FDA-Approved Meeting Gives a Voice to Childhood Cancer Families Impacted by Life-Threatening Cardiac Late Effects

Children's Cancer Cause is accepting comments from childhood cancer families and survivors impacted by cardiotoxicity until October 17, 2022.

Behind the scenes of the September 15th Externally-led Patient Focused Drug Development meeting.

WASHINGTON, DC, USA, September 26, 2022 /EINPresswire.com/ -- Pediatric cancer survivors and caregivers spoke to the Food and Drug Administration (FDA) earlier this month about the "ticking time bomb" of cardiac late effects caused by harsh chemotherapy and radiation treatments. During this Externally-led Patient Focused Drug Development (EL-PFDD) meeting, hosted by Children's Cancer Cause, survivors and families shared their experiences with treatment-induced cardiac late effects that may lead to a lifetime of health challenges, describing symptoms ranging from heart failure to high blood pressure, chronic fatigue, and more. In live polling, survivors expressed anxieties about the possibility of heart surgery, heart transplants, or having a heart attack as top concerns.

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> *A survivor of childhood cancer*

"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."

This "Reducing Cardiac Late Effects in Childhood Cancer Survivors" event took place on September 15, 2022 - midway through Childhood Cancer Awareness Month. The virtual meeting gave childhood cancer survivors, parents, and caregivers an opportunity to share their personal stories with a wide range of stakeholders, including staff at the FDA and the National Cancer Institute (NCI), pediatric oncologists and other healthcare providers, and representatives from pharmaceutical companies. In total, over 150 people participated in the event livestream, which featured patient and family testimonials, panel discussions, research presentations, and interactive polling. The meeting included testimony from parents whose children survived their cancer but later died from cardiac complications caused by the harsh, toxic treatments.

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.

“The impact of this meeting and your collective voice will be felt for years to come,” said Steve Wosahla, Chief Executive Officer of Children’s Cancer Cause. “Many of the drugs we use today were developed 40 to 50 years ago, and it's clear that we need less toxic and more effective solutions to treat childhood cancers. We also urgently and desperately need better treatments for people living with cardiomyopathy and other cardiac late effects.”

A survivor of Hodgkin’s lymphoma testified during the meeting about her experience receiving a full open-heart bypass at age 32 as a consequence of cardiac damage resulting from her childhood radiation and chemotherapy treatments. 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.

Survivors spoke about challenges with everyday activities due to shortness of breath, racing heart beat, fatigue, and depression and anxiety. 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.

“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 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.”

As a follow-up outcome from the meeting, Children’s Cancer Cause will submit a Voice of the Patient report to the FDA in January 2023. Children’s Cancer Cause is accepting comments from families and other stakeholders about treatment-induced cardiac effects until October 17, 2022,

to be considered for inclusion in the final report. A recording of the meeting and the comment form is available at childhoodcancerpfdd.org/livestream.

The PFDD Program was created by the FDA ten years ago 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 helps inform FDA's drug development and evaluation process.

Children's Cancer Cause thanks the FDA for approving this meeting topic and all the participants who made it a success. This meeting 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.

Children's Cancer Cause also acknowledges Day One Biopharmaceuticals, Whole Foods Market, Community Health Charities (CHC), and the Stewart Initiative for Childhood Cancer Survivors, for their sponsorship to help make this meeting possible.

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Children's Cancer Cause is the 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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