grant in 2019 to better understand survivors' perspectives regarding aspects of their cancer experience. Following a delay due to the pandemic, results of our national survey and interviews with patients were published in two manuscripts in 2021.

> [Clin Lymphoma Myeloma Leuk.](#) 2021 Aug 1;S2152-2650(21)00317-7. doi: 10.1016/j.clml.2021.07.034. Online ahead of print.

Perceptions of Role in Treatment Decision Making and Understanding of Late Effects Among Hodgkin Lymphoma Survivors: Results From a National Survey HL Decision Making and Late Effects

Anita J Kumar¹, Rachel Murphy-Banks², Ruth Ann Weidner², Susan K Parsons³

Affiliations + expand

PMID: 34452864 DOI: 10.1016/j.clml.2021.07.034

Abstract

Background: Hodgkin Lymphoma (HL) survivors are at risk of treatment-related late effects (LEs). With these potential risks and increasing numbers of treatment options for newly diagnosed patients, communication and shared decision making are essential to supporting patients throughout the cancer care continuum. We aimed to gather perspectives of HL survivors about their actual role in treatment decision making and their understanding of LEs.

Materials and methods: After initial pilot testing at a cancer survivor conference, we disseminated a 23-question survey in a single-wave e-mail through the Leukemia & Lymphoma Society's national listserv. We focused on 4 constructs: (1) patient's understanding of HL at diagnosis; (2) initial discussions with an oncologist; (3) factors in decision making of treatment, and (4) current health status.

Results: A total of 135 participants responded to the survey. While 73% of survey respondents perceived some involvement in decision making, one-half of respondents felt the treatment plan was a shared decision with their provider. Among patient-level factors, side effects/LEs were most frequently endorsed as important to treatment decisions. Eighty-four percent of respondents had been educated about risk for potential LEs. Thirty-six percent had been diagnosed with a LE at the time of survey completion with 3% reporting a second cancer diagnosis.

Conclusion: Survey respondents described their role in treatment decision making for newly diagnosed HL. Nearly half of patients did not endorse participating in shared decision making. A substantial number had experienced LEs. Future work should focus on improving patient-provider communication in decision processes for newly diagnosed HL.

> [Support Care Cancer.](#) 2021 Sep 15. doi: 10.1007/s00520-021-06538-6. Online ahead of print.

Hodgkin lymphoma survivor perspectives on their engagement in treatment decision-making and discussion of late effects

Rachel Murphy-Banks^{1,2}, Anita J Kumar^{1,2,3}, Mingqian Lin^{1,3}, Nicole Savidge^{1,3}, Emma Livne¹, Susan K Parsons^{4,5,6}

Affiliations + expand

PMID: 34524526 DOI: 10.1007/s00520-021-06538-6

Abstract

Background: Hodgkin lymphoma has a bimodal age distribution with the first peak occurring within young adulthood and the second, among older adults. Although current therapy provides excellent disease control, survivors are at risk of developing treatment-related late effects (LEs). We sought to understand how survivors in active survivorship care perceived their role in treatment decision-making and when they acquired an understanding of LEs.

Methods: Semi-structured interviews were conducted until saturation was reached. Themes were identified through direct content analysis and consensus coding by a multidisciplinary team of coders, including hematology/oncology providers, patient navigators, and survivor stakeholders.

Results: Seventeen interviews were conducted. Role in initial treatment decision-making fluctuated between passive and active engagement with providers identified as being crucial to this process. Half of interviewees (53%) expressed unmet information needs. Survivors reported having learned about LEs at multiple time points, spanning from before treatment commenced through when a LE was diagnosed. The majority (71%) expressed a desire to have learned about LEs before initial treatment ended. The impact of cancer and fertility discussions were also disclosed.

Discussion: Participants highlighted the importance of discussions on LEs early in the care continuum. These preliminary data will be incorporated in a planned treatment decision-making tool that incorporates information on potential LEs.

Implications for cancer survivors: Patient-centered communication approaches should be embraced to assist in treatment decision-making, while considering long-term health consequences. Survivors must be educated on their risk of LEs and encouraged to disclose their perspectives and preferences with their providers to optimize outcomes.

To read the abstracts online: [Survey Results PMID:34452864](#); [Interview Results PMID:34524526](#)

Interview with Dr. Parsons

The American Society of Clinical Oncology (ASCO) Women Who Conquer Cancer Initiative interviewed Dr. Parsons about her career-long mentoring of researchers and providers.

The screenshot shows the ASCO Connection website. The header includes the ASCO Connection logo and the tagline 'The professional networking site for our worldwide oncology community'. Navigation links include 'myConnection', 'Membership Directory', and 'Sign In'. A menu bar contains 'Home', 'Blogs', 'Magazine', 'Tumor Boards', 'Trainee & Early Career', 'Career Guidance', and 'About'. The breadcrumb trail reads 'Home > Magazine > Asco Member News'. The main article title is 'Women Who Conquer Cancer: Dr. Susan K. Parsons Believes That Mentoring Is a Team Effort' with a date of 'May 14, 2021'.

To read the article online: <https://connection.asco.org/magazine/asco-member-news/women-who-conquer-cancer-dr-susan-k-parsons-believes-mentoring-team-effort>

PRESENTATIONS & CONFERENCES

Connecting and Sharing our Work

Education about AYA/survivorship care and outreach to members of the AYA community have been a facet of the AYA Cancer Program, since its inception. The opportunity to share our work on a local, regional, national, and international scale continued to broaden in 2021.

Medical Provider Audience

Tufts-Affiliated:

- Dr. Kumar provided an overview of survivorship to Rehabilitation Medicine Residents and Dr. Parsons introduced AYA survivorship to incoming Hematology/ Oncology (Hem/Onc) Fellows at Tufts MC
- Dr. Linendoll was an invited speaker in the Tufts University School of Medicine ethics course
- Dr. Parsons and Rachel had the opportunity to share our progress with Tufts MC Cancer Center's new Executive Director of Hem/Onc Cancer Services, William Decaneas, Director, Dr. Rachel Buchsbaum, and Manager of Business Operations, Lilla Rogers.

Tufts Clinical and Translational Science Institute (CTSI) & Brandeis University: Team Science Summit: The Covid-19 impact of Healthcare: Dr. Linendoll, PhD, presented 'Telehealth within Adolescent & Young Adult Cancer Programs' at this September summit.

Grand rounds: Dr. Parsons was invited to give grand rounds (a formal meeting for physicians to share their research, methodology or practice) at multiple hospitals including:

- Boston Children's Hospital
- Children's Hospital of Atlanta/Emory University
- Memorial Sloan Kettering Cancer Center

Children's Oncology Group (COG): Dr. Parsons presented at multiple sessions at the Fall meeting. COG brings together many pediatric-trained oncologists who are interested in improving the care of AYAs.

4th International Symposium on Childhood, Adolescent, and Young Adult Hodgkin

Lymphoma: A few years ago, Dr. Parsons co-founded the **Hodgkin Lymphoma International Study for Individual Care (HoLISTIC)** consortium. She presented on the consortium's work to date at this virtual conference.

Global AYA Cancer Congress: Hosted by the Teen Cancer Trust in the UK, in collaboration with Teen Cancer America in the US (page 13) and CanTeen in Australia, this conference is truly global in its reach. Dr. Parsons presented a plenary session titled '*Addressing the Paucity of AYA Clinical Trials through a Pediatric-Adult Partnership*' with her colleague Dr. Roth from MD Anderson (page 8).

PRESENTATIONS & CONFERENCES

Provider & Patient/Survivor Audience

Northeast AYA Cancer Conference: AYA Cancer Program supporters, The Reid R. Sacco AYA Cancer Alliance (page 14), launched an inaugural conference in April 2021. The conference brought together experts in AYA care including Dr. Archie Bleyer who is considered to be one of the AYA cancer movements catalysts.

- Dr. Parsons presented a session titled *'The Current State of AYA Cancer and of AYA Survivorship Care'* and joined a panel titled *'The Next Decade of the AYA Cancer Movement: Emergent Risks, Challenges and Solutions,'* with esteemed colleagues Dr. Stuart Siegel, Dr. David Freyer of Keck School of Medicine, University of Southern California, and Dr. Roth of MD Anderson.
- Dr. Linendoll presented a session titled *'Putting Lives Back on Track: Onco-fertility.'*
- Rachel joined an AYA panel moderated by Dr. Rebecca Johnson of Mary Bridge Children's Hospital titled *'The Patient Perspective.'*
- Dr. Kumar moderated the day's sessions.

AYA Patient/Survivor Audience

Leukemia & Lymphoma Society (LLS) Patient Education Workshop: Drs. Parsons and Linendoll, and Rachel had the opportunity to speak to AYAs located throughout New England at this virtual workshop.

Aims included:

- Share ways to advocate for long-term follow up care following cancer treatment
- Highlight the importance of receiving a Survivorship Care Plan

LEUKEMIA & LYMPHOMA SOCIETY Patient Education

Young Adult Cancer Survivorship

We hope you can join us for this informative virtual program

SPEAKERS:

Susan Parsons, MD, MRP
Senior Oncologist
Medical Director

Nadine Linendoll, PhD, MDiv
Oncology Nurse Practitioner

Rachel Murphy-Banks, MA
Program Manager YA Survivor

Reid R. Sacco Adolescent & Young Adult Cancer Program
Tufts Medical Center

PROGRAM:
Please join LLS for a free virtual education program for young adult cancer patients/survivors and their families.

Do you have a Survivorship Care Plan to help manage and monitor for potential late effects (e.g., physical, emotional, social or financial impacts) from the cancer treatment you received? Please join our guest survivorship specialists for a discussion about advocating for your long-term follow-up care.

In addition to learning about survivorship care, participants will learn about the resources available in their community and those provided by The Leukemia & Lymphoma Society. We encourage you to invite your caregiver and family members.

VIRTUAL/ONLINE AND PHONE EDUCATION PROGRAM
Optimal viewing for this program is on a computer or mobile device using the Zoom application. Audio only is an option. Email required to register and participate in the program. If you do not have a valid email address, please call the staff person listed on the sidebar to register.

BEATING CANCER IS IN OUR BLOOD.
The mission of The Leukemia & Lymphoma Society (LLS) is to cure leukemia, lymphoma, Hodgkin's disease and myeloma, and improve the quality of life of patients and their families. Find out more at www.lls.org.

TUESDAY
MAY 4, 2021
6:00PM – 8:00PM EST

REGISTRATION INFORMATION
This is a **FREE** virtual program for all patients and caregivers. Each person participating should register separately. Login and call-in information will be provided to all participants after registering.

PRE-REGISTRATION IS REQUIRED.

SCAN ME

SCAN QR CODE:
1) Open your camera. 2) Hover over image.
3) Click on the message directing you to the registration website.

ONLINE REGISTRATION:
<https://live.events.ccsd.org/YASurvivorship>

Courtney Rinaldi, M.A.
Patient & Community Outreach Manager
608.810.1304 | Courtney.Rinaldi@LLS.org

For more information or for assistance for people with disabilities please use the contact information above.

National support for this program provided by:

Genentech | **Biogen**
Takeda | **ONCOLOGY**

AYA-Aged Audience

Emmanuel College/Tufts University: Rachel virtually returned to Boston-area undergraduate classes to share the young adult cancer experience. Begun in 2016 this initiative aims to bring awareness of AYA cancer to AYA-aged peers in a university setting.

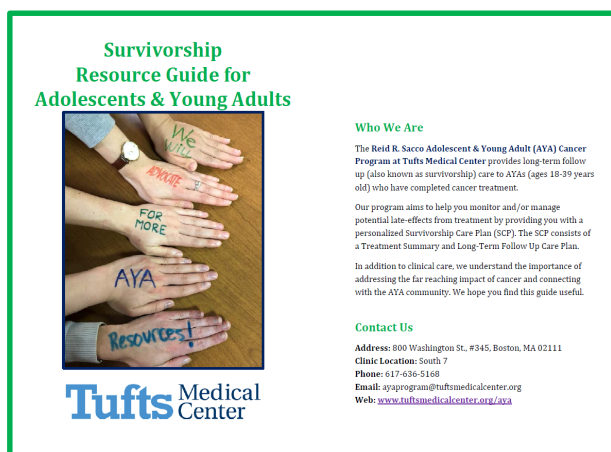
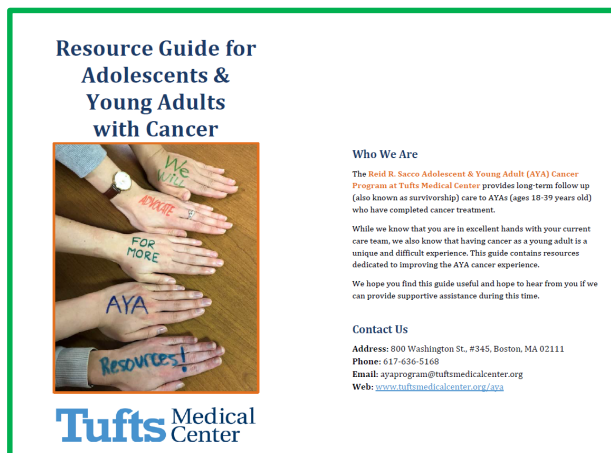
AYA RESOURCE GUIDES

Guide for Newly Diagnosed/In Treatment AYAs

While the AYA Cancer Program provides survivorship care to AYAs who have completed treatment, this year we took further steps to expand our reach to connect patients newly diagnosed or in treatment to the AYA cancer community and to ensure AYAs know our program is available, as needed. Guides have been disseminated in Hematology/Oncology and are available at www.tuftsmedicalcenter.org/ayaresources.

Guide for AYAs Post Treatment/Survivorship

A curated guide to resources dedicated to AYAs who have completed treatment is available at www.tuftsmedicalcenter.org/ayaresources. Prospective patients and AYAs seen in our program are sent a guide as well.



Guide Content

Each guide includes:

- Advice from AYA cancer survivors
- Links with information about local and national resources
- Suggested questions to ask your care team
- Space to take notes

Topics include:

- Tips for Treatment (AYAs with Cancer guide)
- Transitioning to Post-Treatment Life (Survivorship guide)
- Fertility – Sexual Health
- Costs – Insurance
- Financial Grants
- School – Work
- Social Connections
- Wellness Activities

The development of the guides was supported by our partnership with Teen Cancer America (page 13).

Covers of curated Resource Guides

PARTNERSHIPS & SPONSORS

The AYA Cancer Program team benefits from the support of Tufts Medical Center, and our philanthropic partners. Aspects of our programmatic activities and expanding our AYA community connection on a national scale are in large part possible, thanks to our supporters. Below, we highlight benefits from these relationships.

Reid R. Sacco AYA Cancer Alliance



Our program's staunchest supporters, the Reid R. Sacco AYA Cancer Alliance, increased their reach in 2021, organizing the inaugural Northeast AYA Cancer Conference (page 11).

Teen Cancer America (TCA)



While our partnership with TCA only began two years ago, there has been tremendous progress in:

- Expanding our reach to AYA patients
- Forming relationships with other AYA programs across the country
- Collaborating with investigators on trials to improve care.

Gift from Gerald Allman

We are also very thankful this year for a two-year gift from Mr. Allman. With programmatic oversight, these funds are available to AYA patients for medical care expenses and support financial navigation of our patients, as needed.

To date funds have been used to:

- Offset cost of medical bills
- Offer complimentary parking passes
- Manage or reduce medical debt