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# CHARGE Accounts

VOLUME 23, ISSUE 2

SUMMER/FALL 2013



## President's Message

By David Wolfe

Another phenomenal conference in the books! This newsletter truly shows what makes our conferences so special: our families, professionals and the more than 180 individuals with CHARGE that attended. As we move past our 11th

Conference and look forward to our 2015 conference I want to send out one last big THANK YOU to all our attendees, volunteers, fundraisers, interpreters, sponsors, advisors, Board members and especially Neal, Brownie and Lisa for helping us to Experience the Wonder that is a CHARGE conference.



Some of this year's youngest conference attendees with their moms.

I know that many of you were not able to attend this year's conference and may not be able to join us in Chicago in 2015. Fortunately, our Foundation is about much more than just conference. Our Director of Outreach, Sheri Stanger wrote a great article in this newsletter about the many services and materials that we provide. Check them out! Your Board of Directors is constantly striving to do more in the areas of outreach, advocacy, education and research. We need your help! Please consider joining our [Sixth Annual Charge It for CHARGE](#). This online fundraiser is a simple way to help the Foundation fund more programs and research. Give it a shot and watch the money roll in.

We are also always looking for more volunteers. If you are interested in getting involved, please shoot me an email at [david@chargesyndrome.org](mailto:david@chargesyndrome.org).

Enjoy the newsletter.  
David

# 2013 Conference

By Lisa Weir

Wow. What an amazing conference we experienced together! I am still in awe of how smoothly everything went, how much we learned, how much fun we had and how, with 925 of us there, we still managed to maintain that feeling of a big family reunion. I think we always wonder if there will be enough hours in the day to pull it all off but somehow, it always happens and it just keeps getting better every time!

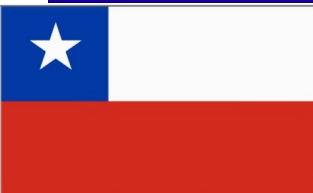
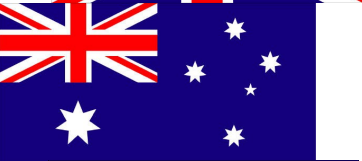
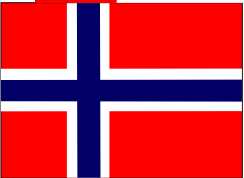
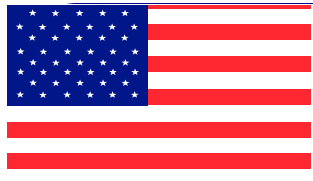
I need to publicly thank everyone involved again for all of their hard work in helping to make 2013 a great conference. Thank you to everyone on the board and to everyone who volunteered their time to help make it a wondrous event. Thank you to the presenters who came and shared their knowledge and experience with us. Thank you to the interpreters who made sure everyone was included. Thank you to the exhibitors and sponsors for your support in making our conference a success. Thank you to all of you who came to conference, whether it was your first or eleventh, or whether you traveled across the state or across multiple continents to get there.

Thank you to everyone who filled out evaluations! This year saw a couple of new things happen that came directly from YOUR ideas on past conference evaluations: on Thursday night we grouped the various regions together so folks could meet other families from their own area; on Saturday, we held a series of Parent Share Sessions; at CHARGE-A-Palooza, we changed up our auction format to a lucky draw basket activity. We were really pleased to see all of the input you provided on this year's evaluations. We thank you for the ideas for future conferences. We held a drawing for an Amazon gift card for all of those folks who included their contact information and the winner was Tracy Inverso. Congratulations Tracy, happy reading!

In closing, I need to say a huge thank you to David, Neal and Brownie one last time. Your support throughout this whole conference planning process was phenomenal.

Here's to 2015!

Thanks!!!



## WE CAME...

|                                                           |             |
|-----------------------------------------------------------|-------------|
| <b>Total Attending Conference and/or Professional Day</b> | <b>925!</b> |
| Conference                                                |             |
| Adults                                                    | 659         |
| Children (including children with CHARGE)                 | 248         |
| Individuals with CHARGE (including adults)                | 181         |
|                                                           |             |
| Registrations                                             | 454         |
|                                                           |             |
| Countries Represented                                     | 10          |
| States Represented                                        | 42          |
|                                                           |             |
| Top States                                                |             |
| Arizona                                                   | 89          |
| California                                                | 82          |
| Texas                                                     | 72          |
| Michigan                                                  | 48          |
| Massachusetts                                             | 42          |
| New York                                                  | 39          |
| Illinois                                                  | 39          |
| Ohio                                                      | 32          |
| Utah                                                      | 32          |
|                                                           |             |
| Outside of the US (including Canada)                      | 89          |
| Canada                                                    | 51          |



## We Learned...

We had an overwhelming response to our request for proposals and with the help of our Program Committee and chair, Marilyn Ogan, an outstanding and comprehensive program was developed.

Thursday saw the 3rd Professional Day, with almost 150 professionals sharing their work with each other.

### [Professional Day Handouts](#)

On Friday morning, we welcomed [Kathy Buckley](#) at our general session with an unforgettable, inspiring and hilarious message about celebrating abilities. Many tears could be seen rolling down cheeks during her talk! This was followed by two full days of 46 conference breakout sessions covering a wide range of topics with something for everyone. On Friday afternoon, we had our Information Central poster and demonstration session where our attendees had full access to our amazing group of professionals.

### [Friday Handouts](#)

### [Information Central Handouts](#)

### [Saturday Handouts](#)

On Sunday morning, we had the privilege of learning from our young adults. Jason Jones, Karlee Ludwig, Yasmin Farhart and Paul Khouri shared their stories with us and left everyone feeling inspired. Yasmin Farhart shared her speech with CHARGE Accounts and we posted it on the website for everyone to read. Visit the following link to read her speech:

<http://chargesyndrome.org/documents/yasminfarhartspeech.pdf>

David Brown once again shared his deep thoughts to end the conference and his talk on the paradoxes in CHARGE was the perfect ending to the weekend. David agreed to share his "Deep Thoughts" notes with CHARGE Accounts. It can be viewed online here:

<http://chargesyndrome.org/documents/BrownDeepThoughts.pdf>

\*Note: All handouts can be found at: <http://chargesyndrome.org/conference-2013.asp>





## 2013 Performers:

Jason Jones

Seth Rossi

Felix Andersen

Megan Stanger

Sean Timberland

Chip Dixon

Hannah Teed

Aubrey Williams

Clare O'Toole

Kennedy Weir

Kristin Ogan

Ysabel Cluver

Sean Campbell

Joselain Anthon

Meredith Dwyer

Brandon Marshall &amp; partner Danielle

Ashley Riva

Chantelle McLaren

Johnyl Wilson

Shannon Boelter

# We Celebrated!

## FRIDAY NIGHT 3RD CONFERENCE IDOL

Congratulations to all of our amazing performers for providing such a joyous celebration of your talents. We had dancing, modeling, singing, joke tellers, Karate masters, skit performers, pianists, artists, constructors and more! Our big winners were Ysabel Cluver and Seth Rossi. We even had an impromptu dance lesson for our fearless leader David Wolfe and his wife Jody! Special thanks also to our emcee Sheri Stanger and our judges: Kim Blake, Jeremy Kirk and Barbara Mason.



Brandon Marshall and his partner, Danielle teaching David & Jody Wolfe how to do the East Coast swing!



Stage Winner:  
Ysabel Cluver

Non-Stage Winner:  
Seth Rossi



Two of our esteemed judges: Jeremy Kirk and Kim Blake

THANK YOU TO VICTORIA JONES FOR THE IDOL PHOTOS ON THIS PAGE!!



# Your 2013 Idol Stars



Top Row L-R: Ashley Riva, Chantelle McLaren, Chip Dixon, Clare O'Toole  
 Middle Row L-R: Ysabel Cluver, Johnyl Wilson, Joselain Anthon, Kennedy Weir  
 Bottom Row L-R: Kristin Ogan, Megan Stanger, Meredith Dwyer, Shannon Boelter



# Your 2013 Idol Stars



Special thanks to  
Sweet Spirit Productions  
for the Idol Stars Photos

Top Row L-R: Seth Rossi, Brandon Marshall & Danielle, Jason Jones  
Middle Row L-R: Aubrey Williams, Sean Campbell, Sean Timberland  
Bottom Row L-R: Emcee Sheri Stanger, Kim Blake, Jeremy Kirk & Barbara Mason, Felix Andersen





# We Awarded

## SATURDAY MORNING AWARDS

Each year the Foundation recognizes those who have made significant contributions to the Foundation, individuals with CHARGE or their families or to better understanding, management and treatment of CHARGE syndrome.

Congratulations to all of this year's recipients:

**Stars-In-CHARGE Awards:** Jody Wolfe, Pamela Ryan (pictured top left)

**Extraordinary Service Awards:** Matthew Murray, Marilyn Ogan, John Wynne

**Recognition Awards:** Tina Prochaska

**Certificates of Appreciation:** Emily Fassi, Kevin Ballard, Mike Fagbemi, Susanne Morgan-Morrow

**Excellence in Fundraising Awards:** Emmadell & Wallace Vernon, Jody & David Wolfe, Sheri & Neal Stanger, Poonam & Amrit Mehta, Brownie & Tom Shott, Eric & Sabrina Bluestone, Julie & Jay Brandrup, Michelle & Michael D'Agostino, Bryan Glines, Dayna Hardwick, Suzanne & Ray Koudelka, Sandy & Phil Kurby, Kristen & Jason Matthew, Tina & Rik Menconi, Tracy & Mike Roth, Corki & Chris Roth, Deanna & Bill Steinhauser

**Creative Fundraising Award:** Minnie Lambert



# We Partied!

Painted faces, people grooving on the dance floor, caricature drawings, carnival games, raffle draws and our new lucky draw auction. That's how we celebrate at CHARGE-A-Palooza on Saturday night!

## Auction

We decided to shake things up and try something new that would be give everyone the chance to win and ease the check-out process. We held a lucky draw basket auction where folks bought tickets to drop into the ticket-bags in front of prize baskets they wanted. By all reports, folks seemed to really enjoy the new format and we are pleased to report that the raffles and this year's carnival auction raised well over \$10,000. Thank you to everyone who solicited or donated items!





# CHARGE-A-Palooza Photo Booth Fun!

Saturday night's party would not have been complete without the PHOTO BOOTH shenanigans!

Here are some of the carnival-goers posing it up for the camera at the party.

How many faces can you recognize?

(Note: names have been withheld to protect the "innocent")





# Photo Booth Fun





# First Impressions...

CHARGE Accounts asked a couple of attendees to share their impressions of their first conference experience:

**Heather Chandler, her 11-month old daughter Allison and friend Candace traveled from New Brunswick Canada to their first-ever CHARGE Syndrome Conference and this is what Heather had to say about the experience:**

Finding out my daughter had CHARGE syndrome was the most difficult thing my family had ever heard. How could this be? The emotions that followed were mixed with the joy of having this amazing little baby girl, and the anxiousness of what was to come. Could we do this?

The internet is one of the first places people turn to. The Foundation's website was the first link to pop up, and I immediately put my name out there. Within days someone had called to see how we were. I instantly felt like there were people out there that DID understand.

With the conference quickly approaching I jumped all over the opportunity. I wanted to learn everything I possibly could!

A good friend of our family joined Allison and I for support and encouragement, and it was amazing to have her on board. There, we learned tons of information, took lots and lots of notes, but best of all, I made connections and friendships with other families who knew exactly what we were going through. Talking face-to-face with all these families who were going through the same struggles we were, gave me a sense of belonging.

The conference changed everything for us, the way we see therapies, the way we see the future, but most of all, we feel part of a family who understand.

I feel extremely blessed to have been given the opportunity to attend the conference, and I will do everything in my power to never miss another one!

*The conference changed everything for us, the way we see therapies, the way we see the future, but most of all, we feel part of a family who understand.*



Heather holding Allison with friend Candace, taking in the preconference activity—a Diamondbacks game!

## First Impressions...

**Tracy Inverso and her husband Jonathan, parents to Logan, attended their first conference and Tracy had this to say about their first experience:**



My husband Jonathan and I were blessed with the opportunity to attend our first CHARGE conference in Scottsdale, AZ. this year. We had absolutely no expectations whatsoever, but after the first few minutes of the conference, we knew our lives would never be the same. Kathy Buckley definitely set the stage with her humor and insight and it carried through the entire weekend. We met so many nice families & beautiful children with CHARGE! We went to many sessions together and some alone. There was always a new friend or family to be made at the conference. You were never alone. Everyone knew how everyone felt. It seems we all live the same busy & complicated life everyday, just in many different places and sometimes even lands. There was a sincere sense of compassion and love throughout the conference; something I never knew existed in my world parenting a child with CHARGE!

*There was a sincere sense of compassion and love throughout the conference...*

We have always been blessed with very supportive family and friends, yet we left Arizona with even a greater support group than we could have ever imagined. From the conference, I can say with confidence that to be a parent to my son Logan, a child with CHARGE syndrome, I have had to give up a lot, we have had to sacrifice a lot, I have cried and cried MANY tears, but I know, without a doubt, I would do it all over again!

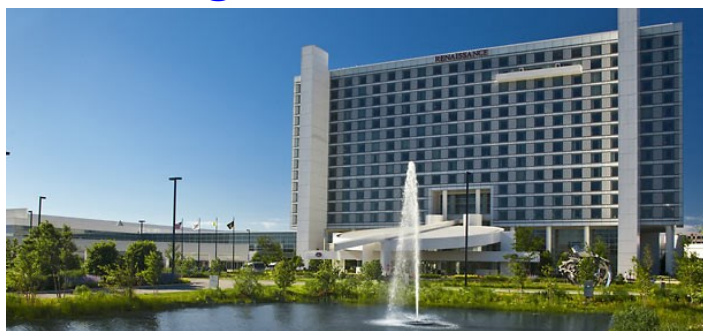
We are still flying high from our first conference and are wholeheartedly looking forward to the next CHARGE conference in 2015~ Chicago here we come!

### **12th International CHARGE Syndrome Conference—Chicago, Illinois**

**The RENAISSANCE SCHAUMBURG HOTEL will be the site for the 2015 conference. Start planning now to join us!**

**Visit the conference hotel website:**

**[www.schaumburgconventioncenter.com/hotel/](http://www.schaumburgconventioncenter.com/hotel/)**



# Accommodation Cards

## ACCOMMODATION CARD

I am deaf. To communicate effectively with you, I need: an American Sign Language interpreter.

For what I need, please contact **ASL Interpreters \R\ Us 555-1212**.

In case of emergency, please contact **June Smith 755-8989**.

Joe Smith

The Americans with Disabilities Act requires that state and local government and all public accommodations provide equal access. If your state is not listed, please contact your state office of the Deaf and Hard of Hearing.

The following information was submitted through the State Deafblind Listserv:

Download a card that lists your preferred accommodations.

People who are Deaf, Deafblind or Hard of Hearing often do not get their requests granted when they ask for a specific accommodation such as interpreter at a doctor's office or therapy appointment.

You can customize and download a card from the HealthBridges website for yourself that lists the accommodations you want (such as interpreter) to have a good health care appointment. [http://www.healthbridges.info/?page\\_id=36](http://www.healthbridges.info/?page_id=36)

Sample  
Accommodation Card  
from the Health  
Bridges site.

# Outreach Infomercial

By Sheri Stanger, Director of Outreach

Spoiler Alert! By reading this article you will increase your knowledge about CHARGE syndrome resources and offerings from the Foundation. If you wish to be kept in the dark, please skip to the next article. 😊

Every once in a while I like to remind our membership what the CHARGE Syndrome Foundation has to offer in terms of Outreach. You have a part time Director of Outreach (hey, that's me!). This is a position that began in November 2010. If a name is added to our mailing list as a new contact, if you become a new member, renew your membership or upgrade your membership, you will receive a call from your Director of Outreach (or an email if you reside outside the USA and Canada). I will respond to direct inquiries and gently guide you to the appropriate resources. The Foundation needs to stay engaged with its membership to provide you with information and links to necessary resources to keep you in the know.

Speaking of connections – did you know that the Foundation can provide you with a list of families from your state, province or country? All you need to do is request a **parent to parent contact list** from your Director of Outreach and a list of parents will be delivered to your inbox! Talk about simple! And hey, we never share your personal information with anyone! These parents have agreed to share their information with other parents for this particular purpose. Thank you to these people for helping and supporting our families!

*Continued on next page*



...continued from page 13

To further help families we developed a **Provider List** of medical personnel and therapists by city, state, province and country too! How can you get one? Please email or call your Director of Outreach and make the request. Our Provider Lists are only as good as the information we receive, so if you know of a good Provider in your area, please add their name on our Provider List submittal form located conveniently on our web site's homepage. It is quick, painless and will help numerous families.

Did I hear you correctly? You haven't been on our Foundation's Resource page in how long? Well, please go take a look at <http://www.chargesyndrome.org/resources.asp>. We have our **New Parent Folder**, the **Management Manual for Parents** in both English and Spanish and the **Professional Packet**. Didn't have time to view our **webinars** live? This is the place to watch them at your leisure. Did you have too much fun at conference schmoozing with other parents and professionals that you didn't have time to read through the conference handouts? Were you unable to attend this year? Well, we archive those **conference papers** on our Resource page too! We even archive our **newsletters** for your reading pleasure. Our Resource page has much to offer with many links to family and professional organizations too.

Thinking about starting a **local CHARGE family group** in your area? Not sure how to begin? Give me a call and we can talk strategy. Have a question and not sure about next steps? Give me a call and we can talk it out. Are you a professional that needs the support of the CHARGE Foundation? You can call me too! We have great respect for the professionals in this field and encourage collaborations at many levels.

What? You don't know about the **National Deaf-Blind Equipment Distribution Program (NDBEDP)**? You didn't know there's money out there for technology that supports telecommunication for your child or adult with combined hearing and vision loss? Well, check out this link: [www.icanconnect.org](http://www.icanconnect.org).

So you like Social Media? Like to Tweet and post on Facebook? Then this is your lucky day. We offer a CHARGE **Twitter** account and an extremely active CHARGE **Facebook** group both of which can be accessed from our web site's homepage. It's an incredible means to share successes, setbacks, information and support.

You know we put on a great conference. You know we encourage fundraising and membership. We want to support more scientific research and improve on what we do. Perhaps now you know a bit more about our Outreach efforts. Don't be shy! Check out our web site and Resource page. Give me a call. Be in the know!

Want to reach your Director of Outreach? Here's how:

**Sheri Stanger, MA, EdM**  
**Director of Outreach**  
**CHARGE Syndrome Foundation**  
**141 Middle Neck Rd.**  
**Sands Point, NY 11050**

**Phone: 1-855-5CHARGE (toll free)**  
**(1-855-524-2743)**  
**914-479-0079 (voice)**  
**914-478-1204 (fax)**  
**Email: [Sheri@chargesyndrome.org](mailto:Sheri@chargesyndrome.org)**



# Database Dispatches

Fun Factoids from the CHARGE Syndrome Clinical Database Project  
By Meg Hefner, MS, Genetic Counselor

## About CSCDP



CSCDP is an Internet, web-based, confidential, parent completed questionnaire designed to collect clinical data on individuals with CHARGE syndrome (CS). The project is supported by the CHARGE Syndrome Foundation and Saint Louis University. For participation information, click on the link <http://chargesyndrome.org/CSCDP.asp>



SAINT LOUIS  
UNIVERSITY

In each issue of CHARGE Accounts, information and updates will be provided from the CHARGE Syndrome Clinical Database Project (CSCDP). The first installment can be found online at:

<http://chargesyndrome.org/documents/Databasedispatchesfall2013.pdf>



### CONFERENCE HIGHLIGHTS AND IDOL DVDS AVAILABLE

- To order a conference highlights and/or conference idol DVD, please contact Janet at [Sweet Spirit Productions janet@sweetsspiritproductions.com](mailto:janet@sweetsspiritproductions.com)
- |                                                                               |       |
|-------------------------------------------------------------------------------|-------|
| - Conference Highlights DVD                                                   | \$27  |
| - Conference Idol DVD                                                         | \$27  |
| - Conference Highlights and Idol 2-DVD bundle                                 | \$50  |
| - HD Digital Files on Flash Drive<br>(both Conference Highlights & Idol DVDs) | \$75  |
| - Complete DVD and Flash Drive Bundle<br>(includes all of the above)          | \$100 |

## Conference Photos

Many of the photos in this issue of CHARGE Accounts were taken by Sweet Spirit Productions and Catherine Lacey Photography. Conference photos by Catherine Lacey Photography are available to view and share online at:

<http://www.catherinelaceyphotography.com/Events/CHARGE-Conference>

## Upcoming Foundation Webinar

The Foundation is excited to announce the third webinar in our 2013 series. Registration is now open for **Physical Education for Children who are Deafblind** to be presented by **Lauren Lieberman** on **November 3, 2013, 7pm EST**. With limited availability, [registration](#) is on a first-come-first-served basis. The session allows plenty of time for questions after the presentation.

Within a couple of days after registration, you will receive a registration confirmation and detailed instructions on how to log in to the webinar, participate and learn from our expert.

Lauren Lieberman, Ph.D. is a Distinguished Service Professor in the area of Adapted Physical Education at the State University of New York College at Brockport. She has taught children who are Deafblind at Perkins and is the founder and director of Camp Abilities, a sports camp for children who are visually impaired, blind or deafblind. Her area of expertise is inclusion, and physical activity and sports for children who are visually impaired, blind or deafblind. She has written seven books and many research articles in this area. Dr. Lieberman co-directs the recently established The Institute for Movement Studies for Individuals who are Visually Impaired at The College at Brockport. This Institute includes research in the area of motor development, physical education, and physical activity for children with CHARGE syndrome.

### Physical Education for Children who are Deafblind

Physical education is a direct service and a core subject area required by law. Physical education is also a place where children can learn all 9 areas of the Expanded Core Curriculum. Very often the physical education teacher and support staff do not know what to do when they have a child who has a dual sensory impairment in their class. This presentation shares the findings of current research and appropriate practical strategies so that children who are deafblind receive the maximum benefit from physical education. By using the instructional strategies, equipment modifications, training methods and curriculum ideas suggested in this webinar, teachers and parents can ensure that children who are deafblind reach their full potential in all areas of life.

### CHARGE Syndrome Foundation, Inc.

141 Middle Neck Road  
Sands Point, NY 11050  
USA

Phone: 516-684-4720  
Toll Free: 1-800-442-7604  
Fax: 516-883-9060

#### Annual Membership

Family – \$25  
Professionals – \$40

#### Lifetime Membership

Silver – \$250  
Gold – \$1,000  
Platinum – \$5,000  
Diamond – \$10,000

### Director of Outreach

**Sheri Stanger**

**Toll Free:** 1-855-5CHARGE  
(1-855-524-2743)

**Phone:** 914-479-0079

**Fax:** 914-478-1204

**Email:**

[sheri@chargesyndrome.org](mailto:sheri@chargesyndrome.org)

**NEW:** Members receive priority registration for our webinar series.

**NEW:** Lifetime members receive a 10% discount off of conference registration.

Email: [info@chargesyndrome.org](mailto:info@chargesyndrome.org)

Visit us on the web: <http://www.chargesyndrome.org>





# Thank You

## Memberships

Katherine Ang  
Bella Jitiam  
Michelle Gomez  
Lois Gannon  
Michael Ortiz  
Jean Rabary  
Dayna Hardwick  
Sharon Stelzer  
Mary Ann Petock  
Erika Watts  
Jackie Bauer  
Tiffani Lanting  
Annette Stocker  
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Karen Miller  
Robert Scharf  
Heather Miele  
Patricia Mosher  
Kate Beals  
Dottie Snyder  
Peg Kolm  
Jackie Ebersole  
Susan Bruce

## Donations

**In Memory of Ruxson Wade Frost**  
Northmont Lions Club

### **In Memory of Doug Cramb:**

Paul Abram  
Kathy Anderson  
Claudine & Dick Ashcraft  
Barbara & Charles Axtell  
Karin & Gary Belden  
Brenda & Roger Budke  
Mary & Tom Claussen  
Rose Cramb  
Linda & Randy Doggett  
Donna & Jay Eck  
Mary & Earl Englebert  
Josephine & Charles Hartman  
Michele & Max Heidrick  
Paula Kisslinger  
Diane & Verline Kolman  
Cyndee & Rick McCullough  
JR & Rosalie Merriman  
Marlene Mispagel  
Carol & Lee Modrow  
Kristine Nelson  
Gail & Robin Pearson  
Ken & Joyce Satterlee  
Janette & Walter Schoen  
Karen & Denis Shumate  
Rita & Hector Soler  
Bonnie & Hal Steiner  
Cheryl Thummel  
Helena Wiegand

**On the Special Occasion of Nicholas Miele, The Miele Family**  
Joseph Antonacci

**In Memory of Kai Shamiyeh**  
Lynette Barcewicz

**In Honor of Erik Cromer**  
Bernard Bardy Union National Mortgage

**In Memory of Tommie Rickel and in honor of Tyler Criswell**  
Sally Bayer  
Marilyn & Leo Batliner

**In Honor of Samuel Beachy**  
Mark Batluck

**In Memory of Samuel Patton Beachy**  
Stan Beachy

**In Memory of Samuel Patton Beachy, my first teacher of CHARGE 101. With gratitude for the time spent in his company, and love to his dear family.**  
Kate Beals, SC Interagency Deaf-Blind Project

**In Honor of Blake Noah**  
Lynda Beaver

**In Memory of Tommie Rickel and In Honor of Tyler Criswell**  
Lillie Buller  
Linda Guardado  
Guy Humphreys  
Kerry O'Connor

**In Memory of Tyler Matthew:**  
Shelly Anderson

**In Memory of Tommy Rickel & In Honor of Tyler Criswell**  
Saint Joseph Ad-Venture Inc.

**In Honor of CHARGE It for Landon**  
David J. Solimine Funeral Service, Inc

**In Memory of Madison Zamora**  
Drs. Phillips, Miller & Roca

IBM Employee Services Center

MSCI Charitable Contributions Employer Match

Nestle

Cyndie Pfohler

**Best Wishes to the Wolfe Family for a Successful Conference**  
Arlene Midkiff

Tracy Morser  
Herbert Mueller

**In Honor of Colton DeVerter**  
Oesa Hauch

Jason Bender

**In Memory/Honor of Kai Shamiyeh**  
Lisa and Gianluca Biccari  
Emily Cheng  
Sue Fuller  
The Hoppes  
Laurie Serge Krassilnikoff  
Christine & Louis Laulhere  
Lee & Jeannette Lawrence  
Jean O'Connell  
Jennifer Sarre

Suzanne Koudelka

**On the Special Occasion of The Schultz Family**  
Beth Knicker

**In Honor of Kennedy Grace Kulas**  
Karin Kulas

**In Memory of Mary Kaliski**  
Emma & Eli Bluestone

**In Honor of Evan Lester my son!**  
Peter Lester

Joanne Lent

**In Honor of the Haggerty Family**  
Stephanie Lowell

**In Honor**

**In Honor of Finley Roth's 4<sup>th</sup> Birthday**  
Margaret Botchie

Karim Bouazoune, Harvard Medical School/ MGH

**In Honor of Maxwell McKinley**  
Elizabeth Boyle, Decorating Your Life

# Thank You

## Corporate Kids Events

### In Memory of Tommie Rickel

Blue Ridge Imports

South Walton High School ASL Club

St. Dominic School

United Way California Capital Region

Value & Purpose

Wells Fargo Community Support Campaign

Network for Good

### On the Special Occasion of Nicole & Paul's Wedding – Congratulations to you both

Token Reichow

### In Honor of Landon D'Agostino

Joseph Holey

### In Honor of Charlotte Cosenza

Paul Cosenza

Eric Donnenfeld

John Passarelli, Long Island Eye Surgical Care P.C.

### In Memory of Samuel Patton Beachy

Greg & Cecelia Clippingier

The Zimelman Family

Anita & Gary Fields

Norma G. Greider

Charles & Susan Job

Paula Johnson

James & Deloris Keogh

Julie Nicholson

Nancy Robeson

Linda & Dave Rose

Jane Sowles

Loren Steenson

Cathy Stevens

John & Julia Tossell

Anne & Al Wasson

### In Honor of Alivia Roth

Sally Roth

### In Honor of Charge it for Landon

Michael D'Agostino

### On the Special Occasion of Elizabeth Nordquist

Karla Brustad

### In Honor of Nicholas Miele

Kay Byrne

The Chatfields

Chris Conforti

Michael Conmy

Jen, Mike, Rory, CC, Em & John Dillon

The Downes Family

Lydia Hart

Jeanne Parsons

### In honor of Anthony Campos, an amazing 9-year-old who has CHARGE in Houston, TX

American Express Philanthropy Employee Giving Program

Audrey Dwyer

Trudy Carpenter

Marlene & James Casey

Cathie Josephson

Catherine Katapodis

Jackie Kenley The ARC Volunteer Services

Beth Kennedy DB Central Michigan Services for Children & Youth Who are Deaf-Blind

### In Honor of Daniella Cotter

Richard Cotter

### In Honor of Tyler Criswell, grandson of Tommie E. Rickel

Janet Cunningham

Margie Cunningham

### In Honor of Tyler Criswell

Joyce Rickel

Bob & Susan Roth

James Roth

### West Community Health Charities

Susan Wolfe

Kelli Woody, Principal Financial Group

### In Honor of Ethan Wolfe's 11<sup>th</sup> Birthday

Nori & Rob Spiro, Dry Cleaning Factory

### In Honor of the Brandrup Family

Mike & Tracey Nowack

Kevin & Katie O'Meara

### In Honor of Christian Roberts

Bekkie Cobb

### In Memory of Tommie Rickel

William Corless

Hazels Employees: Jesse, Stacey, Travis,

LeErika, Taylor, Megan and Marty

Jamie Allen Ferguson

Beverly Hesting

Russell Hill

Lori Holliday, Buchanan County Circuit

Court-Division 4

Holly Neal

Marjorie Needham

Dianna Power DBA Dianna's Tax Service

Sue & Bradley Sherffius

Jockey Smock

Linda Spotts, J&B Group

Erin & Lee Tieman

### In Honor of Mia Menconi

Andrew Turnbull

### In Memory of your mother Francine

Allen Tennbaum

Joe Sutton, Pershing Square

### On the Special Occasion of 50<sup>th</sup> Anniversary of Rebecca and Bernardo Saruski

Carol & Jaime Suchlicki

Sheri & Neal Stanger

Jorge Cotter

THANK YOU FOR YOUR GENEROUS SUPPORT OF THE  
CHARGE SYNDROME FOUNDATION

# Thank You

Deby Davis, United Way of Kentucky

Karen & Perry Dawson, DBA Santa Susana Station

**In Memory of Lee Heymen Oliveira**  
Judy Ann Dennis, Sebring Falls Property Owners

**On the Special Occasion of Happy 50<sup>th</sup> Wedding Anniversary. Many more with lots of health**  
Jaime and Jenny Edelstein

**In Honor of Kyla Burke**  
Lisa Ellison

**In Memory of Jaycee Rose Biscamp**  
Rita Emke

**In Honor of Scarlett Leurey Peach**  
Gerald Ewing

**In Memory of Masen Herrera**  
Sally Filosa

**In Honor of Isla Fisher**  
Allan Fisher  
Alan Lowrie Fluor Canada Ltd

**In Honor of Adele Brandrup**  
Nickolas Gibietis

Joshua Fultz

**In Memory of William "Gauge" Landrum**  
Robyn Hallman

**In Memory of Eunice Conners, Mother of Pam Conners**  
Kathy & Dodie Harte

**In Honor of Doug & Angela Beebe**  
Mark Heithoff

Katherine Helmer

Martha Majors Perkins School for the Blind

**On the Special Occasion of Taylor Shott's Graduation from School**  
Pamela Ryan

**On the Special Occasion of Kristin Ogan's Graduation from High School**  
Pamela Ryan

Pamela Ryan Perkins DeafBlind Program

**In Honor of Anna Lobaugh**  
R.Rene Ryan

Melva Strang-Foster

**In Memory of Tobin Frederick Talbert**  
Kevin Varney, Varney Tax Service, Inc.

Emmadell Vernon

## Charge It for CHARGE Tributes

From Robin Ackerman

From Bill Positive Sigma In Honor Of Zachary Bluestone

From Cynthia & Keith Antaya~~ In Support Of The Foundation - Jean's Day Fundraiser

From Cynthia & Keith Antaya ~~ In Honor Of Our Jean's Day Fundraiser

From Lisa Benkowski ~~ In Honor Of Finley Roth

From Pammy & Tony ~~ In Memory Of Joshua Kurby

From Hannah Bledsoe ~~ In Honor Of Taylor Shott

From Grandma & Grandpa ~~ In Honor Of Eric, Sabrina, Zachary

From Christopher Brown ~~ In Honor Of The Blkuestone Family

From Michael Byron ~~ In Honor Of Zachary

From Harry Capers ~~ In Honor Of Taylor Shott

From Cheryl Chandler ~~ In Honor Of Taylor Shott

From Margaret Crowl ~~ In Honor Of Jonathan Ferguson

From Helena Czerwinski ~~ In Honor Of Elizabeth Kijowski

From Grandma with love ~~ In Memory Of Joshua

From John and Jane DeCoursey ~~ In Honor Of The Bluestone Family

From Meredith & Jerry DelBene ~~ In Honor Of Zachary Bluestone

From Elizabeth DiBartolo ~~ In Honor Of Zachary Bluestone

From Marcia & Mark Didio ~~ In Support Of Jean's Day Fundraiser

From The Donatelli's ~~ In Support Of The Bluestones

From Melissa Fernandes ~~ In Support Of Jean's Day Fundraiser

From Kevin & Erin Flesch ~~ In Memory Of Joshua Kurby

From Peter Florey ~~  
From Martha Forbes ~~ In Honor Of Taylor Shott

From Kelly Gaines ~~ In Honor Of Taylor

From Morgan and Everett Gibson ~~ In Support Of Taylor Shott on his High School Graduation

From Karen Goehl ~~ In Honor Of Kristin Ogan's high school graduation

From Alan and Lori Gunn ~~ In Support Of Taylor Shott



# Thank You

From Nonna & Grampa ~~ In Memory Of Joshua Roy Kurby

From Nonna and Grampa ~~ In Memory Of Happy Birthday Joshy

From Charge for CHARGE 5K ~~ In Support Of 5th Annual Joshua Kurby Charge for CHARGE 5K! Thank you all!

From Amy Kurens ~~ In Honor Of Zachary Bluestone

From Minnie Lambert ~~ In Honor Of The Alaniz Family participating in the Flat Charlie Project!

From Minnie Lambert ~~ In Honor Of The Martin Family participating in the Flat Charlie Project!

From Minnie Lambert ~~ In Honor Of Travis Nesbitt donating a suitcase to Flat Charlie! Thanks T!

From Minnie Lambert ~~ In Honor Of The Northrup Family participating in The Flat Charlie Project!

From Minnie Lambert ~~ In Honor Of The Fergusons participating in the Flat Charlie Project!

From Minnie Lambert ~~ In Honor Of The Herod Family participating in the Flat Charlie Project!

From Minnie Lambert ~~ In Honor Of Kate Beals and our friends at SCSDB and the great job they did with Charlie!

From Janina Staszal ~~ In Honor Of Elunia

From Allison Steinhauser ~~ In Honor Of Dominic's Steinhauser 5th Birthday - we love you!

From Park Ace Hardware ~~ In Honor Of Dominci Steinhauser

From The Landicino Family ~~ In Honor Of Zachary Bluestone

From Fred & Nancy Lanford ~~ In Honor Of Taylor's graduation

From Compufit ~~ In Honor Of Zachary Bluestone

From Wayne Leland ~~ In Honor Of Joshua Kurby

From Les & Faith Lerner ~~ In Honor Of Zachary

From Darren Lis ~~ In Honor Of Zachary Bluestone

From Flory Mahoney ~~ In Honor Of Bluestone Family

From Robert Miller ~~ In Support Of Jean's Day Fundraiser

From Jodi Montgomery ~~ In Honor Of The Bluestone family

From Montgomery Family ~~ In Honor Of Zachary Bluestone

From Jadwiga Mulica , Susan Peloso, Barb Perski~~ In Honor Of Elizabeth Kijowski

From Ann Pisetznier ~~ In Honor Of Eric Bluestone

From Felipe Ramirez ~~ In Honor Of Juluius Ramirez

From Lalitha Reddy ~~ In Honor Of Elizabeth Kijowski

From Jeff and Joy Schneider ~~ In Honor Of The Amazing Bluestone Family!

From Sarah Scutt ~~ In Honor Of Zachary Bluestone & Family  
From sarah spruill ~~

From Sheri & Neal Stanger ~~ In Honor Of Flat Charlie & Minnie!!!!

From Alexandra Hanson ~~ In Honor Of The Bluestone Family

From Mayer Horn ~~ In Honor Of Eric, Sabrina, & Zachary

From The Lurato Family ~~ In Honor Of The Bluestone Family

From Nicole & Kevin Klinger ~~  
From Steph and Don K. ~~ In Memory Of Joshua Kurby

From Adam, Sophia Kowalczyk ~~ In Honor Of Elizabeth Kijowski

From Danuta Kozieliec ~~ In Memory Of Krystyna Tylka, Stanislaw Bednarz and Stanislaw Kozieliec

From Karen Krull ~~ In Honor Of Jean's Day Fundraiser

From Grandma and Grandpa ~~ In Honor Of Jonathan Ferguson

From Thomas Stiberth ~~ In Honor Of Ethan Wolfe

From Testwuide Family ~~ In Honor Of Zachary Bluestone

From Jennifer Tomaszek ~~ In Honor Of Elizabeth Kijowski

From Andrew Turnbull ~~ In Honor Of Mia Menconi

From Elizabeth Unger ~~ In Honor Of Zachary Bluestone

From William Vitacco ~~

From The Wayman Family ~~ In Memory Of Josh. Happy Birthday! Great race day too!

From Jody & David Wolfe ~~ In Honor Of Taylor's graduation

THANK YOU FOR YOUR GENEROUS SUPPORT OF THE  
CHARGE SYNDROME FOUNDATION



# Help us reach our goal!

## \$150,000

Our sixth annual Charge It for CHARGE is now underway! With the end of the year giving season rapidly approaching, what a great way to use the power of email and Facebook to raise money for the Foundation. This year we hope to raise more than \$150,000 for support, outreach, awareness, and research. With about an hour of your time and the e-mail addresses of friends, family, and colleagues, you can help us reach our goal. To get started, go to <http://csfsixthannual.kintera.org/> to begin your campaign or to make a donation to another participant. You will be amazed at the support you receive from your friends, family and colleagues.

Don't forget, if you are hosting an event, party or participating in a run, walk, or bike trip, to benefit the Foundation we can help you create your own web page to collect donations and track your progress. For any questions about fundraising, contact our president and fundraising chair, David Wolfe, at [david@chargesyndrome.org](mailto:david@chargesyndrome.org).

## IT CAN BE DONE!