THE CHARGE SYNDROME FOUNDATION

# CHARGE *Accounts*

Fall 2014

*The mission of the CHARGE Syndrome Foundation is to lead and partner to improve the lives of people with CHARGE syndrome locally, nationally and internationally through outreach, education, and research.*

## *In This Issue*

## *THANK YOU!*

*The Sixth Annual*
*CHARGE It for CHARGE*
*set a new record…*

***$101,000!!***

**Please Join the**
**Seventh Annual**
**Charge It for**
**CHARGE**

**Become a Fundraiser**

## *President's Message*

Happy Holidays! This has been another extraordinary year for the Foundation. With a research symposium, fabulous webinars, research grants, new outreach initiatives, and much more, we are working together to make the world a better place for all individuals with CHARGE. Thank you to our members, donors, fundraisers and volunteers who make it all possible!

On a personal note, this has been a very difficult time for my family. On October 15th, my 12 year-old son Ethan suddenly passed away. Our family has been touched by the out-pouring of support from our CHARGE family. Ethan has always been, and remains, my inspiration and hero. My family and I will continue to honor his memory, as well as the memory of all those individuals with CHARGE we lost, through our volunteer work with the Foundation.

It is my hope that each of you will find your own motivation to help the Foundation. Through our joint efforts, we can more than double our 2015 research budget, spend more on outreach and advocacy, and help families attend our 2015 Conference. Together, it can be done!

Enjoy the newsletter, spend time with your families, and please help make 2015 a fantastic year for all of us.

*David*

David Wolfe
*President*

Our New Address

**The CHARGE Syndrome Foundation, Inc.**
**318 Half Day Road, #305 • Buffalo Grove, Illinois 60089**
**info@chargesyndrome.org • 800.442.7604**

# Get Ready for Conference

It may be fall, but it's not too early to plan for the **12th International CHARGE Syndrome Conference, July 30th – August 2nd, 2015**. We hope you can join us at The Renaissance Schaumburg Hotel in suburban Chicago.

Registration opens in the spring, but you can make your Hotel reservations --A special rate of $149 per night is available now.

Make your reservations.

### *Seeking Support for Conference Costs*

The Foundation's funding guide provides ideas to search for organizations that may be able to assist you with conference costs. The guide includes general tips, a sample request letter, and a cost breakdown template.

By helping the Foundation obtain new sponsors and advertisers, **you can earn you FREE registrations to attend conference**. There's no limit to the number of registrations you can earn for your family and friends. Find out more about our incentive program.

### *Call for Presenters*

The deadline to respond to the 2015 Call for Presentations is January 31, 2015. Notifications of acceptance will be issued by March 1. Please email Lisa Weir, Program Chair, with any questions.

### *Volunteers Wanted*

If you, or someone you know, is interested in volunteering at conference, please fill out or share the Volunteer Packet. Please email Joanne Lent, Volunteer Coordinator with any questions.

*We look forward to seeing you this summer!*

### *Saturday Night CHARGE-A-PALOOZA is Back*

Saturday night at Conference is CHARGE-A-PALOOZA, and you can help make the event an even bigger celebration. We seek themed baskets for auction, with a value of at least $50 (date night, game night, spa day, etc.). We are also accepting high-end items for the silent auction including timeshares, fine jewelry, airline tickets, electronics, and sports memorabilia. Copies of our donation letter and form are now available. Please contact Neal Stanger for more information.

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# WOW

## Watch Our Webinars

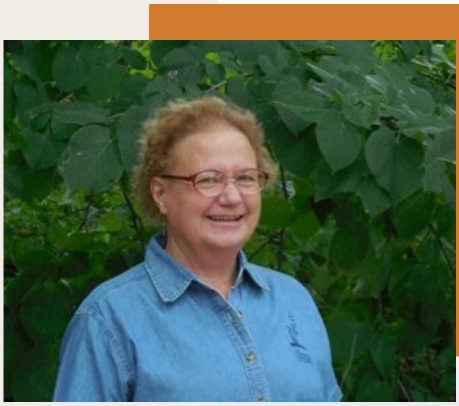
The Proprioceptive Sense

- Helps us to plan, position, and grade our movements without looking to see what we are doing.
- "An awareness, or a feeling, of one's own self".
- One specialized aspect of the complex sense of touch, like a kind of 'internal touch'.
- Receptors of this sense respond to the stretching or compression or twisting of joints and muscles.

Our 2014 Webinar Program closed in October with a discussion focusing on the state of CHARGE research. This year, three sessions focused on a variety of topics ranging from research to social behaviors. Our thanks to the presenters, and all of this year's Webinar participants. All Webinars are available to view on our website.

The first Webinar in our 2015 series focuses on OCD behaviors. As with previous sessions, registration is offered on a first-come-first-served basis. Due to high popularity and limited space available, **current members of the Foundation are eligible for Early Bird Registration**. You can join or renew your CHARGE Syndrome Foundation membership today.

## *University of Michigan Honors Meg Hefner*



The Genetic Counseling Program of the University of Michigan recently honored Meg Hefner as the recipient of the 5th Annual Diane Baker Award. Meg, an alum of the University of Michigan, is one of the founders of the CHARGE Syndrome Foundation.

Hefner is an Adjunct Associate Professor in the Division of Medical Genetics at the Saint Louis University School of Medicine. Meg Hefner is an internationally recognized expert in CHARGE syndrome.

Meg co-authored CHARGE Syndrome, a book focused on the description of the sensory, physical, and behavioral findings of the condition. Clinically, Meg founded the first US CHARGE Syndrome clinic at the Cardinal Glennon Children's Medical Center in St. Louis, where she continues to provide education and support to patients and their families.

Congratulations to Meg on receiving this special honor!

CHARGE Syndrome
Clinical Database Project
(CSCDP)

### Participants Needed!

*There is increasing demand for information about individuals with CHARGE from research professionals. The CHARGE Syndrome Clinical Database Project can be a valuable resource for studies, without the need for parents to repeatedly fill out questionnaires.*

*For more information:*
*http://chargesyndrome.org/CSCDP.asp*
*or meg@chargesyndrome.org*

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# Call for Board Nominations

Nominations are open for Foundation members interested in donating their time and expertise as members of the Board of Directors. Guiding the Foundation is an incredibly rewarding experience. If you, or someone you know, has the dedication and skills to help the Foundation flourish, please submit a nomination form.

The nomination form is available online. Important dates:

- April 1: Nomination forms due
- May 15: Completion of the interview process
- June 15: Notifications made to all elected Board members
- July 29 : Become an active member of the Board at conference

Applicants should familiarize themselves with our Policies and Procedures. Please email David Wolfe to obtain a copy of the policies or to discuss serving on the Board. Please note, the Foundation is led by a working Board of Directors. If you become a candidate, please make sure you can commit at least 5 hours per week to Board activity.

***Together, we make a difference!***

## Our Little Corner of the World

Submitted by Sheri Stanger, Director of Outreach

Whether you are a new or seasoned parent – there's always something to learn. This section will shed some light on the plethora of information available to you from the Foundation.

The CHARGE Syndrome Foundation is a nonprofit organization based in the USA. It was established in 1993, and is run by a board of volunteers from the USA and Canada. The Foundation regularly shares news about research, webinars, events, and articles within the world of CHARGE syndrome. We aim to keep you informed. If you don't already receive our eNews, you can sign up here.

Parent connections are crucial and the Foundation addresses this critical need. Contact the Director of Outreach anytime at 1-855-5CHARGE (855-524-2743) or sheri@chargesyndrome.org. You can also connect with the Foundation and other parents through our Facebook, Twitter, and Listserv. Visit the Resources page of our website to review the New Parent Folder, the Management Manual for Parents, and other important information. A Professional Packet for professionals who work with individuals with CHARGE is also available .

Mark your calendar for the 2015 International CHARGE Syndrome Conference scheduled for July 30th – August 2nd, 2015. This is your opportunity to connect with parents and experts in the field of CHARGE syndrome for three days of networking, workshops, and fun for the whole family.

The Foundation is here and ready to help you make the connections you need. While CHARGE is labeled as a low incidence disability, we are a well-connected and highly motivated community offering support in our little corner of the world.

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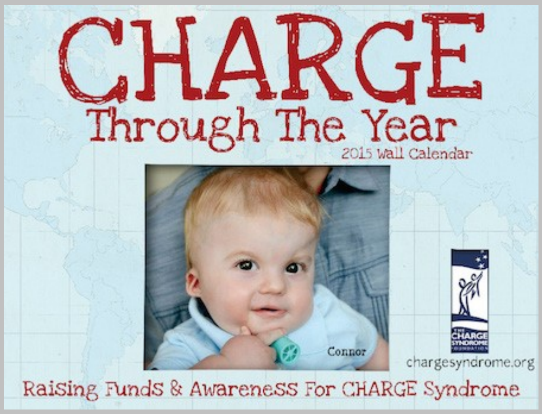
# Awareness makes this a better world for people with CHARGE

## A Year of Awareness

Submitted by
Anna Miller

While giving my daughter, Andi, a bath one morning in 2013, I was struck with an idea – create a calendar to raise funds and awareness for CHARGE syndrome. Energized, I took to the computer, and emailed the first 12 moms I could think of to gauge their interest. I was beyond excited!



The name struck me one day – 'CHARGE Through The Year' – as each month features a kid with CHARGE syndrome. I soon had photos of 11 kids, showcasing their name, age, accomplishments and goals. I found a publisher and created our first edition. Using an e-commerce website so people could place orders, and social media to market the product, we sold out in a matter of weeks.

It was tough to choose our participants for the 2015 edition, as so many parents wanted their child with CHARGE featured. So the 2015 calendar showcases 80 kids with CHARGE syndrome! The CHARGE Through The Year calendar is not only a fundraiser and celebration of CHARGE adorableness, it's also an opportunity to educate. The main purpose is to end the question, *"CHARGE syndrome, what's that?"* Be sure to get your copy before we sell out. Visit www.chargecalendar.com.

## Shop to Spread the Word

Whether you wear it on your wrist, hang it on the fridge, or use it to cover your bald spot, the CHARGE Syndrome Foundation logo helps spread the word.

With the holidays approaching, consider gifts that give back. Every purchase at the CHARGE Syndrome Awareness Store not only supports the Foundation, but also spreads the word about CHARGE.

New Items

Visit the CHARGE Syndrome Awareness Store.

## Online Awareness

The CHARGE Syndrome Foundation is a Google Grant recipient. This special award entitles the Foundation to a Google AdWords account (valued at $10,000 per month) to build awareness of our mission and programs.

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# Brady Makes an IMPACT

Team IMPACT works to improve the quality of life for children facing life-threatening and chronic illnesses by matching these courageous kids with college athletic teams. The child gets to join a team, and in turn, the athletes become part of the child's support team. Each child gains great strength, camaraderie and support, while the athletes learn lessons about courage and resiliency.

Brady Antaya is 7 years old with CHARGE syndrome, and is part of Team IMPACT.  Brady joined the Merrimack College men's soccer team and recently caught the attention of the NCAA.  Brady appeared on the cover of the fall issue of NCAA Champion magazine.

Read more about Brady at NCAA Champion Magazine

Learn more about Team IMPACT

NCAA CHAMPION

VOLUME 7 • ISSUE 4

FALL 2014

Truly teammates

Team IMPACT's Brady Antaya – just another Merrimack Warrior

PLUS

Before the College Football Playoff: four decades of college football playoffs

How a community and a college are helping Julio Luevano achieve his American dream

www.NCAAChampionMagazine.org

# Meet Jack

*Submitted by Elaine Murray-Bell*

Jack is 17 years old and has been through so much in his life, but he doesn't let it hold him back.  He has had over 25 surgeries and procedures– Open Heart Surgery, surgeries to insert a PEG feeding tube, to remove kidney stones, to repair a detached retina, orchiopexy and various cardiac catheter, MRI & CT scans.

He did not walk independently until he was 4, and has poor balance.  Jack uses a long cane to help him get around.  Living with CHARGE is never easy, but Jack has a determination to succeed in all he does.  He has no vision in his left eye and limited vision in his right but his favorite activities are reading and computer games.  He also goes Pony Carriage Driving and loves the freedom and exhilaration it gives him.

Jack is very outgoing and sociable with adults but prefers his own company to that of his peers.  He is happier in small groups, as large groups and crowds overwhelm him.  He attends mainstream school with 1:1 support and was recently presented an Outstanding Achievement Award from University of West of Scotland for Overcoming Barriers to Learning.

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# Meet Dominic

Submitted by Deanna Steinhauser

Dominic is 6 years old and in Kindergarten. He has vision and hearing impairment, and does not swallow independently all the time. He has a suction machine to clear his secretions, and wears a pulse oximeter to monitor his oxygen levels. He needs oxygen at night to sleep, and eats solely through g-tube feedings. He uses sign language to communicate and LOVES life. If you take away all the machines, Dominic is a typical little boy who loves to play Miracle League Baseball, go to gymnastics and play with his friends. He is always happy, loves hugs and kisses and wants to always include everyone in everything he does. Dominic embraces the life he has been given and doesn't take any minute for granted.

## A Day in the Life

Lately I feel like more and more people ask me questions, so I thought I would lay out a day in the life of Dominic.. I am not writing this for pity. I am simply writing this to give people a true perspective on everything that goes into Dominic. From explaining why we don't go anywhere to stay over for just one night, to why we have to pick hotels based on whether they have a fridge and a sink in the room. Even having to stress over paying for a whole house generator because when the power went out, and he was sick it scared me half to death. There's even the small things: Is he healthy enough to go to Thanksgiving? Can I let him go to the Children's museum without worrying about all the germs he will be exposed to? Will this restaurant fit his wheelchair? Every decision I make is based on Dominic's day, and if he is able to be a part of what we are doing, or if I need to have a nurse to stay with him while we do what we have to and he is home with someone else. It is not easy constantly going somewhere with part of your family missing, but that's our reality, and what goes into a day in the life of Dominic.

Read More About a Day in the Life of Dominic

Submissions for the Spring 2015 edition of CHARGE Accounts are due by February 15th.

We love to include personal stories from families as well as individuals with CHARGE syndrome. Submit articles to Joanne Lent.

The CHARGE Accounts Submission Guidelines

# Partnership Opportunity: Council for Exceptional Children

Submitted by
Amy Parker, Ed.D.
CEC's DVIDB Deafblind Committee Chair

Council for Exceptional Children
The voice and vision of special education

As the mother of two children, one with a disability, I know, in an intimate way, the power of family and professional partnerships. For individuals with the rarest disabilities, partnership isn't simply a nice idea; it is essential to define a field of expertise and practice. The CHARGE Syndrome Foundation is known for its dynamic action to generate research, education, and empowerment to better the lives of families and people with CHARGE syndrome across the United States and internationally. As a professional in the field of DeafBlindness, I grow through my affiliation with your organization. Now I am reaching out to you from an organization where many invest their energy to serve students who are DeafBlind.

The Council for Exceptional Children (CEC) is a highly respected international organization for special education professionals that the Department of Education, Office of Special Education often looks to for guidance when creating and implementing policy. Additionally, the CEC works to define and improve upon special education practices for all students with exceptionalities. Through its divisions, CEC members seek to address specific areas of need and focus. Recently, the Division on Visual Impairments stepped forward to include DeafBlindness in the name of its division — DVIDB. Just a few years ago, leaders within DVIDB worked with the field to create knowledge and skills competencies for teachers of the DeafBlind and for interveners. These competencies help to define standards for specific direct service roles for students who are DeafBlind in educational systems; they are also useful for designing appropriate training programs for these roles. Our division needs family partners to be aware of and invested in the ways teachers and interveners are prepared and supported in serving students who are DeafBlind.

As we ready our field for the future by collaborating to create policies and practices that meet the needs of students who are DeafBlind, our professional and family organizational partnerships can provide us with a compass. This year, the CEC's DVIDB is focusing on policy that makes a difference for students at the local level. We need your voices and influence as organizational partners so that we may effectively represent students who are DeafBlind throughout our efforts. For more information about the newly named Division on Visual Impairment and DeafBlindness, please visit this website and be sure to check out the DeafBlind portal: http://community.cec.sped.org/dvi/home/

*I look forward to seeing many of you in Chicago this summer.*
*Consider this your official invitation to attend the CEC convention in San Diego in April 2015.*

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THE CHARGE SYNDROME FOUNDATION

318 Half Day Road, #305
Buffalo Grove, Illinois 60089

Our New Address

## *Holiday Shop for a Cause*

With the holidays just around the corner, start your online shopping at one of the following links, choose *The Charge Syndrome Foundation* as your charity, and we receive a percentage of your purchase as a donation:

goodshop

amazonsmile
You shop. Amazon gives.

iGive.com

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