

children's cancer fund

## HOPE & HEROES

children's cancer fund



contact@hopeandheroes.org www.hopeandheroes.org



2010





We are pleased to present our Annual Report for the fiscal year ending June 30, 2010.

The Hope & Heroes Children's Cancer Fund is a charity dedicated to helping children with cancer and their families. The Fund supports the Herbert Irving Child & Adolescent Oncology Center, the academic division of pediatric oncology at Columbia University Medical Center and NewYork-Presbyterian Morgan Stanley Children's Hospital. With philanthropy, the division is empowered to offer its patients with cancer and serious blood disorders prestigious clinical care, cutting edge research initiatives and innovative supporting programs to guide them through the labyrinth that is childhood cancer.

For the past 40 years, childhood cancer researchers and physicians have worked cooperatively at institutions throughout North America, setting up clinical trials, and collectively studying the results. During that time, the childhood cure rate has risen from almost zero to well over 75% for children with cancer.

But despite this medical miracle, childhood cancer has stubbornly remained the #1 disease killer of children in the United States - a sobering and alarming fact. As parents, donors, friends, doctors, family and concerned citizens, our mission is clear and urgent: to change the landscape of medicine by supporting our physicians, our scientists, clinicians, and young investigators in their service to finding a cure. And as there is almost nothing more heart wrenching than a pediatric cancer diagnosis, our aim is to provide our families with the best care possible.

Within this year's annual report, you will see people changing lives - their own, ours and those of hundreds of children and families. From the Jay and Corbett families of Staten Island hosting an annual community family fundraiser; to the Financial Communication Society's annual ski race in Stowe, Vermont; to the Prince family's commitment to long term research initiatives; to the family of Jamie Deutsch, funding experimental treatments in her memory; and to the hope and promise of Avery Hoffman, who after surviving cancer, now dedicates himself to raising awareness and funds for Hope & Heroes.

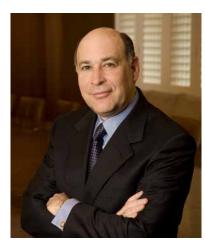
It is our desire to touch the lives of these children and their families by offering them hope for today and hope for the future. We pledge to never forget the daily battle they must face and we are dedicated to give them the emotional and financial support that they need to face the challenges ahead. From all of us at Hope & Heroes – the exceptional medical staff, our volunteers, corporate partners and dedicated donors: we are continually encouraged by your dedication to our mission. On behalf of our young patients and the staff that serves them, thank you for making a difference in their lives and ours.

Sincerely,



Rob Kapito

Board President Hope & Heroes Children's Cancer Fund





## **OUR MISSION**

The Hope & Heroes Children's Cancer Fund supports the medical treatment of children with cancer and their families. Our sole beneficiary is the Herbert Irving Child & Adolescent Oncology Center (HICAOC) at Columbia University Medical Center. Philanthropy allows HICAOC to provide exemplary patient care and specialized programs to assist our patients and their families through the cancer journey. Our young patients have free access to complementary and alternative medicine (massage, acupuncture, aromatherapy, etc.), counseling and emotional support, novel drugs through clinical trials for hard to treat pediatric cancers and survivorship wellness initiatives. These programs cannot exist without public and private support.

## **OUR BENEFICIARY**

The Herbert Irving Child & Adolescent Oncology Center (HICAOC) is one of the largest and most distinguished pediatric oncology programs in the United States. Our division is in the Department of Pediatrics at Columbia University Medical Center (CUMC) and is located at NewYork-Presbyterian Morgan Stanley Children's Hospital.

The professional staff of the HICAOC provides care to children and adolescents not only throughout the New York tri-state area, but also serves as a referral center for patients across the country and abroad. The division is comprised of health care professionals including: physicians, basic scientists, fellows, behavioral psychologists, complementary and alternative medicine (CAM) practitioners, nurse practitioners, clinical nurse specialists, research nurses, social workers, child-life specialists, and administrative personnel. Together as a team, they provide world-class clinical care and conduct the research that one day may help prevent and eradicate these dreaded diseases.

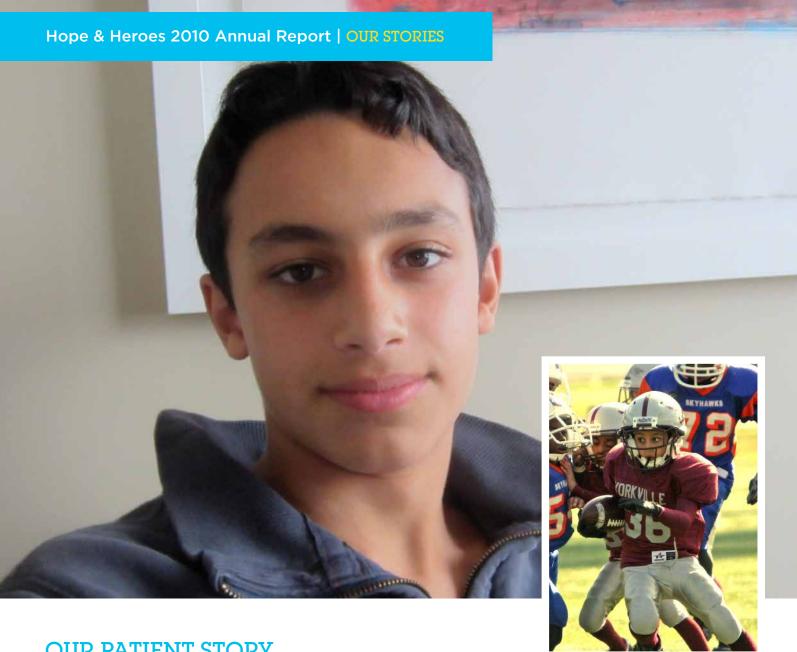
At the Center, 125-150 newly diagnosed patients are treated each year and the division follows over 1,000 patients. This leads to over 6,000 outpatient visits per year. Forty percent of our patient population resides in Washington Heights, Harlem and the South Bronx, home to the largest Dominican, Hispanic and African American populations in New York. Our division treats all patients regardless of their financial situation and, as a community program, we reflect the needs and health of the population we serve. Providing care at the level of excellence we are known for is dependent upon a collaborative partnership with our philanthropic community.





## YOUR PHILANTHROPIC SUPPORT

The organization's base of support includes patient families and friends, a dedicated Board of Directors, community organizations, private and public foundations and concerned individuals. Together, with fundraising initiatives both big and small, the fund has created a diverse philanthropic community. These efforts and our donors' contributions are a critical component in providing the clinical care, innovative supporting programs and the world-renowned research that has attracted the recognition of both national and international oncology circles.



## **OUR PATIENT STORY**

#### **AVERY HOFFMAN**

**Long-term Survivor** Youth Chair, Hope & Heroes Walk 2012

When Avery Hoffman completed his treatment for Burkitt's lymphoma, he decided to take the opportunity to teach his fourth grade class about his disease. "I missed most of my science lessons while I was having chemotherapy, so to make up for that, I put together a Powerpoint presentation about my specific type of cancer and what had been going on in my body," says Avery. Avery's illness came on suddenly, right before his 10th birthday. "One day he was playing tennis and running around like usual and the next day he woke up with excruciating abdominal pain," recalls his father, Steven. "I'd never seen him in pain like that." When they arrived at the emergency room at New-York Presbyterian Hospital, they learned that Avery's appendix had burst, requiring emergency surgery—but that wasn't the end of it. A biopsy of his appendix after the operation revealed cancer cells, which had most likely caused the rupture. Avery was diagnosed with Stage 2 Burkitt's lymphoma, a very aggressive form of non-Hodgkin's lymphoma. Several months of intensive chemotherapy followed. In a show of support and solidarity, several of Avery's classmates shaved their heads during his treatment.

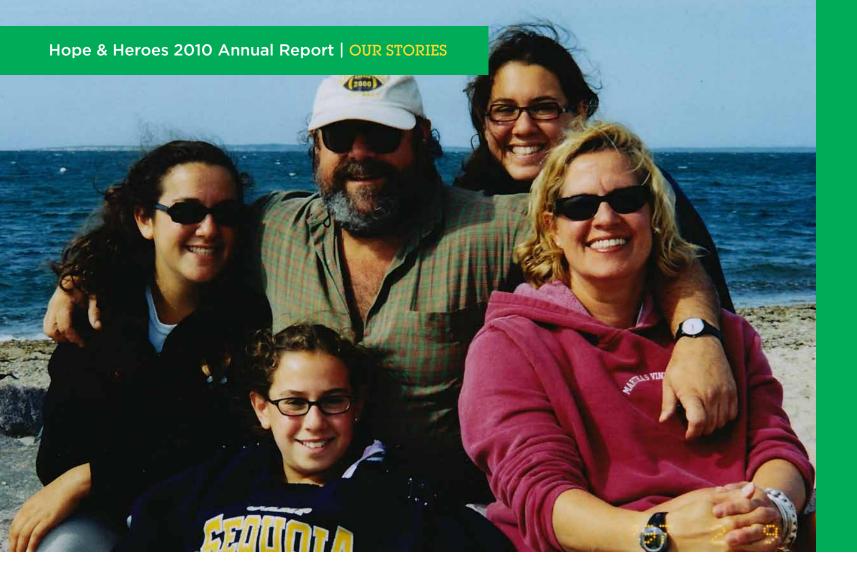
IF CHILDREN HAVE THE ABILITY TO IGNORE ALL ODDS AND PERCENTAGES, THEN MAYBE WE CAN ALL LEARN FROM THEM. WHEN YOU THINK ABOUT IT, WHAT OTHER CHOICE IS THERE BUT TO HOPE? WE HAVE TWO OPTIONS, MEDICALLY AND EMOTIONALLY: GIVE UP, OR FIGHT LIKE HELL.

Lance Armstrong

Though Steven plainly calls his son's cancer "a horrifying and terrible experience" for their whole family--which includes mom Abigail and sisters Talia and Phoebe--he feels incredibly glad that they chose The Herbert Irving Child & Adolescent Oncology Center for his care. "We immediately got the sense that this hospital was very attuned to the particular needs of each patient and open-minded about tailoring the treatment accordingly." Dr. Kara Kelly, who treated Avery, made some changes to the standard chemotherapy protocol to account for his slender frame and to accommodate the fact that he was also healing from the appendectomy. Shortly after finishing treatment, Avery was declared cancer-free and is now considered 99.9 percent cured. But his desire to educate others—especially his peers—about cancer continues to grow. Avery has spoken about his experiences at Hope & Heroes events and helped raise over \$20,000 during the charity's recent walk. He has also been designated as the Youth Chair of the 2012 Walk, which means he'll be responsible for recruiting and communicating with the other kids who will be walking and fundraising for childhood cancer. (Both of Avery's parents sit on the Hope & Heroes board of directors as well.)

No matter what form his activism takes, Avery's message is clear: "As much as having cancer was a bad experience, it made me look at life in a different way. I always thought kids who got cancer were different from me, but cancer can happen to anyone. Now I pay more attention to my health and I am grateful every day for my life."

PHOTO: Avery today and playing football



IN THE COLD YOU WRAP ME.
IN MY UNCERTAINTY YOU LISTEN.
IN ALL MY JOYS YOU CELEBRATE.
AT EVERY TURN YOU MEET ME WITH
COMPETENCE AND GRACE.
WHAT A FINE DANCE WE HAVE
TOGETHER.

- Mary Anne Radmacher



#### JULIA GLADE BENDER, MD AND THE JAMIE DEUTSCH FOUNDATION

#### A doctor, a patient and her loving family

The relationship between the Deutsch family and oncologist Dr. Julia Glade Bender has always been unique. "I could call Dr. Glade Bender any time of the day or night when she was treating my daughter," recalls Robin Deutsch, whose daughter, Jamie, passed away in 2006 at age 18, six weeks into her freshman year at college. "It wasn't a typical doctor-patient relationship."

Two years earlier, Jamie had returned from a trip to Thailand looking weak and unwell. The next day she was diagnosed with Ewing's sarcoma, a rare cancer of the bones and soft tissue; it had already metastasized to her bones, lungs, and around her heart. Jamie was treated at another medical center with several rounds of chemotherapy and radiation, but after that, doctors told the family there was nothing more they could do. "We were not ready to give up," says Robin, who was then referred by a family friend to Dr. Glade Bender, who runs the Developmental Therapeutics program at The Herbert Irving Child & Adolescent Oncology Center. It is one of only 20 programs in the country to have been awarded a Phase I contract by The National Cancer Institute—a designation that allows patients to receive the newest, most cutting-edge treatments. "Dr. Glade Bender put Jamie on a new kind of chemo, which worked so well that it allowed her to finish her senior year and graduate from high school," says Robin.

Though losing Jamie was devastating, the Deutsch family found some comfort and meaning when they started The Jamie Deutsch Foundation, which has become a major supporter of Dr. Glade Bender and her team, whose research focuses on Ewing's sarcoma, among other types of cancers.

"Every year we go up to Columbia and meet with Julia's team on the same floor where Jamie was treated," explains Robin. "We present them with a gift and they come equipped with slides and data and share the work they're doing. They talk about molecules and cells, but we've learned to dance between their polysyllabic words and understand most of what they're saying!"

Dr. Glade Bender also finds it rewarding to maintain such a wonderful connection with Jamie's family. "Jamie was a very special kid," she says. "She never participated in a clinical trial, but she was one of my first patients to receive what was then a new form of chemotherapy. It is now accepted as one of the best treatments for refractory Ewing's sarcoma."

While a cure for the disease remains elusive, the Deutsches and Dr. Glade Bender are inspired by all the strides that have been made since Jamie's death. "We still don't talk about a cure in patients with a similar disease profile to Jamie, "says Dr. Glade Bender. "But we are able to control the disease better and preserve quality of life and that feels very empowering."





COURAGE DOESN'T ALWAYS ROAR.
SOMETIMES COURAGE IS THE
QUIET VOICE AT THE END OF THE
DAY SAYING, "I WILL TRY AGAIN
TOMORROW."

- Mary Anne Radmacher

## **OUR COMMUNITY PARTNER**

#### FCS RACE FOR KIDS

The Financial Communications Society
Tim Hart, Bob McCourt, Kevin Windorf, Ahmed Yearwood

For four days each winter, professionals from the financial, marketing, advertising and media industries converge at Stowe Mountain Resort in Stowe, Vermont, and shift their focus from business-as-usual to the business of raising funds to cure childhood cancers.

The event, called the FCS Race for Kids, is sponsored by The Financial Communications Society (FCS), a longstanding not-for-profit networking organization of financial services marketing professionals. The three men at the helm are Kevin Windorf, NBC executive and FCS president, and co-chairs Tim Hart, a VP at The Financial Times, and Ahmed Yearwood, owner of Y Interact, a multimedia design studio. Their passion for the cause is demonstrated by the amount of time they devote to it, given their already-hectic work schedules and family lives. "We are just so thrilled to be part of an organization that benefits a charity as important as Hope & Heroes," says Hart. Their efforts have paid off, too; in 2011, the Race for Kids raised \$50,000 for Hope & Heroes, bringing their contribution to over \$300,000. The fundraiser benefits two other charities as well—The Downey Side, an adoption agency that specializes in placing older children, and The Make-A-Wish Foundation of Vermont, which grants the wishes of children fighting life-threatening illnesses.

The FCS Race for Kids annual check presentation, May 2011. PHOTO (From left to right): Ahmed Yearwood, Heather Maloney &, Jeremy Shatan (Hope & Heroes), Jim Davis (Make A Wish Vermont), Brother Terry Taffe & Father Paul Engel (the Downey Side) Michael Colburn (Stowe Mountain Resort), Tim Hart, Kevin Windorf

The original inspiration for the event came in 1999 from Hope & Heroes board member Robert McCourt and Stuart Arnold. They worked together on projects together while employed by AIG and The Financial Times respectively. But they had more than that in common; both men had also recently been through some difficult experiences involving their children. Arnold's teenage son had been tragically killed in a boating accident, and McCourt's son was battling fibromatosis, a rare form of invasive tumor. "Stu and I decided we needed to do something to help children," explains McCourt, whose son, Peter, was being treated at Columbia at the time. (Peter is now 27 years old and has been in remission for 10 years). "I was looking to replace a previous fundraising event at Stowe called the Olympic Ski Challenge and AIG Chairman Hank Greenberg agreed to a new concept, which is how the Race for Kids was born." In time, the FCS took over the event, which has grown significantly over the past five years.

The long weekend takes place every first weekend in January, kicking off with a cocktail reception on Thursday evening. The race itself is on Saturday morning and requires participants to take two runs on skis or a snowboard. Coaching from Olympic Freestyle Skiing Gold Medalist Donna Weinbrecht and Olympic Downhill Skiing Bronze Medalist Doug Lewis has probably improved some race times! Panel discussions called "Fireside Forums" are peppered throughout the weekend, giving members a chance to network and give presentations on topics relevant to the industry. There are also off-slope winter activities offered for the children and family members of participants.

Thanks to the year long efforts of Windorf, Hart and Yearwood, along with Bob McCourt's continued involvement, it's clear the endeavor has been a win-win for all involved—past, present and future.

Join us at the next FCS Race For Kids, January 5-8, 2012, Stowe Mountain Resort, Stowe, Vermont www.fcsraceforkids.org



I HAVE HEARD THERE ARE TROUBLES OF MORE THAN ONE KIND.

SOME COME FROM AHEAD AND SOME COME FROM BEHIND.

BUT I'VE BOUGHT A BIG BAT. I'M ALL READY YOU SEE.

NOW MY TROUBLES ARE GOING TO HAVE TROUBLES WITH ME!

- Dr. Seuss

## **OUR HOPE-RAISERS**

#### THE CORBETT FAMILY & THE JAY FAMILY

Tommy Corbett & Jeffrey Jay, Long-term Survivors Kim Corbett & Deborah Jay, Mothers and Fundraisers

When Kim and Tom Corbett learned that their 3-year-old son, Tommy, had been diagnosed with Wilms' Tumor, they felt like all families do upon hearing such news—which is to say scared, alone, and like their world had been turned upside down.

Things got a little brighter, though, when Kim was introduced by mutual friends to fellow Staten Island resident Deborah Jay, whose 7-year-old son Jeffrey had just completed treatment for the same stage (III) of the same disease at the Herbert Irving Child & Adolescent Oncology Center. Both boys ultimately underwent surgery to remove a kidney, followed by radiation and six months of chemotherapy. "It was so helpful and comforting to find someone who had already been through the exact same thing we were in the middle of," says Kim. "I was able to ask Deb questions about the treatments, so I knew what to expect throughout the whole process."

Both boys were lucky; today they are healthy and active, and their moms have not only remained close friends, but have joined together to create a fundraising event to benefit Hope & Heroes. "We were on the phone one day and started talking about wanting to give something back to the

doctors and staff that were so good to us," recalls Deborah. The result was The Jeffrey Jay and Tommy Corbett Wilms' Fundraiser, which is now in its fourth year. It occurs on Staten Island for a full day each summer and includes a barbeque, games, a massive silent auction and a raffle. So far, the event has raised a total of \$180,000, all of which is used specifically to fund research on Wilms' Tumor done by Columbia oncologists Dr. Darrell Yamashiro (who was Jeffrey's doctor) and Dr. Alice Lee. The charitable impulse has spread throughout the Jay family, including a "band-aid day" started by Jeffrey and his younger brothers Joseph and Nicholas to collect decorative band-aids from their classmates and bring them to the kids at the clinic to use over catheter ports and injection sites.

Kim says their hope is that by helping to promote research on Wilms' Tumor, it will become easier to identify the disease in children—some of whom are genetically pre-disposed to developing it—and provide more targeted therapies, which work by interfering with cancer cells without doing as much damage to normal cells.

Both women also have nothing but praise for everyone who works at the clinic. "I remember how I would enter feeling like a nervous wreck about my son's health and whether he would be well enough to undergo certain phases of the treatment," recalls Deborah. "Without fail, I always left feeling reassured and relieved when I walked out—every single time. The staff is phenomenal, just amazing."

PHOTO (Left to Right): Kim Corbett, Tommy Corbett, Darrell Yamashiro, MD, Jeffrey Jay, Deborah Jay





# ONCE YOU CHOOSE HOPE, ANYTHING'S POSSIBLE.

Christopher Reeve



## **OUR LEGACY BUILDERS**

#### THE PRINCE FAMILY

Aaron Prince, Long-term Survivor Scott & Sharon Prince, Parents, Donors, Board Members

Although it's been almost a decade since their son Aaron was diagnosed with cancer, Scott and Sharon Prince continue to express their gratitude for his survival by staying closely involved with Hope & Heroes. The Princes, who live in Scarsdale, NY, both sit on the charity's board, and Aaron has spoken at fundraising events about his experience with Stage IV Hodgkin's Disease, which was successfully treated by Dr. Michael Weiner, director of the Herbert Irving Child & Adolescent Oncology Center.

Aaron is now 20 years old, healthy, and fully engaged in his life as a college student at the University of Pennsylvania, but he and his family have never forgotten the period when he was ill and how lucky they were to have ended up at Columbia. "When we were deciding where to have Aaron treated, our pediatrician immediately told us that if we wanted to be listened to and wanted our whole family to be treated with dignity, we should go to Columbia Presbyterian [as the hospital was called in those days]," says Sharon. "They treated Aaron in the most loving way you could possibly expect. We still feel so connected to the place and wanted to do something to give back."

Recently, in consultation with Dr. Weiner, the Princes generously donated \$250,000 to help launch Hope & Heroes' New Enterprise Fund, which will focus on funding innovative pediatric cancer research. Childhood cancer is generally underfunded, with most grants and other financial resources directed toward adult cancers and well-established areas of research. The Princes were attracted to the New Enterprise Fund's ability to give a sense of security to younger scientists, who may be pursuing edgier, more risk-taking research that might have a harder time getting funded, or who might need additional resources to become part of a consortium or close a gap in funding. Ideally, the Fund will enable things to move more quickly when it comes to new and novel therapies for hard-to-treat childhood cancers.

The Princes are thrilled to be able to do something to ensure that families going through what they did will receive the best and most cutting-edge level of care. "Our goal is to assist the Pediatric Oncology division in creating the best facility for research and treatment of childhood cancers," says Sharon. "Dealing with an ill child is painful and stressful. It makes all the difference to know that your child has access to the best care possible."

PHOTO (Left to Right): Aaron Prince, Scott Prince, Michael Weiner, MD and Sharon Prince announcing their \$250,000 gift at Hope & Heroes annual dinner 2010

## FISCAL YEAR 2010

JULY 1, 2009 - JUNE 30, 2010 (YEAR ENDED JUNE 30, 2010)

### REVENUES

SPECIAL EVENTS	914,815
CONTRIBUTIONS	1,141,635
TOTAL REVENUE	2,056,450

#### **EXPENSES**

GRANTS TO HICAOC	1,390,709
FUNDRAISING EXPENSES	437,017
OFFICE EXPENSES	48,726
POSTAGE AND DELIVERY	12,130
ADVERTISING AND PROMOTIONS	114,420
PROFESSIONAL FEES	27,565
TRAVEL AND ENTERTAINMENT	17,554
MISCELLANEOUS	532
TOTAL EXPENSES	2,048,653

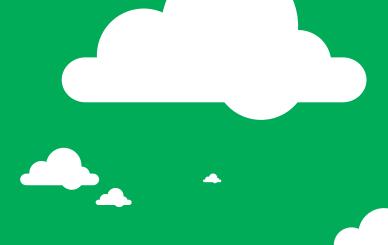
**INCREASE IN UNRESTRICTED NET ASSETS** 

UNRESTRICTED NET ASSETS, BEGINNING OF YEAR

**UNRESTRICTED NET ASSETS, END OF YEAR** 







## **SUMMARY**

REVENUE
PROGRAM EXPENSES
FUNDRAISING EXPENSES (21% OF TOTAL EXPENSES)
ADMINISTRATIVE EXPENSES (4% OF TOTAL EXPENSES)

2,048,653 1,530,528 437,017 81,108

#### Note 1: Restricted Gifts

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Please note 100% of donor-directed funds are given to programs they are designated to.

#### Note 2: Organization and Business

Hope & Heroes Children's Cancer Fund (the "Organization") was organized in 2002 to solicit funds for the benefit of, and to provide financial resources for, program support and development, patient services, education and research at Herbert Irving Division of Child and Adolescent Oncology at the Children's Hospital of NewYork-Presbyterian, Columbia University, College of Physicians and Surgeons or other organizations that qualify as exempt organizations under Section 501(c)(3) of the Internal Revenue Code. The Organization operates as a non-profit organization under the laws of the State of New York and is exempt from federal income taxes pursuant to Section 501(a) of the Internal Revenue Code. The Organization is not a private foundation. Morgan Stanley Children's Hospital of NewYork-Presbyterian provides office space and employee services to the Organization for which no fee is charged.

#### Note 3: Summary of Significant Accounting Policies

Basis of Accounting: The accompanying financial statements present financial results on the cash basis of accounting, which is a comprehensive basis of accounting other than accounting principles generally accepted in the United States of America. That basis differs from accounting principles generally accepted in the United States of America in that revenue is recognized when cash is received instead of when an unconditional promise to give is made and expenses are recognized when paid instead of when they are incurred.

Concentration of Credit Risk: The Organization maintains cash balances at two separate banks. Interest bearing accounts at each of these institutions are insured by the Federal Deposit Insurance Corporation up to \$250,000 through December 31, 2013. To date, the Organization has not experienced any losses on such amounts.

Unrestricted Net Assets: Revenue is reported as increases in unrestricted net assets unless its use is limited by donor-imposed restrictions. Expenses are reported as decreases in unrestricted net assets. The Organization reports donor-restricted contributions where restrictions are met in the same reporting period as changes in unrestricted net assets.



10-2 Club Ms. Susan Blatt Ms Carolann M Baal Mr & Mrs William V Campbell 3201 Pub Inc Ms. Margaret Babadzanova Mr. & Mrs. Eric Blattman Campbell and Dawes, Ltd./Mr. Gary Dawes Ms. Barbara Blenn Mr. & Mrs. Mace Blickman 947 McLean Pub Inc Ms. Cynthia Babak Ms. Melissa D. Canaday Mr. & Mrs. George Aaronson Ms. Colleen Bachman Mr. Luis F. Canarte Mr. & Mrs. Leonard Aaronson Ms. Jennifer Bagoslawsky Mr. & Mrs. Lawrence Bligh, Jr. Candu Management, Inc./Ms. Peg Canniff Mrs. Carter Abbott Mr. Steven Bahar Ms. Susan Bloom Mr. Douglas Cannaliato Mrs. Marcella Abbott Mr. & Mrs. W. Edward Bailey Ms. Kimberly Blozie Ms. Elaina M. Caola Ms. Patricia J. Abiuso & Ms. Fran C. Weinstein Ms. Ada Baisre de Leon Mr. Josh Blye Ms. Anne Capasso BNY Convergex Group Mr. & Mrs. David M. Aboodi Ms. Julie Baker Ms. Geraldine A. Capece Dr. & Mrs. Steven Abramow Ms. Bosiljka Bakrac Mr. Richard S. Bobal Ms. Sherri Capitelli Mr. Alan Abramson & Ms. Cvnthia Swartz Mr. Darren M. Baldo Mr. Robert H. 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