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Good afternoon. Thank you for giving me the opportunity to testify today.

My name is Ruth Hoffman. I am a proud Marylander, and the CEO of the American Childhood Cancer Organization—otherwise known as ACCO. ACCO, which is based in Maryland, is the oldest and largest childhood cancer non-profit in the nation. Founded by parents of children with cancer, ACCO has been the leader in establishing federal funding for childhood cancer research since 1970 – funding which sadly has increasingly failed to meet the research needs of this vulnerable patient population. We are also the sponsor of the current law – Maryland’s Pediatric Cancer Fund Act. I am here to ask for your support for the amendments to Maryland’s Pediatric Cancer Fund Act which will bring clarity to its original intent and operationalize the existing law.

In 2018—to address the unmet childhood cancer research needs at the federal level—ACCO performed a state landscape analysis and recognized that only two states were providing funding for childhood cancer research, yet almost all states were appropriating funds for adult cancer research. Shockingly, only eleven states included childhood cancer language in their state cancer plans. This was largely based upon a strategy of decreasing adult cancer deaths through the practice of establishing cancer screening and prevention in all 50 states. I cannot emphasize enough—this screening and prevention strategy does not apply to children diagnosed with cancer. Infants and children did not smoke to cause their cancer! No amount of screening and lifestyle prevention strategies would change their cancer diagnosis. To address the disparity between adult and childhood cancer research funding at the state level, ACCO established a program called, What About Kids? In the past 4 years, we’ve secured commitments from 44 states to add *childhood-cancer-based-strategies*—which are not focused on prevention—to their cancer plans.

Additionally, the intent of Maryland’s Pediatric Cancer Fund Act was to *support research to enhance* the treatment of childhood cancer, not to fund individual cancer treatments. There are existing mechanisms in place including private medical health insurance and Medicaid that pay for individual cancer treatment.

As such, to bring clarity to the original intent of the law, I am asking for your support of the amendment to delete “prevention and treatment” from the bill language to ensure that funds from the appropriation are allocated to much-needed and pediatric-appropriate cancer research.

In addition to our work to ensure all 50 states adopted pediatric-appropriate strategies and objectives in their state cancer plans, ACCO has also been successful in securing \$98.8 million in state-based childhood cancer research funding in 7 states, with legislation currently at various stages of being passed in an additional 5 states. Childhood cancer IS a Maryland problem! Maryland has the 13th highest incidence rate of childhood lymphoma and a childhood cancer death rate that is above the national average. So, I’m proud that Maryland was ACCO’s 4th state to pass the Maryland Childhood Cancer Fund into law in order to address this unmet research need. It’s also important to note that ACCO is the ONLY

national non-profit organization that is sponsoring state-based legislation and securing appropriations for childhood cancer research across the US.

The focus of the appropriations—as ACCO continues to roll them out across the country—has consistently been to increase much-needed childhood cancer research, and to ensure that an expert group of experts review grant applications that will make the greatest impact in developing new therapies to treat children with cancer. It must be recognized that most children diagnosed with cancer today continue to receive the same cancer treatment as children who were diagnosed more than 30 years ago. Just 6 new drugs have been approved by the FDA to treat childhood cancer in the last 30 years. This compares to more than 220 new drugs approved to treat adult cancer over the same time period. Cancer continues to be the leading disease cause of death of children in Maryland, and across the US. There is a desperate need for research to develop new treatments for children with cancer, and states play a huge role in making this possible.

To demonstrate the disparity in progress between adult and childhood cancer treatments, I am also here today as the mother of a daughter who, in 1987, at the age of 7, was diagnosed with acute myelogenous leukemia (AML)—the type of cancer that Dr. Civin referenced. My daughter was given a 5% probability of reaching her 8th birthday. Fortunately, she became one of the first children to survive a bone marrow transplant. She was treated with toxic chemotherapy and total body radiation. She voiced on national television at the time, that her hope was that other children would not have to go through such horrible treatments in the future. It's been 37 years since her transplant, and sadly, treatment for childhood AML today has changed little from what it was for her, and the prognosis for survival continues to be poor.

Treatment for childhood cancer remains toxic. Most of our children are “burned” through radiation, “poisoned” through chemotherapy, and “cut” with surgery in the hope of finding a cure. My daughter's oncologist described her total body radiation as, “deliberately performing a nuclear bomb in a kid.” Children are receiving these toxic therapies at a time in their lives when they have growing bodies and developing brains. The impact is forever. In addition to immediate side effects of treatment, 96% of survivors of childhood cancer experience a severe or life-threatening condition directly caused by the toxicity of the cancer treatment that initially saved their lives.

My daughter is now a young woman, but her survival came with a cost. She has endured a secondary cancer, has endocrine dysfunction, lymphedema, and she learned two months ago that she is officially in heart failure. My daughter's cancer also impacted the next generation. When she miraculously learned as a young adult that she was pregnant, she also learned that the total body radiation she received as a 7-year-old resulted in vascular uterine insufficiency (lack of blood supply to the uterus) and cervical incompetency. That meant that my granddaughter had to be induced at 24 weeks gestation. She weighed 1 pound 6 ounces and has grand mal epilepsy because of being born as a micro-preemie. My daughter's toxic cancer treatments—which remain the only method of treatment for the majority of kids with cancer today—was the direct cause of my granddaughter's epilepsy. We MUST do better!

To ensure expert, timely, and pediatric cancer-specific distribution of the appropriations of the Maryland Pediatric Cancer Fund, and in keeping with other states that are funding childhood cancer research, I am asking that you support the amendments that would operationalize the grant review process including the creating of the Fund Commission. Doing so will ensure that appropriations to Maryland's Pediatric Cancer Fund will be used in the most impactful way to advance much-needed

childhood cancer research and will establish Maryland as a leader in state-funded childhood cancer research to other states across the country.

Ruth Hoffman