MESSAGE FROM OUR DIRECTOR

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

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

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

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

AYA CANCER PROGRAM TEAM

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

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

Rachel Murphy-Banks, MA
Program Manager
SURVIVORSHIP CARE

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

1) Prevention of recurrent and new cancers, and of other late effects;

2) Surveillance for cancer recurrence or second cancers;

3) Intervention for consequences of cancer and its treatment (e.g., cardiac problems, psychological distress, financial burden); and

4) Coordination between specialists and primary care providers.

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

References:

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

- AYA-aged survivors of pediatric cancer (diagnosed 0-14 years old)
- AYA-aged survivors of AYA cancer (diagnosed 15-39 years old)

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

New Patients

- 2019
- 2013
- 2014
- 2015
- 2016
- 2017
- 2018
LONG-TERM FOLLOW-UP CARE PLAN

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

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

<table>
<thead>
<tr>
<th>Organ System</th>
<th>Test</th>
<th>Indication</th>
<th>Time Interval</th>
<th>Last Completed/Plan</th>
<th>Responsibility</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cardiac</td>
<td>ECHO</td>
<td>Doxorubicin (500 mg/m²) with mediastinal radiation, risk of cardiomyopathy, coronary artery disease</td>
<td>Every Other Year</td>
<td>7/17/2019</td>
<td>Survivorship, Cardiologist, PCP</td>
</tr>
<tr>
<td></td>
<td>EKG</td>
<td>At baseline at entry into clinic and then as clinically indicated</td>
<td>7/17/2019</td>
<td>Survivorship, Cardiologist, PCP</td>
<td></td>
</tr>
<tr>
<td></td>
<td>BMI</td>
<td>At every visit</td>
<td>7/17/2019</td>
<td>Survivorship, Cardiologist, PCP</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Blood pressure</td>
<td>Cardiac modifiable risk factors</td>
<td>At every visit</td>
<td>7/17/2019</td>
<td>Survivorship, Cardiologist, PCP</td>
</tr>
<tr>
<td></td>
<td>Fasting lipid profile</td>
<td></td>
<td>Every Other Year</td>
<td>7/17/2019</td>
<td>Survivorship, Cardiologist, PCP</td>
</tr>
<tr>
<td>Endocrine</td>
<td>Thyroid exam, Thyroid function tests</td>
<td>Mediastinal radiation; History of hypothyroidism</td>
<td>Annually</td>
<td>6/30/2019</td>
<td>Endocrinologist</td>
</tr>
<tr>
<td>Breast Health</td>
<td>Breast Exam</td>
<td>Mediastinal radiation; Risk of secondary breast cancer</td>
<td>Every six months</td>
<td>11/13/2019</td>
<td>Breast Health</td>
</tr>
<tr>
<td></td>
<td>Mammogram/Breast MRI</td>
<td>Mediastinal radiation; Risk of secondary breast cancer</td>
<td>Yearly beginning at age 25</td>
<td>11/13/2019</td>
<td>Breast Health</td>
</tr>
<tr>
<td>Pulmonary</td>
<td>Pulmonary Function Tests</td>
<td>Bleomycin, mediastinal radiation, and history of asthma</td>
<td>Baseline and then as clinically indicated</td>
<td>6/30/2019</td>
<td>Survivorship</td>
</tr>
<tr>
<td>Dermatology</td>
<td>Skin exam with special attention to radiation fields</td>
<td>Mediastinal radiation; Risk of secondary skin cancer</td>
<td>Annually</td>
<td>6/30/2019</td>
<td>Dermatology</td>
</tr>
<tr>
<td>Neurologic</td>
<td>Neurologic Exam</td>
<td>Vinblastine; at risk for peripheral neuropathy</td>
<td>Baseline and then as clinically indicated</td>
<td>7/17/2019</td>
<td>Survivorship/PCP</td>
</tr>
<tr>
<td>Psychosocial</td>
<td>Psychosocial assessment; attention to depression, PTSD, anxiety</td>
<td>Cancer diagnosis and treatment</td>
<td>Assess at each visit and make referrals as needed</td>
<td>7/17/2019</td>
<td>Survivorship, Psychology</td>
</tr>
</tbody>
</table>

*Sample of a Long-Term Follow-Up Care Plan ©
COMPREHENSIVE CARE COORDINATION

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

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

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

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

Lauren Boehm, Tracey Weisberg, Nadine Linendoll, A. Circe Damon, John K. Erban, Susan K. Parsons

*Abstract*

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

*Keywords: Coordinating care, Electronic medical record integration, Hormone therapy, Implementation, Late effects*

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

Emily Anderson, M.S.P.H., Nadine Linendoll, Ph.D., GNP, Carl B. Heilman, M.D., Ron I. Riesenberg, M.D., Miram A. O’Leary, M.D., Kranik Arunk, M.D., Tara J. Nail, M.D., Martin Goodman, M.D., and Susan K. Parsons, M.D.

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

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

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

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

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

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

We thank them for their interest and contributions!

Aram Bedrosian  
Summer Scholar  
Medical Student  
TUSM

Megan Catalano  
Summer Scholar  
Undergraduate Student  
Brandeis University

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

Mathew Lucas  
Summer Scholar  
Medical Student  
TUSM

Emma Livne  
Research Elective  
Medical Student  
TUSM

Diana Mihalache  
Research Elective  
Medical Student  
TUSM

Ben York  
Summer Scholar  
Medical Student  
TUSM
BUILDING COMMUNITY & RAISING AWARENESS

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

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

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

15th Annual Reid’s Ride

Back Row – Left to Right
Todd Stanganelli, Executive Director Tufts Medical Center Cancer Center; Pamela Chase; Dr. Rodday

Front Row – Left to Right
Drs. Linendoll, Kumar, Parsons, and Erban; Ruth Ann Weidner; Drs. Boehm and N. Bankoff; Rachel Murphy-Banks; and Dr. M. Bankoff

Riders missing from photo:
Jonathan McEuen, Timothy Montgomery, Sarah and Rabiah Fresco

To learn more about Reid’s Ride, July 19, 2020, please contact the AYA Cancer Program Team.
AYA Red Carpet Holiday Gala

Back Row – Left to Right
Drs. N. Bankoff, Anderson, and Boehm; Emma Livne; Walter Armstrong; Rachel Murphy-Banks; Drs. Rodday, Linendoll, Kumar, Upshaw, Scharman, and Hachem

Front Row – Left to Right
Drs. Parsons and Waheed; Diana Mihalache; Dr. Karim

Missing from photo:
Dr. Apkon, CEO and President of Tufts Medical Center and his spouse Michelle; Dr. Buchsbaum, Director of Tufts Medical Center Cancer Center and her spouse Michael Arwe; Maura Lynch; Susan Harrington; Dr. Erban and his sister Barbara; Ted Schwartzberg; Drs. M. Byrne, J. Byrne, and Andujar Vazquez; Christina Graham; Thomas Armstrong; and Elizabeth Peabody
Reid R. Sacco Adolescent & Young Adult (AYA) Cancer Program

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World Cancer Day, February 4, 2019