



AMERICAN  
**childhood**  
CANCER ORGANIZATION

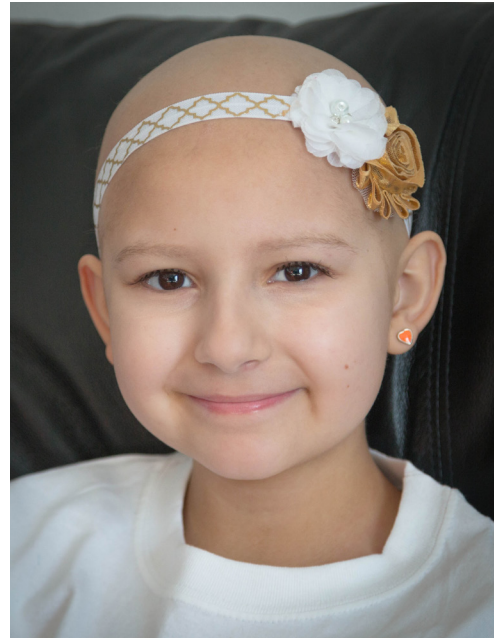
Annual Report

2014-2015



# WHAT IS OUR MISSION?

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 globally. Together with our ever-expanding network of support programs across the country, we provide essential programs and services to address the critical needs that families encounter every day as they make treatment decisions for their critically ill children.



## WHAT Do We Do?

### Keep Families Informed

Nothing is scarier than sitting in a doctor's office and being told that your child has cancer. You 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 your child's life and future. The ACCO empowers children with cancer and their families to make those informed decisions by providing them with comprehensive informational resources about the childhood cancer diagnosis, treatment procedures, medications and clinical trials—in simple, easy-to-comprehend terminology—in order to facilitate the critical decisions required to fight this life-threatening disease.



### Help Kids Understand

Cancer's littlest patients are often too young to understand what is happening to them: why they feel sick, why they must spend so much time in the hospital, why they must take so much medicine and undergo so many scary and sometimes painful medical procedures. Through ACCO's Comfort Kit, Medical Play Kit, journals, illustrated treatment books, and other resources that we develop and provide without cost just for children with cancer, we help them understand what they are going through, empowering them in the fight that lies ahead.





# Support Families

The impact of having a child diagnosed with cancer is deeply felt by the entire family. The diagnosis of a child with cancer often comes at a time when the family is young and has a limited income. Often there are other small children to care for, and one parent has to stop working to care for their sick child. ACCO understands the impact childhood cancer has on the entire family, and we are dedicated to providing services and support, to help families understand that they are not alone. Through our national onile 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 cancer survival rate. **Financial assistance**

**not only assists the family during this difficult time, it also improves the probability of a cure for the child.**



## Advocate for Childhood Cancer

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. At the ACCO, we continue to build on our strong advocacy heritage. Since 1970, the 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.



# Raise Awareness

ACCO is constantly working on new, innovative ways to raise awareness about pediatric cancer and spreading the message about the dire need to increase funding for childhood cancer research. Many of our awareness initiatives utilize digital technology and social media to encourage constituent and community participation.

## ACCO's Signature Awareness Events Include:

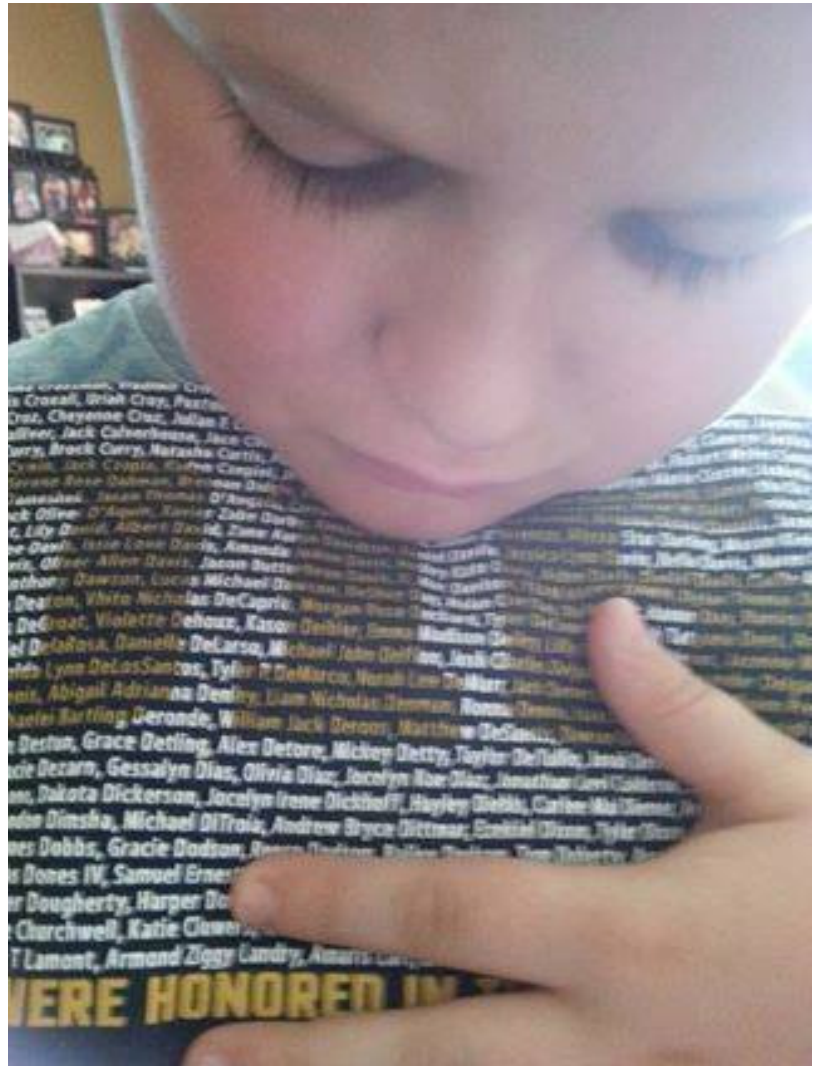
- "Go Gold®": Gold Ribbon Awareness
- National Childhood Cancer Awareness Tree each December Holiday Season
- ACCO Awareness T-Shirts
- September Childhood Cancer Awareness Month
- PJammin for Kids with Cancer®
- Pedi-CURE
- Light Up The World Gold (Illuminate Gold)

Approximately 20 years ago, when ACCO was known under its former name, the Candlelighters Childhood Cancer Foundation (CCCCF), the gold ribbon was chosen to serve as the universal symbol for Childhood Cancer Awareness by CCCC board member Gigi Thorsen and a group of parents whose lives had been affected by childhood cancer.

Although many colors were considered, gold was agreed upon as the ideal choice for childhood cancer awareness because gold is a precious metal, and is therefore the perfect color to reflect the most precious thing in our lives—our children.

The CCCC funded production of the first gold ribbons in 1997 (in the form of lapel pins), and thanks to the dedication and commitment of this group of parents during the early years of our organization, the gold ribbon has now become an internationally-recognized symbol for childhood cancer awareness.

Today, the ACCO continues to utilize the emblematic power of the gold ribbon to build momentum for our campaigns, allowing individuals from all over the world to unite in solidarity behind this unifying symbol and to join in the ongoing fight for the eradication of all forms of childhood cancer. Through ACCO's awareness signature programs, awareness is raised that children get cancer too and that they have unique cancer types, treatment needs and increased research leading to cures for all children diagnosed with cancer.



...because kids can't fight cancer alone!®



# WHAT DID WE ACCOMPLISH?

This past fiscal year, ACCO's library of free learning resources continued to grow! We delivered more than 40,000 individual items free of charge across the US. We are especially excited about the introduction of ACCO's Medical Play Therapy Kit—a learning tool designed to familiarize children with the medical devices used during their cancer treatments. In the words of one parent, "My little Gabriel received his medical play kit yesterday! He loves it! What a brilliant idea to give our cancer kids back a sense of control, when there is so much they can't control through treatment." Another parent wrote to say, "For a patient like Liam, one of his biggest obstacles has always been overcoming the fear of his port being accessed. Thanks to your play kit Liam is finding fun and new ways of exploring the entire process of port activation. Thank you ACCO for our play kit." We could ask for no better evidence of the importance of our organization than these powerful testimonials.



Awareness is building across the nation, and the world! The world sparkled with gold lights illuminating countless buildings and historic monuments during Childhood Cancer Awareness Month including more than 100 government buildings, bridges and fountains across the United States.

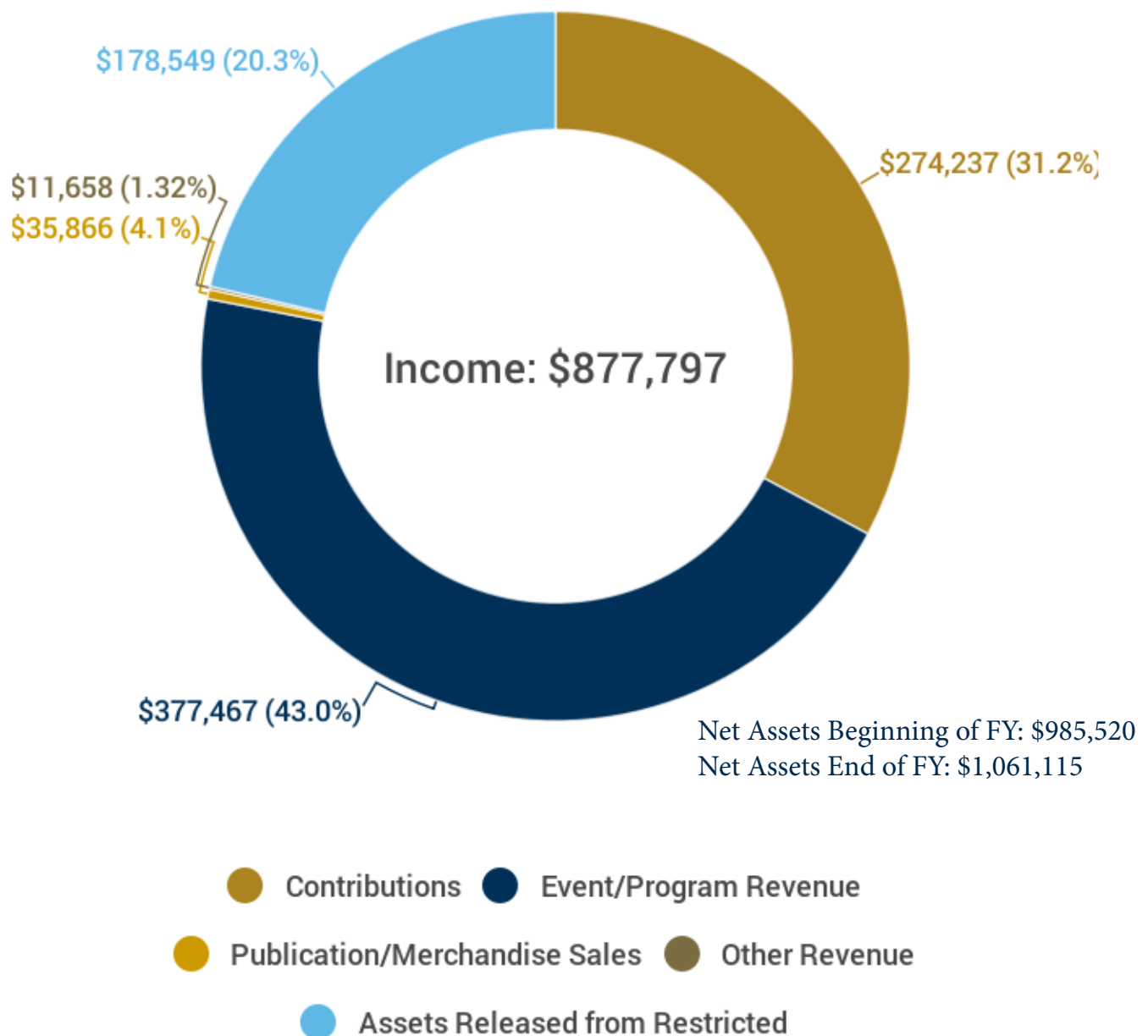
Our 2015 Go Gold for Kids with Cancer® t-shirt campaigns raised more awareness than we could have ever imagined, with more than 12,012 shirts, honoring the names of 4,892 children who have suffered from childhood cancer, proudly bringing awareness of childhood cancer right into the heart of your local communities. Our new website gives families even easier access to our amazing wealth of learning resources, insightful blogs, and online support community, and **through social media we connect more than 75,000 individual family members, survivors, and supporters with our ever-expanding ACCO family.**

Our voice is spreading! In the US, ACCO participated in the writing of the Childhood Cancer STAR Act (Survivorship, Treatment Access & Research), which brings hope to tens of thousands of children on active treatment and to the hundreds of thousands of survivors through increased government appropriations. And our efforts do not end at our borders. Cancer remains the leading non-communicable disease-related cause of death of children in the world, primarily due to lack of access to quality healthcare and effective treatment options. **Our Executive Director was proud to have served on the planning committee of the 68th World Health Assembly's first side-event on childhood cancer, along with ACCO Board Member Dr. Greg Aune as invited speaker.** This past year, ACCO's Executive Director was invited to be a member of the World Health Organization's (WHO) Childhood Cancer Task Force where she will continue to represent the U.S. in global childhood cancer advocacy initiatives.

ACCO's programs and services grew during our 2014-2015 fiscal year to the point where we have outgrown our current rental location. We will be moving to a larger facility which will allow us to more efficiently house and ship our resources across the country. Our mission won't end until these learning resources and support are no longer needed. Only through the generosity of our donors can we continue to impact the lives of cancer's littlest patients, to raise awareness about childhood cancer and to provide national and international advocacy, support, and essential learning resources to children and their families.

# WHERE DO DONATIONS GO?

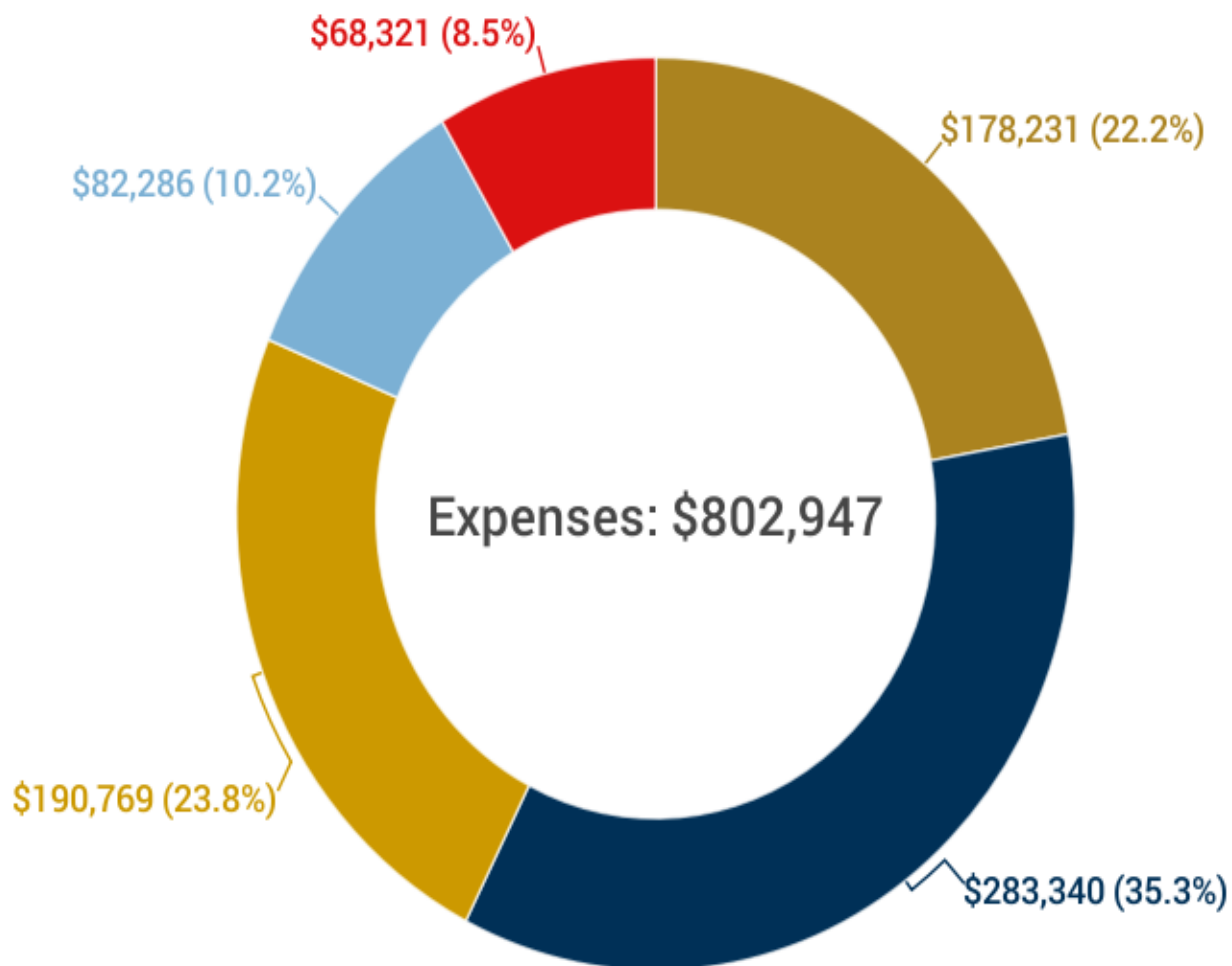
## 2014 - 2015 Fiscal Year Income Breakdown



# WHERE DO DONATIONS GO?

## 2014 - 2015 Fiscal Year Expense Breakdown

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# ACCO's LEADERSHIP

Our organization was founded in 1970 by a talented and committed group of parents of children with cancer, and we have placed a priority on ensuring that those making leadership decisions for our organization today understand what a family goes through when their child has been diagnosed with cancer. Over two-thirds of our organization's Board of Directors are either survivors or a direct family member of a child or adolescent who had cancer. We understand personally that this is a family disease and it is a disease that impacts the family for life. The board and staff of ACCO are committed to serving our community until the day no child dies, or is left with life-long effects from this devastating disease.

## Board Of Directors

### **Janine Lynne, President**

Janine has been a board member of ACCO since 2003. Her teenage son is a survivor of acute lymphoblastic leukemia. Janine has worked and volunteered as a child advocate in many capacities over 20 years with a special interest in children with special needs. She has a B.S. in Child Development and Family Studies from Montana State University, and pursued graduate work in psychology and education. She currently lives in Hawaii.

### **Ken Phillips, Treasurer**

Ken is a retired Air Force Officer of 23 years and following that retired from Computer Sciences Corporation after an additional 20 years of service. He holds a Bachelor of Science degree in Mathematics from the University of Massachusetts at Amherst, MA. Ken has been on the Board of Directors of CCCF since 1994, and has held the office of Treasurer since 1995. Ken and Marie are bereaved grandparents. Their precious granddaughter died from acute myelogenous leukemia.

### **Jennifer Cullen Meyer, PhD, MPH, Secretary**

Jennie earned her doctorate in Epidemiology from UC Berkeley in 2000, with emphasis in cancer risk assessment and bio-statistics. Her professional positions have included her current role as Director of Epidemiologic Research for the Department of Defense Center of Excellence, the Center for Prostate Disease Research (CPDR); Director of Research at the American Legacy Foundation; and a faculty appointment in Georgetown University's Lombardi Comprehensive Cancer Center. She is a co-author on roughly 40 peer-reviewed scientific publications. In March 2011, Jennie and her husband Reggie learned that their daughter, Alexandra, had an aggressive pediatric brain tumor, known as a medulloblastoma. For 13 months, Alexandra fought bravely undergoing surgery, chemotherapy, and radiation to her head and spine. On New Year's Day 2012, Alexandra completed her treatments and the future seemed bright. Sadly, only two months later, nearly one year after the cancer diagnosis, a follow-up MRI revealed new tumor growth. Little Alexandra passed peacefully on April 6, 2012 in her home.

### **Judy Mendoza, Member**

Judy Mezoa Mendoza grew up in Lafayette, IN, where she obtained a Bachelor's Degree in Education from Indiana University in May 1993. Subsequent teaching jobs led her to the corporate world of an education publishing company and then to the formation of her own free-lance education business. In February 2007, Judy and her husband Michael's lives changed forever. It was then when they learned that their three-and-a-half year old daughter had Stage IV neuroblastoma. After supporting her daughter Abigail through six cycles of high dose chemotherapy, followed by a stem cell transplant, twelve radiation sessions, and a very rough clinical trial with monoclonal antibodies, Judy now regards herself as a proud Cancer Mom on a Mission. Judy lives by the premise that she continues to teach her children to never give up! Judy is active in raising awareness of the gold ribbon for childhood cancer.



# ACCO's LEADERSHIP

## **Steve Payne, Member**

Steve is an active board member and father to Kristin, a stage IV neuroblastoma survivor diagnosed at a mere seven months old. Being an active part of the ACCO board, he is able to support those children, families, and professionals nationwide who battle this dreaded disease until a cure is found. Steve works for IBM and served as ACCO Board President 2003 & 2004.

## **Jeff Walters, Member**

Jeff is a Senior Director in the Commercial & Consumer Products division of Acumen Solutions where he is responsible for the delivery of business and technology consulting services to the Educational Services and Non-Profit Sectors. In his professional career, Jeff helps organizations to maximize their efficiency and impact and he brings that same passion to his work with ACCO. Jeff holds a Masters of Business Administration from the Lally School of Management and Technology at Rensselaer Polytechnic Institute and a Bachelor of Science in Aerospace Engineering from Pennsylvania State University. Jeff and his wife Valeria live in Chantilly, Virginia with their two daughters.

## **Dr. Greg Aune, MD, PHD, Member**

Dr. Greg Aune's interest in pediatric oncology began at age 16 when he was diagnosed with Hodgkin's lymphoma. The experiences he encountered as a patient initiated a path towards a research and clinical career aimed at developing less toxic chemotherapy regimens. His experience as a long-term survivor included open-heart surgery at age 35 to replace his aortic valve and triple bypass due to damage caused by his teenage cancer therapies. Dr. Aune directs the Greehey Children's Cancer Research Institute Shared Resource for Cardiac Function Assessment. He is also Director of Survivorship Research for the South Texas Pediatric Cancer Survivorship program at University Hospital and appointed to the National Cancer Institute Community Cardiotoxicity Task Force, the Children's Oncology Cardiometabolic Task Force and the National Cancer Institute Council of Research Advocates (NCRA).

## **Clint Janson, Member**

Clint is a Principal at Mojo Lab LLC an advertising agency and production house in Spokane, WA. He first became interested in cancer fundraising and charity work when inspired by his brother-in-law, Michael Moyles, a three time brain cancer survivor. Together Michael and Clint started Team Michael Moyles, a cancer charity fundraising team in 2010. In 2012 Michael and Clint participated in a 5k run that was lead off by dozens of pedicabs carrying local children who were battling cancer. Clint was so moved and inspired by those brave kids that he decided he needed to do more. Soon after returning to Spokane, he created HOPE Run Spokane. He was introduced to Ruth Hoffman in February of 2015 and is proud of the collaboration between ACCO and Mojo Lab and also honored to now be a member of the ACCO board.

## **Ken Wegner, Member**

Ken Wegner is President of the Jel Sert Company and father of a childhood cancer survivor. A graduate of Denison University in Granville, Ohio, Mr. Wegner has a long and noted history of charitable and philanthropic endeavors, including serving as Chairman of the Elmhurst Memorial Hospital Foundation Board, a board member at the Max McGraw Wildlife Foundation, and membership in WPO – Chicago. Mr. Wegner's partnership with ACCO began in 2008 with the introduction of the gold ribbon awareness symbol for childhood cancer on their Fla-Vor-Ice freezer pops product, as well as the founding of Jel Sert's Take a Pop, Share a Smile program. Recognizing that freezer pops play a critical role in easing the pain of mouth sores, keeping children hydrated, and alleviating many other negative side effects of cancer treatment, Jel Sert generously donates freezers and a continuous supply of freezer pops to children's cancer treatment centers across the United States. Jel Sert's ongoing partnership with the ACCO and support of the ACCO's mission to raise awareness about this disease became personal for Mr. Wegner when his teenage son was diagnosed with cancer in 2011.

...because kids can't fight cancer alone!<sup>®</sup>

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