2019 ANNUAL REPORT
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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.

*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.
Dear ACCO Supporter

2019 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 more than ever before. From the 2019 State of the Union to leading Amazon’s global childhood cancer initiative and fighting the recent drug shortage threatening kids’ life-saving treatment options - 2019 was quite the 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.
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.

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.
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 explain to children diagnosed with cancer and their families what they are going through, empowering them in the fight that lies ahead.

**Explain**

Nothing is scarier than being told that your child has cancer. Families are suddenly inundated with medical terminology, a life-threatening diagnosis, numerous medical professionals and then are asked to make crucial treatment decisions that will drastically impact their child's life and future. ACCO empowers children with cancer and their 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. This facilitates the critical decisions required to fight this life-threatening disease.

**Inform**

The impact of having a child diagnosed with cancer is deeply felt by the entire family. ACCO understands the impact childhood cancer has on the patient, siblings and parents, and we are dedicated to providing services and support to help families understand that they are not alone. 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.

**Support**

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. Since 1970, ACCO has devoted our attention to advocate for increased government funding for research programs dedicated to eradicating all forms of childhood cancers, with treatments designed for the small, delicate bodies of our children.
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 soccer team raising money at a home game with players wearing gold t-shirts, college basketball teams wearing gold socks and shoelaces; 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.

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

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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.

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!
In the past 50 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.

**Emotional Communication Kit**

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.

**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!

**Approximately 17,000 of ACCO's free resources were received by children and their families in 2019 alone!**
Awareness is the cornerstone, or foundation, for all other childhood cancer related work. Awareness means sharing information on statistics but also sharing personal stories. Without awareness there is no urgency to take action via advocacy, fundraising, and local support of children/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 2019, thousands of gold ribbons cover the tree located in Newport Beach, California, each placed in honor or in memory of a child with cancer.

### Light It Up Gold
In 1998, ACCO launched the first gold ribbon awareness campaign through the production of gold ribbon lapel pins. Since then, ACCO has been a founder and global leader in raising awareness during September Childhood Cancer Awareness Month. Together with our followers and Founding Hope chapters we, "Light Up Gold" in recognition of childhood cancer awareness. Throughout the world monuments, government buildings, bridges and skylines light up gold to show solidarity for children facing a childhood cancer diagnosis.

### The Color Run
For nearly ten years, The Color Run has hosted more than 7 million Color Runners at 1,000 events in 40+ countries and is now the single largest event series in the world. In 2019, The Color Run decided to do even more to make sure its events leave a positive impact. On a national level, The Color Run partnered with ACCO at events across the country to raise awareness for children fighting cancer. Recognizing kids can’t fight cancer alone, The Color Run + ACCO invited diagnosed children on stage during events for runners to cheer them on in their fight against cancer.

### Awareness Shirt
Through the sale of t-shirts, hats, and other awareness items in partnership with Custom Ink, approximately $13,000 was collected to further ACCO’s mission of helping kids fight cancer and supporting them throughout their journey. Donors were able to select either a gold ribbon in honor of their childhood cancer warrior, or a gold ribbon with wings in memory of their precious child.
2019 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.

State of the Union
American Childhood Cancer Organization’s (ACCO) Gold Ribbon Hero and Amazon + ACCO’s 2018 Ambassador Grace Eline attended the State of the Union at the U.S. Capitol on February 5, 2019 as a guest of the White House. Her attendance and recognition demonstrates the growing awareness of childhood cancer as a child health priority in the U.S. and around the world.

WHY NOT KIDS
ACCO is the only national childhood cancer organization collaborating with the National Governors Association and Council on State Governments to make childhood cancer a priority in every state across the country through state cancer action plans and state-level legislation. ACCO is also leading a national workgroup through the Alliance for Childhood Cancer to organize efforts among the 30+ national organizations in the coalition to share model legislation towards synchronized efforts and eliminating silos for more impactful and efficient change to overcome the national disparity between adult and childhood cancer research, treatment, and support programs.

Advocates from around the country took action using ACCO’s Voter Voice Platform on state proclamations and drug shortages, providing support for full funding of $30 million for the Childhood Cancer STAR Act and a historical new $500 million for the Childhood Cancer Data Initiative.
Childhood Cancer International

ACCO is uniquely positioned as the only U.S. member of Childhood Cancer International (CCI). Childhood Cancer International was founded by ACCO and 4 other international childhood cancer parent-led organizations in 1994 as a global umbrella organization of childhood cancer grassroots and national parent organizations. Today, under the leadership of ACCO’s CEO, CCI is the largest patient support organization for childhood cancer globally, representing 167 parent organizations, childhood cancer survivor associations, childhood cancer support groups, and cancer societies in 90 countries across 5 continents. It was through ACCO’s CEO that CCI successfully submitted an application to the World Health Organization (WHO) and was recognized in January 2018 as being in official relations with the WHO.

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.
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.

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 appreciates the support from Servier to aid in the expansion of our Why Not Kids state-level advocacy program, our Founding Hopes, Global Nutrition Programs and provide resources to execute essential programs and services that address the critical needs of children being treated for cancer.

Matilda Jane

For the second year, Matilda Jane Clothing line launched a GO GOLD® Matilda Jane Platinum dress celebrating the bravery of little girls battling cancer and their desire to express their girly-ness, even after losing their hair. The Bennett dress, designed by two cancer moms, features gold fabric and glitter, representing the international symbol for childhood cancer, the gold ribbon. Once released, this dress sold out in an astounding five minutes and Matilda Jane generously donated a portion of the proceeds to ACCO.
Amazon

For the third 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 is now partnering with ACCO on federal and state public policy issues.

For the first time, Amazon joined ACCO on Capitol Hill alongside 7-time childhood cancer survivor Patrick McSweeney and State of the Union guest Grace Eline to attend the annual Childhood Cancer Caucus Summit hosted by Texas Congressman and House Foreign Relations Chair Michael McCaul.

Special Thanks to Our 2019 Partners

... and many more!
Thank You