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.

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.

Enjoy the newsletter.
David
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!
**WE CAME...**

<table>
<thead>
<tr>
<th>Total Attending Conference and/or Professional Day</th>
<th>925!</th>
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<tbody>
<tr>
<td>Conference</td>
<td></td>
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<tr>
<td>Adults</td>
<td>659</td>
</tr>
<tr>
<td>Children (including children with CHARGE)</td>
<td>248</td>
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<tr>
<td>Individuals with CHARGE (including adults)</td>
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<tr>
<td>Registrations</td>
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<td>Arizona</td>
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<td>Ohio</td>
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<td>Utah</td>
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<tr>
<td>Outside of the US (including Canada)</td>
<td>89</td>
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<tr>
<td>Canada</td>
<td>51</td>
</tr>
</tbody>
</table>
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:


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

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

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

Special thanks to Sweet Spirit Productions for the Idol Stars Photos
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 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!

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!

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/
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)

### 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
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](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
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

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@sweetspiritproductions.com
- Conference Highlights DVD $27
- Conference Idol DVD $27
- Conference Highlights and Idol 2-DVD bundle $50
- HD Digital Files on Flash Drive (both Conference Highlights & Idol DVDs) $75
- Complete DVD and Flash Drive Bundle (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.

NEW: Members receive priority registration for our webinar series.

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

Email: info@chargesyndrome.org
Visit us on the web: http://www.chargesyndrome.org
Memberships
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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
Susan Hall
Jeanne Meyers
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 Misagel
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

Cydnie 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 Biccar
Emily Cheng
Sue Fuller
The Hoppes
Chris & Louis Lauhere
Yuan & 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 4th 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
Josepholey

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 & Cecilia Clippinger
The Zimbelman 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 Conny
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 Dywer
Trudy Carpenter
Marlene & James Casey
Cathie Josephson
Catherine Katapodis
Jackie Kenlen 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

In Honor of Ethan Wolfe's 11th 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
Beverly Hesting
Sue & Bradley Sherflus
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 50th 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
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 50th 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 Enke
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 “Gaige” 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 Bluestone 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 Czerwinska 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 DeBene 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
<table>
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<tr>
<th>From Nonna &amp; Grampa</th>
<th>In Memory Of Joshua Roy Kurby</th>
</tr>
</thead>
<tbody>
<tr>
<td>From Nonna and Grampa</td>
<td>In Memory Of Happy Birthday Joshy</td>
</tr>
<tr>
<td>From Charge for CHARGE 5K</td>
<td>In Support Of 5th Annual Joshua Kurby Charge for CHARGE 5K! Thank you all!</td>
</tr>
<tr>
<td>From Amy Kurens</td>
<td>In Honor Of Zachary Bluestone</td>
</tr>
<tr>
<td>From Minnie Lambert</td>
<td>In Honor Of The Alaniz Family participating in the Flat Charlie Project!</td>
</tr>
<tr>
<td>From Minnie Lambert</td>
<td>In Honor Of The Martin Family participating in the Flat Charlie Project!</td>
</tr>
<tr>
<td>From Minnie Lambert</td>
<td>In Honor Of Travis Nesbitt donating a suitcase to Flat Charlie! Thanks T!</td>
</tr>
<tr>
<td>From Minnie Lambert</td>
<td>In Honor Of The Northrup Family participating in The Flat Charlie Project!</td>
</tr>
<tr>
<td>From Minnie Lambert</td>
<td>In Honor Of The Ferguson Family participating in the Flat Charlie Project!</td>
</tr>
<tr>
<td>From Minnie Lambert</td>
<td>In Honor Of Kate Beals and our friends at SCSDB and the great job they did with Charlie!</td>
</tr>
<tr>
<td>From Janina Staszel</td>
<td>In Honor Of Elunia</td>
</tr>
<tr>
<td>From Allison Steinhauser</td>
<td>In Honor Of Dominic’s Steinhauser 5th Birthday - we love you!</td>
</tr>
<tr>
<td>From Park Ace Hardware</td>
<td>In Honor Of Dominci Steinhauser</td>
</tr>
<tr>
<td>From The Landicino Family</td>
<td>In Honor Of Zachary Bluestone</td>
</tr>
<tr>
<td>From Fred &amp; Nancy Lanford</td>
<td>In Honor Of Taylor’s graduation</td>
</tr>
<tr>
<td>From Compufit</td>
<td>In Honor Of Zachary Bluestone</td>
</tr>
<tr>
<td>From Wayne Leland</td>
<td>In Honor Of Joshua Kurby</td>
</tr>
<tr>
<td>From Les &amp; Faith Lerner</td>
<td>In Honor Of Zachary</td>
</tr>
<tr>
<td>From Darren Lis</td>
<td>In Honor Of Zachary Bluestone</td>
</tr>
<tr>
<td>From Flory Mahoney</td>
<td>In Honor Of Bluestone Family</td>
</tr>
<tr>
<td>From Robert Miller</td>
<td>In Support Of Jean’s Day Fundraiser</td>
</tr>
<tr>
<td>From Jodi Montgomery</td>
<td>In Honor Of The Bluestone family</td>
</tr>
<tr>
<td>From Montgomery Family</td>
<td>In Honor Of Zachary Bluestone</td>
</tr>
<tr>
<td>From Jada Wigia Mulica, Susan Peloso, Barb Perski</td>
<td>In Honor Of Elizabeth Kijowski</td>
</tr>
<tr>
<td>From Ann Piszczek</td>
<td>In Honor Of Eric Bluestone</td>
</tr>
<tr>
<td>From Felipe Ramirez</td>
<td>In Honor Of Julius Ramirez</td>
</tr>
<tr>
<td>From Lalitha Reddy</td>
<td>In Honor Of Elizabeth Kijowski</td>
</tr>
<tr>
<td>From Jeff and Joy Schneider</td>
<td>In Honor Of The Amazing Bluestone Family!</td>
</tr>
<tr>
<td>From Sarah Scott</td>
<td>In Honor Of Zachary Bluestone &amp; Family</td>
</tr>
<tr>
<td>From sarah spruill</td>
<td>In Honor Of Zachary Bluestone</td>
</tr>
<tr>
<td>From Sheri &amp; Neal Stanger</td>
<td>In Honor Of Flat Charlie &amp; Minnie!!!!</td>
</tr>
<tr>
<td>From Alexandra Hanson</td>
<td>In Honor Of The Bluestone Family</td>
</tr>
<tr>
<td>From Mayer Horn</td>
<td>In Honor Of Eric, Sabrina, &amp; Zachary</td>
</tr>
<tr>
<td>From The Lurato Family</td>
<td>In Honor Of The Bluestone Family</td>
</tr>
<tr>
<td>From Nicole &amp; Kevin Klinger</td>
<td>---</td>
</tr>
<tr>
<td>From Steve and Don K.</td>
<td>--- In Memory Of Joshua Kurby</td>
</tr>
<tr>
<td>From Adam, Sophia Kowalczyk</td>
<td>--- In Honor Of Elizabeth Kijowski</td>
</tr>
<tr>
<td>From Danuta Koziełek</td>
<td>--- In Memory Of Krystyna Tylka, Stanislaw Bednarz and Stanislaw Koziełek</td>
</tr>
<tr>
<td>From Karen Kruhl</td>
<td>--- In Honor Of Jean’s Day Fundraiser</td>
</tr>
<tr>
<td>From Grandma and Grandpa</td>
<td>In Honor Of The Amazing Bluestone Family!</td>
</tr>
<tr>
<td>From Thomas Stiberth</td>
<td>In Honor Of Ethan Wolfe</td>
</tr>
<tr>
<td>From Testwuide Family</td>
<td>In Honor Of Zachary Bluestone</td>
</tr>
<tr>
<td>From Jennifer Tomaszek</td>
<td>In Honor Of Elizabeth Kijowski</td>
</tr>
<tr>
<td>From Andrew Turnbull</td>
<td>--- In Honor Of Mia Menconi</td>
</tr>
<tr>
<td>From Elizabeth Unger</td>
<td>In Honor Of Zachary Bluestone</td>
</tr>
<tr>
<td>From William Vitacco</td>
<td>---</td>
</tr>
<tr>
<td>From The Wayman Family</td>
<td>--- In Memory Of Josh. Happy Birthday! Great race day too!</td>
</tr>
<tr>
<td>From Jody &amp; David Wolfe</td>
<td>--- In Honor Of Taylor’s graduation</td>
</tr>
</tbody>
</table>
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.

IT CAN BE DONE!