



2021

ANNUAL
REPORT



AMERICAN
childhood
CANCER ORGANIZATION

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*It doesn't start and end with a **Cure.***

The most that anyone could hope to do for a child with cancer is to make their cancer go away. However, defeating cancer can take years or a lifetime, and too many children lose the battle. In the time between a first diagnosis and the first cancer-free day — if that day ever comes — these children are facing the most intense challenge of their lives.



A cure is victory, but cancer is a battle.

At ACCO, we support children on the front lines in the fight for their lives. They all deserve a cure. But until that day comes, they will have our care.

Dear ACCO Supporter

2021 has been an incredible year of milestones reached in our quest to change policy and support children fighting cancer.

ACCO is honored and proud to be leading the way as we work collaboratively to create change at the state, national, and international levels. From our expansion of ACCO's What About Kids Advocacy initiative from \$2.5 million appropriated in one state to \$27.5 million collectively appropriated in 3 states for childhood cancer research, to providing education and support to thousands of newly diagnosed children with cancer and their families - 2021 was a transformational year!

Through it all, there has been one constant - **YOU**. You are what drives our passion every day and it is your support that has made the victories possible. And we thank you for that.



WHAT WE DO



The American Childhood Cancer Organization (ACCO) is the nation's largest grassroots organization at the forefront of the crucial battle against childhood cancer. Our mission is to provide information and support for children and adolescents with cancer and their families, to provide grassroots leadership through advocacy and awareness, and to support research leading to a cure for all children diagnosed with this life-threatening disease.

Since our founding in 1970, we have dedicated our organization to improving the lives of children living with cancer and its long-term impacts, both nationally and across the globe. Working alongside our partners, funders, and local supporters, we provide essential programs and services to address the critical needs that families encounter each and every day in the process of caring for their critically ill children.



Advocate

In 2021, ACCO's leadership resulted in \$25,000,000 in new state appropriations for childhood cancer research. Unfortunately, the majority of cancer's smallest victims continue to be treated with medications that were developed in the 1960s and 1970s. Many of the drugs were developed and approved to fight adult cancers and used off-label to treat children with cancer. Even when the treatments work, they result in serious long-term health problems including secondary cancers that have a devastating impact on the future of these children.

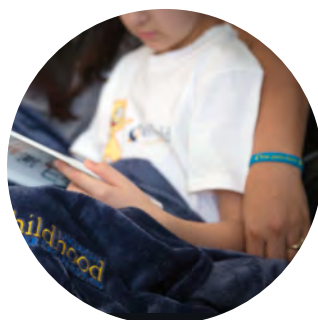


Inform

Nothing is scarier than being told that your child has cancer. Families are suddenly inundated with medical terminology, a life-threatening diagnosis, and numerous medical professionals. In this overwhelmed state, they are then asked to make treatment decisions that will drastically impact their child's life and future. ACCO empowers cancer families to make informed decisions by providing them with comprehensive informational resources about the childhood cancer diagnosis, treatment procedures, medications and clinical trials in simple and easy-to-comprehend terminology.

Comfort

One of the most powerful sources of fear is the unknown. Cancer's littlest patients are often too young to understand what is happening to them. Through ACCO's Comfort Kit, Medical Play Kit, journals, illustrated treatment books, and other resources that we develop and provide without cost, we help children understand what's happening to them, empowering them in the fight that lies ahead.



Support

When a child is diagnosed with cancer, the entire family is impacted. ACCO understands the shockwaves that childhood cancer sends through the patient, siblings, and parents. Through our national online support network we provide emotional support 24/7. With the help of our Founding Hope programs across the country, we provide on-the-ground services, including financial assistance. Research has shown that children treated for cancer from families with a low socioeconomic status (SES) have a poorer survival rate. Financial assistance not only assists the family during this difficult time, it also improves the probability of a cure for the child.

SIGNATURE CAMPAIGNS



Pjammin®

Pajamas are the battle uniform of children with cancer. As they undergo critical treatments such as chemo and surgery, our smallest cancer patients live in their pajamas. They can be isolated for months or years at a time, missing normal childhood experiences like school or time with their family, as they battle cancer in their pajamas.

A Pjammin® event is a way to stand in solidarity with these cancer warriors, raise awareness of their struggle, and raise funds to support them. By organizing a Pjammin® day at your school or business, you can help spread the word of these children and their amazing courage, strength, and perseverance.



GO GOLD®

As the international symbol for childhood cancer, the gold ribbon represents a united stand in the fight and the ongoing search for new and innovative treatment options. Sadly, when asked, most people are not able to identify the gold ribbon as the symbol for childhood cancer awareness. We can't raise awareness of the importance of the Gold Ribbon without help from others across the country and across the globe.



A fun-filled GO GOLD® event is the perfect way to get a school or workplace to come together in the fight to beat childhood cancer and provide hope to those who need it most. Some examples of GO GOLD® events include a high school sports team wearing gold gear; a restaurant hosting a GO GOLD® party that encourages patrons to come in on a specific night dressed in gold; jewelry stores devoting specific items to childhood cancer awareness, and even breweries committing to the fight with new golden lagers.

Founding Hope

ACCO recognizes that families whose lives had been impacted by childhood cancer often want to honor their child's legacy by helping people in similar situations. Traditionally, this resulted in many small childhood cancer charities being created in a child's name with the families forced to deal with the headache and hassles of the administrative responsibilities that accompany the formation and ongoing operation of their own non-profits. This is where our Founding Hope program has stepped in.

2021 saw 37 Founding Hopes across 23 states



The Founding Hope program empowers individuals to work under ACCO's Federal ID number in the process of establishing their very own local program. In addition to providing the charitable structure and recognized ACCO brand to assist with the individual's charitable goals, ACCO also provides a custom webpage, a user-friendly donation page, a peer-to-peer fundraising platform and a designated staff person to give direction and take care of the time-consuming administrative duties required by the IRS. Every chapter is unique; families are encouraged to name their own fund, develop strategic goals, and decide how to allocate donations. Creating a Founding Hope Fund enables individuals and childhood cancer families to stay focused on what is important to them, while leaving the time-consuming administrative details to ACCO!



RESOURCES



In the past 51 years ACCO has responded to over 500,000 requests for assistance. Tens of thousands of comprehensive books, play therapy kits, and much more are distributed without charge each year to children and their families.



Hero Beads®

With support of the Finn Family Foundation, the ACCO Hero Beads® Program is a resilience-based palliative care and quality of life program that combines art and medicine to help children and teens map out and cope with their childhood cancer treatment. Hero Beads® are designed to let children and teens with cancer commemorate their personal cancer journey. Every time that a child or teen has a procedure—whether a chemotherapy infusion, radiation therapy, a bone marrow aspirate, a blood transfusion, etc., a parent or a member from the medical team can give him or her a special bead to add to his or her string of beads. Each bead represents a specific treatment that the child received.

Medical Play Kit

This free resource is designed to familiarize children battling cancer with many of the medical instruments and procedures they will encounter during their hospital stays. It is our hope to empower children by helping them become more comfortable in a hospital environment and giving them the opportunity to play the role of doctor/caregiver rather than always being in the role of patient.

Kids can test out their Medical Play Kit supplies on Cozy the Port-a-Cat, the soft, snuggly stuffed animal that serves as both a teaching tool and a companion for children before, during, and after their cancer treatment. With Cozy as a guide, children can use their medical play kit to see where a particular procedure will take place, and he or she can even watch Cozy have the procedure first!

In 2021, ACCO
distributed over **16,000**
free resources to children
and their families!



Books for Kids

One of the most powerful fears is that of the unknown. ACCO develops books for cancer kids to help alleviate this fear. Balancing reassurance and comfort with realistic information, these books explain cancer and its treatments in language that kids can understand. In a time when everything feels different and wrong, these books normalize new experiences and help children make sense of things.



Books for Teens

A young child will have a different emotional journey with cancer than a teenager will. To respect this different developmental stage, ACCO develops resources targeted at teenagers and their unique experiences. One of our resources is a journal that allows teenagers to express themselves in their own words, taking charge of their cancer narrative.

Books for Parents

A childhood cancer diagnosis is confusing and alarming not just for children, but also for their parents. To help parents cope with this most harrowing ordeal, ACCO offers books covering medical terminology, symptom management, treatment options, clinical trials, and more. Written by experts in the field, and balanced with parents' personal experiences these books are designed specifically for parents.



Books for Siblings

A cancer diagnosis is a turbulent time for the whole family. Siblings may be just as scared and confused as the child who was diagnosed, and may feel ignored on top of that. ACCO offers *Oliver's Story*, a book for siblings of children with cancer that addresses this specific emotional impact.

Travel Bags & Support Gear

Since most childhood cancers are rare and not all facilities can provide treatments, the diagnosis often requires travel. To accommodate these unexpected trips, ACCO provides durable and practical travel bags for cancer families. These bags are vetted to provide everything a tired parent might find convenient: comfortable straps, waterproof interior, many pockets, and just the right size to carry on a plane. These bags and other helpful gear are provided to cancer families at no cost to them.



AWARENESS



Awareness is the cornerstone for all other childhood cancer related work. Awareness means sharing information and statistics as well as personal stories. Without awareness there is no urgency to take action through legislation, fundraising, and local support of children and hospitals. ACCO raises awareness through advocacy, corporate support, and community engagement utilizing our signature programs.

Awareness Tree

Since the year 2000, the ACCO Childhood Cancer Awareness Tree has recognized over 50,000 children.

In 2021, cognisant of the pandemic, ACCO allowed families to honor their cancer hero with a ribbon on a virtual tree. This proved to be not merely a convenience for the time, but a preferred system for many families! A physical ribbon is still mailed to every single family to be hung on their own trees at home, but our awareness tree has gone completely digital. This is not only safer, but allows all families to visit the virtual tree and see the pictures and posts left in honor or memory of the children.



Personalized September Shirts

This year, ACCO's awareness shirt tied into our advocacy campaign by asking the crucial question: what about kids? 2021's September awareness shirt was customizable, allowing loved ones to honor their child by name. This campaign sold over 2,532 shirts and brought in \$24,714 of revenue. The design is still available in our store.

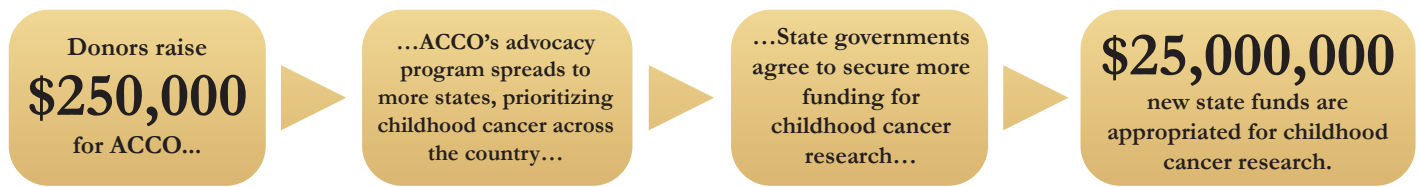


ADVOCACY



2021 has been an incredible year of milestones reached in our quest to change policy and support children fighting cancer. The American Childhood Cancer Organization (ACCO) is honored and proud to be leading the way as we work collaboratively to create transformational change taking place at the state, national, and international levels with greater awareness and policy change occurring in childhood cancer than ever before.

Through ACCO's What About Kids? advocacy initiative, donated funds can amplify by a *hundredfold*.



What About Kids?

In the past year, ACCO's leadership produced \$25,000,000 in new state appropriations, transforming childhood cancer research funding! ACCO has proven that states play a critical role in overcoming the national disparity between adult and childhood cancer research, treatment, and support. This has only been possible through our donor-funded What About Kids?[®] advocacy initiative.



As part of our What About Kids[®] program, our twice-monthly training has recruited more than 600 childhood cancer advocates across 48 states who have begun state-specific initiatives through ACCO-led targeted workgroups. ACCO's goal is to secure state-based childhood cancer research funding in 25 states by 2030. As a proud member of the World Health Organization's (WHO) Global Initiative for Childhood Cancer (GICC), ACCO's goal is in keeping with the WHO's Targeted Goal: To increase the global survival of childhood cancer to 60% by 2030, thereby saving an additional 1 million children's lives.

INTERNATIONAL



Nutrition and Social Work

Since 2017, ACCO has supported TAPCCO (Tesfa Addis Parents Childhood Cancer Organization) by providing in-hospital meals to children undergoing cancer treatment at Black Lion Hospital, Addis Ababa, Ethiopia. Malnutrition in children with cancer in LMICs can reach 50% to 70% and is associated with higher treatment toxicity and decreased survival.

Most treatment centers in Africa do not have cafeterias or kitchens so parents travel to markets to purchase food. Children with compromised immune systems from the treatment are exposed to germs and possible infections as they accompany their families to the marketplace. ACCO's financial support pays for food as well as a chef who uses a table-top burner to cook in the hospital for the children on the oncology ward. This allows children and parents to stay on the hospital ward, spend time together in the playroom, or rest during treatment while providing essential nutrition.

ACCO also funds the social worker and psychologist at Black Lion Hospital. Together they assist the patients with school lessons, play sessions, art therapy programs, and organize the follow-up treatment.

ACCESS

A major impediment to the effective care of children with cancer in low and middle-income countries (LMICs) is lack of access to essential medicines. Lack of robust context-specific data on the determinants of drug access in many LMICs hampers institutional and national efforts to reliably and efficiently procure childhood cancer drugs, and to ensure they reach the patients who need them. Our research project seeks to generate high-quality evidence of existing challenges and opportunities related to childhood cancer drug access in East Africa to inform national policies and catalyze regional solutions. We believe this initiative, the first of its kind, holds considerable potential for policy innovation in drug procurement, distribution and access in the East African region.



World Health Organization

ACCO developed the 3-year #nomore campaign messaging as well as all of the global campaign materials for International Childhood Cancer Day. In collaboration with the World Health Organization, our goal is to bring the global survival rate of childhood cancer up to 60% by 2030.



PARTNERSHIPS



Jel Sert

Since 2008, ACCO's key partner Jel Sert has played a vital role bringing happiness to children with cancer through the *Take A Pop, Share A Smile* program. Started in 2008 to help children across the U.S. cope with painful side effects of cancer and all that it brings to their lives, this program involves the donation of freezers and a continuous supply of Jel Sert's well-known freezer pops to more than 100 cancer treatment centers and Ronald McDonald Houses throughout the U.S.



La Roche-Posay

In 2019, ACCO partnered with LA ROCHE-POSAY US to launch a unique tool: an emotional communication kit, similar to the established pain scale. This emoji-based resource helps children identify and express their feelings.



Cancer is a life-changing diagnosis, and the emotions it produces can be complicated and difficult for children to express. ACCO is proud to offer this emotional communication kit where children can use emojis to let their caregivers know how they're feeling. Historically, when caregivers want to know how a sick child is feeling they ask, "How much does it hurt, on a scale from one to ten?" Currently, there is no standardized way to gauge their emotional state. This kit will allow kids to easily share how they're feeling emotionally throughout their treatment with their family, nurses, and doctors.

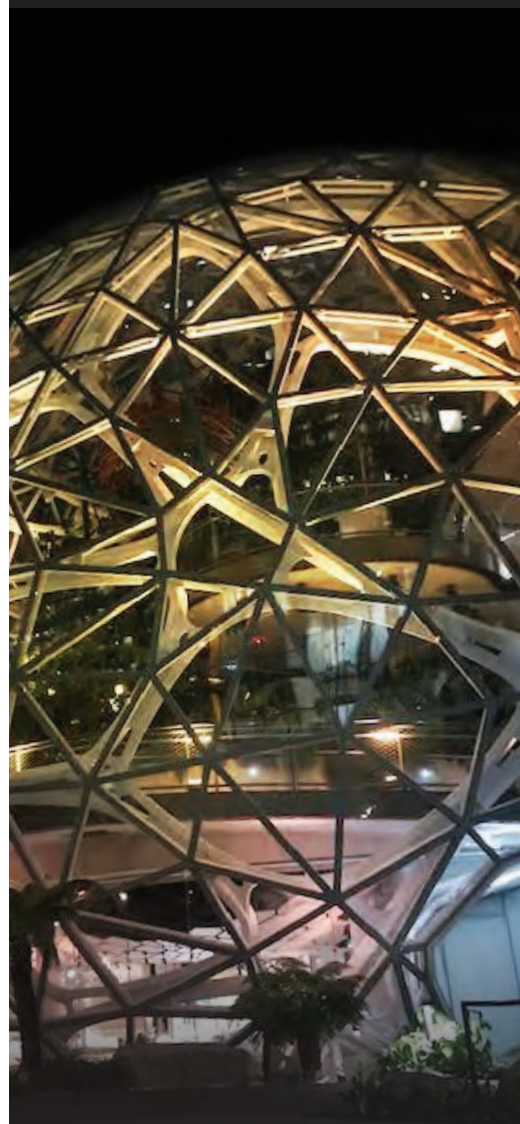
Amazon

For the fifth consecutive year, Amazon and ACCO teamed up to raise awareness for childhood cancer. In addition to hosting PJammin events with ACCO, shipping tens of millions of special packages emblazoned with gold ribbons, and expanding their childhood cancer engagement to fulfillment centers globally, Amazon increased their commitment to ACCO's What About Kids Advocacy initiative to expand funding for childhood cancer research at the state level.



Servier

The American Childhood Cancer Organization (ACCO) is grateful for the support from Servier Pharmaceuticals – a U.S. subsidiary of the Servier Group, an international pharmaceutical company that is governed by a non-profit foundation. Servier Pharmaceuticals' drug pipeline includes Oncaspar® (pegaspargase) – a chemotherapy drug essential to the successful treatment of pediatric acute lymphoblastic leukemia (ALL). ACCO greatly appreciates support from Servier to aid in the expansion of our What About Kids state-level advocacy program, our Global Nutrition Programs, and the reprint of our journals which provide essential educational programs and services that address the critical needs of children being treated for cancer.





Thank You

