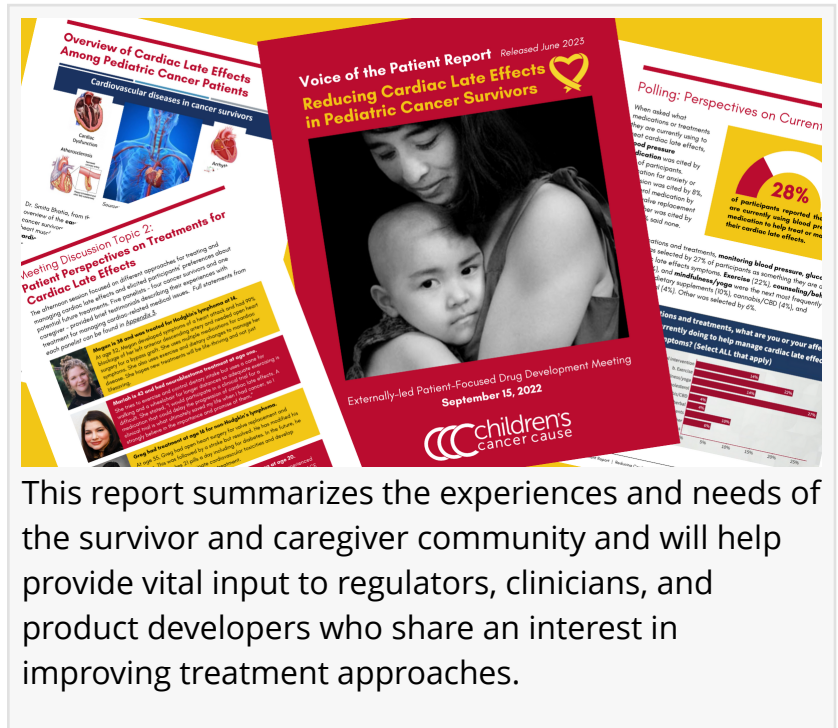


New Report Emphasizes Burden of Lifelong Cardiac Late Effects in Pediatric Cancer Survivors

Report stems from FDA-approved meeting on the impact of cardiac late effects for childhood cancer survivors and caregivers.

WASHINGTON, DC, USA, June 15, 2023 /EINPresswire.com/ -- There is a tremendous unmet medical need for childhood cancer survivors suffering from what one described as the “ticking time bomb” of cardiac late effects resulting from their cancer treatment, according to a new report published today from the national childhood cancer advocacy group [Children's Cancer Cause](https://www.childrenscancercause.org).



This report summarizes the experiences and needs of the survivor and caregiver community and will help provide vital input to regulators, clinicians, and product developers who share an interest in improving treatment approaches.

The [Voice of the Patient report](#) stems from an Externally-led Patient-Focused Drug Development (EL-PFDD) meeting on reducing cardiac late effects in pediatric cancer survivors, held in September 2022. This virtual meeting was an opportunity for childhood cancer survivors and caregivers to speak to the Food and Drug Administration (FDA) and other experts about the need to develop new drugs that protect the heart and reduce cardiac late effects caused by harsh chemotherapy and radiation treatments.

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The impact of this meeting & your collective voice will be felt for years to come.”

Steve Wosahla, CEO of Children's Cancer Cause

“It breaks my heart to know the only means of saving her life condemned her to a lifetime of debilitating and chronic physical and mental issues. I hold my breath every time we go [to the doctor], waiting for the results that will confirm

she has more time until her heart shows signs of late effects,” said one mother of a pediatric cancer survivor. “I know the clock is ticking, and I live in fear of when that day arrives.”

Anthracyclines and radiation therapy are the backbone of treatment for a significant percentage of pediatric cancer patients, but they can lead to serious, chronic, and sometimes life-threatening cardiovascular complications that can increase with age and impact long-term well-being. Childhood cancer survivors are at a 15-fold increased risk of developing congestive heart failure (CHF) and are at a seven-fold higher risk of premature death due to cardiac causes, when compared with the general population.

“We are so grateful to the many courageous survivors and caregivers who came forward to describe how these late effects impact their quality of life and provide their insights about why new treatments are needed,” said Steve Wosahla, Chief Executive Officer of Children’s Cancer Cause. “Many of the drugs used today were developed decades ago when we didn’t understand the harm they cause. We hope that this Voice of the Patient report will impact the way we think about this population’s needs, encourage future research, and advance successful new treatments as survivors transition into adulthood and face a lifetime of significant health challenges.”

The report is an outgrowth of a meeting that was presented in collaboration with the American Academy of Pediatrics, the American Society of Clinical Oncology (ASCO), the American Society of Pediatric Hematology/Oncology (ASPHO), The Andrew McDonough B+ Foundation, and Teen Cancer America.

Among the report’s key messages:

- Managing ongoing cardiac late effects can have devastating quality of life impacts and too often becomes central to a survivor’s daily life.
- Survivors and caregivers feel that they lack information to prepare for the future. They express disappointment, frustration, and feelings of trauma. For parents, trauma is compounded by guilt and anxiety over the difficult decisions they’ve had to make regarding their child’s care.
- Survivors rely on a wide range of medical interventions, from heart medications to control blood pressure and manage cholesterol to more significant interventions like pacemaker placement, valve replacement, and even heart transplant.
- For survivors and caregivers, the most important potential new treatments are protective treatments to prevent heart effects from cancer treatments, as well as less toxic cancer treatments with reduced impact on heart health.
- There needs to be even greater incorporation of the survivor and caregiver voice in drug development to prevent, mitigate, or improve treatment for these late effects.

The report includes survivor stories about challenges with everyday activities due to shortness of breath, racing heartbeat, fatigue, depression, and anxiety, in addition to testimony from parents whose children survived their cancer but later died from cardiac complications caused by the harsh, toxic treatments.

One survivor who is 20 years old and was treated for neuroblastoma at age five, discussed the life-altering impacts of requiring portable oxygen and a wheelchair as a young adult. Another

survivor also testified about open-heart surgery in his 30s, which was followed by a stroke. He now takes 21 pills every day to manage diabetes and prevent heart failure.

“Aging, as a survivor of childhood cancer, is terrifying. The treatments that saved my life now seems to be slowly stealing it,” said another survivor who was treated for Hodgkin’s lymphoma as a child and has spent subsequent decades suffering from multiple cardiac late effects. “On difficult days, I feel as if survivorship is a progressive terminal illness. The effects of childhood cancer last a lifetime.”

The Voice of the Patient report is available at childhoodcancerpfdd.org/cardiac-effects, along with the full meeting recording.

The PFDD Program was created by the FDA as a mechanism to more systematically gather information from patients and survivors about their conditions, available therapies, and what matters most to them in balancing risks and benefits. This information, conveyed through the Voice of the Patient report structure, helps inform FDA’s drug development and evaluation process. Held during the 10th anniversary year of the PFDD program, this meeting on September 15, 2022, became the 74th EL- PFDD meeting and the 35th to be held virtually (due to the COVID-19 pandemic).

Children’s Cancer Cause thanks the meeting’s sponsors Day One Biopharmaceuticals, Whole Foods Market, Community Health Charities (CHC), and the Stewart Initiative for Childhood Cancer Survivors (a program of the Children’s Cancer Cause), for their support in helping to make this meeting possible.

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Children’s Cancer Cause is a leading national policy and advocacy organization, working at the federal level to ensure that children have access to less toxic and more effective cancer therapies; to expand resources for research and specialized care; and to address the unique needs and challenges of childhood cancer survivors and their families.

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Steve Wosahla
Children's Cancer Cause
+1 202-552-7392

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