



PROGRESS UPDATE WINTER 2020-21

Swim Across America Foundation





Lisa Diller, MD, Vice Chair, Clinical Affairs; Medical Director, Clinical Cancer and Blood Disorders Service Line; Medical Director, David B. Perini, Jr. Quality of Life Clinic



Lisa Kenney, MD, MPH



Christopher Recklitis, PhD, MPH, Director of Research, Perini Family Survivors' Center

Introduction

Since 1996, the Swim Across America Foundation and Dana-Farber Cancer Institute have been working together to advance the field of survivorship. Over this time, Swim Across America has cultivated the careers of junior investigators who have conducted pioneering survivorship research aimed at improving care and informing the development of treatment regimens that lessen the long-term effects of cancer care.

Today, under the direction of **Lisa Diller, MD**, leaders in Dana-Farber's David B. Perini, Jr. Quality of Life Clinic—many of whom are former Swim fellows themselves—are developing a new paradigm of survivorship care that integrates a robust telemedicine component. Although the Perini Clinic team had been advancing telemedicine prior to the COVID-19 outbreak, the pandemic catalyzed these efforts. In March 2020, to protect the health of patients and staff, Dana-Farber encouraged virtual visits whenever possible.

This report describes our advances in telemedicine, work by Swim Fellows in the study of psychosocial late effects, and introduces the new director of the Stop & Shop Family Pediatric Neuro-Oncology Outcomes Clinic. Thank you for your generous support of such vital work.

New Models Can Expand Access to Survivorship Care

Within a month after the onset of the COVID-19 pandemic, telemedicine accounted for more than half of appointments Institute-wide. Through more than 200 virtual survivorship visits from March through November 2020, Perini Clinic staff have leveraged telemedicine to educate survivors about their treatment history, health risks, and testing recommendations—knowledge that empowers them to discuss their medical needs with their care providers.

Looking ahead, to ensure that the Institute continues to provide the best possible support to patients, the Perini Clinic team is rigorously assessing the efficacy and feasibility of integrating telemedicine more deeply into survivorship care. Under the direction of **Lisa Kenney, MD, MPH**, and **Christopher Recklitis, PhD, MPH**, the team is conducting satisfaction surveys with providers and patients, and simultaneously developing guidelines that ensure survivors receive physical exams when they are needed. These innovations have the potential to make survivorship care available to the tens of thousands of survivors who do not live near a major cancer center, greatly expanding the impact of the work being done at Dana-Farber.



Donghao Lu, MD, PhD



Lydia Chevalier, PhD, received the 2020 University of Washington Psychology Internship Director's Prize. This prize is awarded to the graduating intern who demonstrates significant achievement in research, teaching, and clinical skills, and who shows promise for an outstanding career in academic psychology.

Project REACH (Research Evaluating After Cancer Health), is comprised of 800 cancer survivors and 200 parents who completed questionnaires on a variety of issues related to physical health and emotional well-being. Started in 2007, Project REACH has been the mainstay for the innovative survivorship research that Dana-Farber has been leading ever since. The most recent Project REACH survey encompasses results from 370 childhood cancer survivors over age 18. These surveys, which were completed seven to 12 years after the participants' first survey, mark an important milestone in collecting data on the long-term impact of cancer treatment on pediatric survivors.

SWIM FELLOW STUDIES THE IMPACT OF SECONDARY CANCERS

Childhood cancer survivors are at increased risk for secondary cancers, but their long-term psychosocial health following a subsequent diagnosis has not been fully explored. **Donghao Lu, MD, PhD**, the 2019-2020 Swim Fellow, gathered data from Project REACH (see sidebar) on fatigue, sleep, depression, anxiety, and body image from 43 participants who had been diagnosed with a second cancer.

Participants with secondary cancers reported higher levels of body image concerns compared to survivors who had not had a secondary cancer, but did not report significantly higher levels of fatigue, insomnia, depression, or anxiety. These findings suggest that psychosocial providers who see survivors with secondary cancers should be prepared to address body image concerns. Published in the August 2020 *Journal of Adolescent and Young Adult Oncology*, Lu's study is the first to address the long-term psychosocial impact of secondary cancers in young adult survivors of cancers.

SWIM FELLOW STUDIES SURVIVORSHIP ACROSS ALL AGES

Throughout her career, 2020-2021 Swim Fellow **Lydia Chevalier, PhD**, has practiced behavioral medicine with children and adults. Prior to her fellowship at Dana-Farber, Chevalier worked in trauma centers, intensive care units, and outpatient settings, where she helped patients of all ages manage pain, anxiety, insomnia, and the psychological impact of debilitating injuries and stroke. In her doctoral research at Boston University, Chevalier examined interactions between parents and children with anxiety-related insomnia and published a study in the September 2020 *Journal of Developmental Behavioral Pediatrics* on how parents' efforts to accommodate their child's sleep disorders, particularly by co-sleeping, can exacerbate insomnia and lead to their own sleep problems.

At Dana-Farber, Chevalier is studying the experiences of children and young adults with cancer through a developmental lens. In adults, having a personal identity as a survivor is associated with healthy outcomes and behaviors, whereas identifying as a victim is associated with unhealthy ones. To explore this question more fully in young adult survivors of pediatric cancers, Chevalier examined data from Project REACH to compare participants' perceptions of their identities and outcomes. A manuscript highlighting her findings has been prepared for publication.



Eric Zhou, PhD, collaborates with investigators at Boston University and introduces doctoral students to the field of cancer survivorship research.

“Eric spoke so highly of the Swim Fellowship and helped me understand how it had given him the freedom to pursue his interests...in a way that wouldn't happen at other places. I'm grateful for the opportunity the Swim Fellowship is giving me to study the impact of cancer treatment at different developmental stages so we can understand the best ways to meet survivors' needs.”

—Lydia Chevalier, PhD

Chevalier's findings suggest that, as in cancer with adults, identifying as a victim after pediatric cancer treatment is associated with negative health outcomes and health behaviors such as inconsistent sunscreen use. However, Chevalier did not find that identifying as a survivor was necessarily tied to positive outcomes, potentially because being a survivor has a range of meanings to those who have been treated for pediatric cancer.

ONLINE PROGRAM EASES INSOMNIA FOR YOUNG ADULTS

Through his work in the Perini Clinic, **Eric Zhou, PhD,** has found that adolescents and young adults who survive cancer often continue to suffer from insomnia after treatment ends. These survivors face sleep-related issues unique to their age group—constraints on sleep schedules by parents or roommates, as well as normal developmental changes in circadian timing. Long-term cancer-related issues such as fatigue, pain, and anxiety may also contribute to insomnia.

To address these complex drivers of insomnia, Zhou and Recklitis partnered with the creators of SHUTi (Sleep Healthy Using the Internet), an online program that has been shown to cure insomnia in adults over 55, to develop a similar program for adolescent and young adults who have survived cancer treatment. Developed by researchers at the University of Virginia, SHUTi was adapted for adolescent and young adult cancer survivors by Zhou and Recklitis. The interactive program uses text, images, and video to explain how insomnia develops and how it can be overcome.

In a study of 22 young adult survivors with insomnia, participants kept a sleep diary to track when they slept and then entered the information into SHUTi, which adjusted sleep recommendations accordingly. At eight and 16 weeks after starting SHUTi, participants reported a significant lessening in insomnia severity, daytime sleepiness, and fatigue, as well as an overall improvement in quality of life.

Notably, participants' insomnia continued to ease after the intervention had ended, suggesting that participants continued to make positive sleep-related decisions. These findings were published in June 2020 *Pediatric Blood and Cancer*. The investigators noted that SHUTi's automated format makes it particularly well suited to the moment as telehealth and online programs increase in popularity due to the COVID-19 crisis.



NEW FACULTY MEMBER FOCUSES ON SURVIVORSHIP FOR PATIENTS WITH BRAIN TUMORS

Tabitha Cooney, MD, has joined Dana-Farber as director of the Stop & Shop Family Pediatric Neuro-Oncology Outcomes Clinic. Cooney completed fellowships at Stanford Children’s Health, Lucile Packard Children’s Hospital, and began her faculty career at University of California San Francisco Benioff Children’s Hospitals San Francisco and Oakland. Cooney and her team are focused on providing holistic, multidisciplinary care for patients and their families to focus on every aspect of their cognitive, mental, and physical health, including survivorship care.

Pediatric brain and spinal cord tumors are second most common childhood cancer after leukemia, accounting for 26% of pediatric cancers. Approximately 78% of children treated for these tumors will go on to become long-term survivors, but the difficult treatment regimens and existential challenges they face ultimately contribute to challenges in survivorship. In Cooney’s words:

“In the field of pediatric neuro-oncology, we see it as our mission to not only develop cures for pediatric brain and spinal cord tumors, but to move these children through their cancer journey in a way that positions them to have as much potential for health and happiness in their adult life as they would have had otherwise. Our research aims to better understand, prevent, and mitigate detrimental effects that [might] happen down the road.”

—Tabitha Cooney, MD

STUDYING PAIN IN SURVIVORS OF BRAIN TUMORS

A recent study led by Recklitis using the Project REACH cohort shows that survivors of pediatric brain tumors experience significant pain even years after their treatment has ended. In a survey of 116 adolescent and young adult pediatric brain tumor survivors, 36% reported clinically significant pain, most commonly headaches and muscular/skeletal pain. Published in the December 2019 *Journal of Adolescent and Young Adult Oncology*, the study was the first to ask long-term pediatric brain tumor survivors directly about their pain rather than relying on caregiver reports. The results paint a more detailed picture of the prevalence of pain in their lives and its impact on their happiness.

Integrating Genetic Testing into Survivorship Care

Due to rapid advances in our understanding of hereditary cancers, many adult survivors of pediatric cancers would not have been aware that genetics might play a role in their cancer at the time they were diagnosed.

The Perini Clinic is contacting survivors who were treated for pediatric cancers at Dana-Farber, encouraging them to have a genetic counseling visit. The team is also developing strategies to share this message with primary care providers, urging them to discuss genetic counseling with their patients and family members who may be at risk.

Tabitha Cooney, MD,
Director, Stop & Shop
Family Pediatric Neuro-
Oncology Outcomes Clinic



Sharon Bober, PhD,
Founder and Director,
Sexual Health Program

Participants with frequent, severe pain reported a decrease in their quality of life, their ability to function socially and emotionally, and their ability to perform in school or the workplace. Developmentally, adolescents and young adults are at a stage of their lives when they are separating from their parents, establishing intimate relationships, and pursuing educational and career paths—and pain interferes with these important transitions. Importantly, these findings indicate that pain is more prevalent, enduring, and detrimental to these survivors than previously known, indicating that clinicians who work with these survivors should ask them about pain and refer them to pain management providers when appropriate.

PROFESSIONAL EDUCATION AND SEXUAL HEALTH

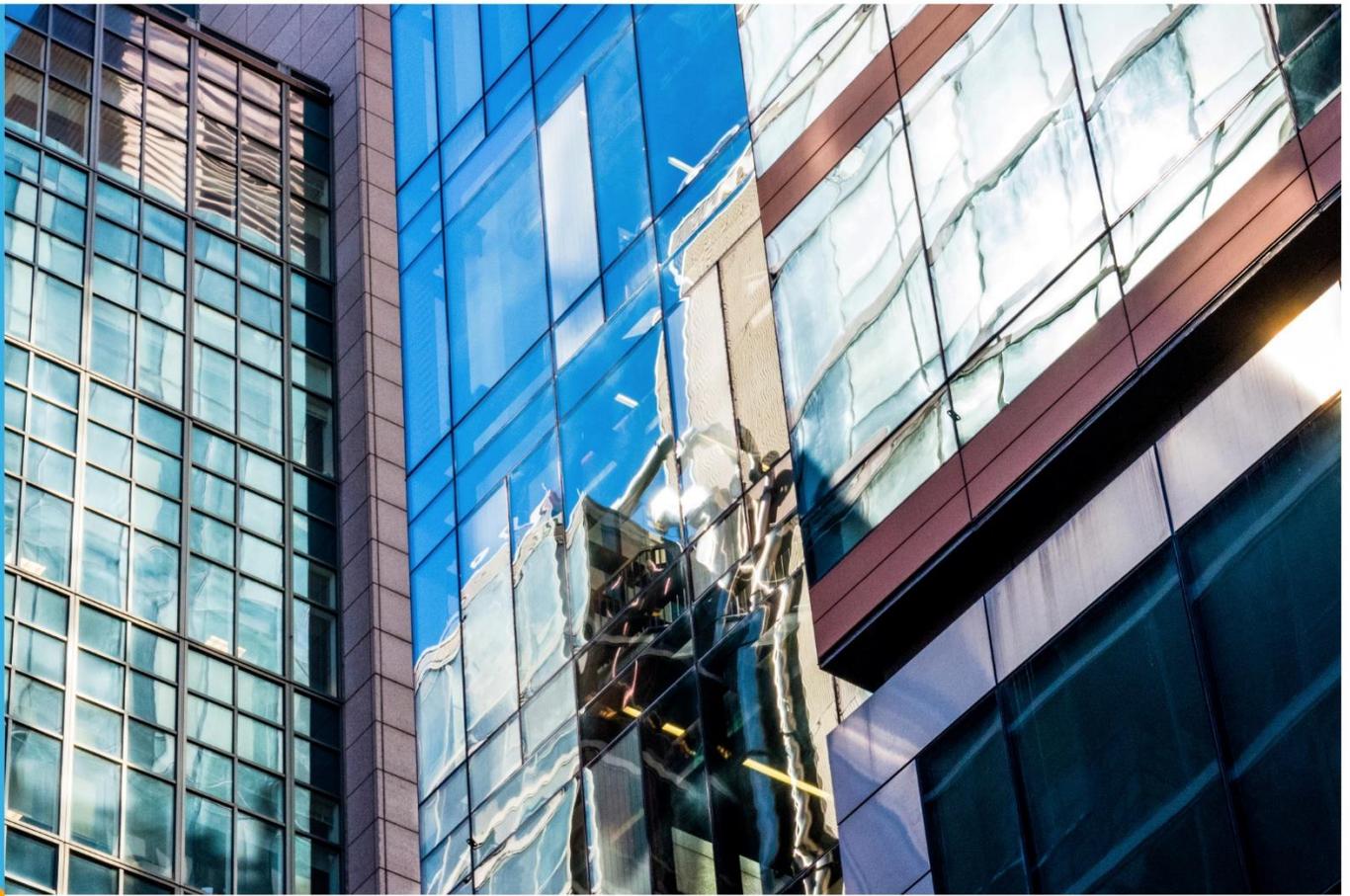
Sharon Bober, PhD, is leading research on sexual function among young adult survivors of pediatric cancers. Previous Project REACH studies showed that a high proportion of survivors of pediatric cancers reported sexual dysfunction and wanted their providers to initiate conversations about sexual issues.

To better understand the training that oncology fellows receive about communicating with patients on these issues, Bober surveyed 63 pediatric oncology fellowship directors and found that while the majority offered education about fertility and reproductive health, most did not offer education about sexual health, including safe sex practices. These findings suggest that fellowship programs should incorporate this training into their curricula. Bober and her colleagues reported these findings in the January 2020 *Psychosocial and Supportive Care*.

The Impact of Your Philanthropy

Thank you for your longstanding support of survivorship research and care. With the advent of remarkable treatments over the past decades, more and more children are being cured of their cancers, but we know that is not enough. Your investment drives our understanding of late effects, helps us develop less toxic treatments and interventions to mitigate lasting effects, and enables us to build and test new models of care that can be implemented to improve the health of more than 500,000 survivors of pediatric cancers in the United States. We are incredibly grateful for your partnership.

Report written by Maria O'Meara.



Dana-Farber Cancer Institute has been the top ranked cancer hospital in New England by U.S. News and World Report for 20 consecutive years, and is the only cancer center in the country ranked in the top 6 for both adult and pediatric cancer programs.



Dana-Farber Cancer Institute was named the #3 cancer center in the world by Newsweek in its World's Best Specialized Hospitals ranking.



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