President’s Message

For many of us, 2020 has turned our normal routines upside down, disrupted our employment, and impacted our lives in ways we never could have imagined. We are a strong and resilient group. We are used to challenges and relying upon our large CHARGE family for help and support. In these chaotic and often disheartening times, I have never been prouder to be a member of the Foundation.

When our families needed help, we put together our Family Assistance Programs to provide much needed financial support to CHARGE families that have been adversely affected by the pandemic. We rallied together with our WalkandRoll4CHARGE and raised over $40,000 to help families. We took to our Facebook group to offer words of encouragement, advice for one another, and to raise over $27,000 for our programs. We provided drop in calls and webinars. We are even providing free clear face masks for all of our members that need them. As you will see in this newsletter, we are not done yet!

This edition is packed full of resources that I am sure you will find helpful. We are also continuing our A Day to Remember tradition. Can you think of a better way to honor those in our community that passed away, than an act of kindness? We are rolling out our new and improved Charge It for CHARGE that will work well with Facebook. The funds we raise will enable us to continue our Family Assistance Programs, research and day-to-day functions.

I hope that as we continue to face the challenges of 2020, we all choose to be involved with the Foundation, to be kind and supportive to each other, and to always put love before hate.

Stay well.

David Wolfe
President
here is so much uncertainty surrounding this school year. Every school district has a different reopening, remote, or hybrid plan and every family has their own idea about the best way to balance their child's health and education. There are no easy answers and the rules are constantly changing. The resources below offer things to consider if you have a choice whether to stay remote or when to have your child return to school in person.

**Map: Where are schools open?**
State-by-state map of where school buildings are open or closed, from *Education Week*.

**What will it take for schools to reopen?**
As parents, educators, and state and local officials grapple with the big question on everyone's minds, Prepared Parents' Co-Founder Mira Browne explains the options and looks at what it will take to reopen schools safely. From Great Schools.

**Supporting your child’s mental health as they return to school during COVID-19** by UNICEF

**STEP's Return to School Planning Guide**
This guide from the Support and Training for Exceptional Parents (TN) features specific worksheets to help families as they prepare for how their children with disabilities will receive the services and supports outlined in their IEPs.

**CDC checklist** to guide your decision making about going back to school.

**Navigating Special Education Today: What Parents Need to Know**
A 4-week workshop presented by the Maryland and DC Deaf-blind Project and the Family Support & Resource Center. The workshop will address how the current situation affects special education while providing a greater understanding of the special education process in general. Begins October 7.

**Rethinking Deaf & Hard of Hearing Accessibility in Post-COVID-19 Classrooms** produced by California Hands & Voices

**Going Back to School During COVID**
Advice from the Child Mind Institute, including Strategies for Supporting Learning at Home, Tips for Partnering with Teachers, and How Teachers Can Support Students during distance learning.

**Strategies to Support IEP Goals During COVID-19**
Children's Specialized Hospital and the Autism Science Foundation video addresses how parents can address their child's IEP goals at home or in the community. Also see the **ASF & COVID-19 Webinar Series: Managing Trauma, Reducing Challenges in Wearing PPE, Resiliency, Telehealth, and Self Care.**

**Establishing Routines at Home**
This webinar is for families, educators, and state deaf-blind projects. It is the first in a series of webinars on instructional strategies for children and youth who are deaf-blind. For information on the full series see the **NCDB Professional Development Series: Deaf-Blind Strategies page.**
Masks, Face Shields and Gloves, Oh MY!

Written by Tara [no last name], a speech/language pathologist who specializes in autism.

Click here for links to social stories about the different types of masks, face shields and gloves people might wear in different settings. (Some of the stories are available in several languages.)

Additional COVID-19 related social stories include: Riding the Bus Will Be Different, What is Social Distancing, Using My Own Materials at School, and When Can I Stop Wearing A Mask?

Key Topics for Families During COVID

The National Center on Deaf-Blindness web page is FULL of useful resource links. Topics range from self care, home activities, assessing services, distant learning to experiences of individuals with deaf-blindness and online training and webinars you can participate in from home, including some state-specific links.

https://www.nationaldb.org/for-families/family-topics/

Virtual IEP Meeting Tip Sheet

The article has links to several one page tip sheets, with topics including Technology Tips for participants, Common Questions and Answers about Hosting Virtual IEP Meetings and several others. The Sample Virtual Meeting Agenda and Participating in Virtual Meetings tip sheets are offered in both English and Spanish. Click here.

Virtual Field Trips

Have you ever wanted to visit Paris, Mars or a Farm but couldn’t? This link is for you! With links to more than 30 virtual Field Trips, you can visit a zoo, a national park or an aquarium.

Have fun and safe travels!!!
Accessible Story Time!

The CHARGE Syndrome Research Lab at Central Michigan University and DeafBlind Central: Michigan’s Training and Resource Project are excited to bring you an accessible, virtual story time! With so many of us stuck at home, we wanted to bring a fun learning opportunity to you and your family! By closely collaborating with an ASL interpreter and an ASL storyteller, we produced recordings of 12 children’s books of varying reading levels (emerging, intermediate, or advanced reader), along with 12 ASL vocabulary lessons for each book. We hope these videos not only provide families with entertainment, but also an opportunity for parents to learn how to make books more accessible for their children, and for youth to develop ASL and reading skills.

All stories have:

• English narration • English closed captioning • Pictures of the book pages
• ASL interpreting • Corresponding ASL vocabulary lessons

How to consume these stories:

• Make a tactile experience box to accompany the books. Use the tactile objects while watching and listening to the videos to increase accessibility and concept development for children with significant vision loss.

• Learn more about tactile experience boxes, here.

• See an example of a tactile experience box for the book *If You Give a Pig a Pancake*, here.

• If possible, try to incorporate real objects into the experience box, as this is helpful for concept development.

• If you are a family in Michigan, contact DeafBlind Central at dbcen@cmich.edu to borrow an experience box for free!

• Watch the ASL vocabulary lessons before watching and listening to the stories. Practice and model the signs during the lessons. Encourage your child to sign along with the ASL vocabulary lessons.

• Watch and listen to the stories! Model the signs during the stories and encourage your child to sign along with the stories. Incorporate the experience box into the story.

• The videos can be found on DeafBlind Central’s website, here!

• Our wonderful book readers are: Anna Weatherly, Beth Kennedy, Lily Slavin, Mae Woodke, Sarah Sykes, Shelby Muhn, and Tim Hartshorne.

Thank you to everyone who made this project possible:
Beth Kennedy, DB Central’s amazing Project Director, who brought our team together and coordinated this project to maximize accessibility
Kristin Knight, DB Central’s excellent Family Engagement Coordinator, who put together the vocabulary lists and helped advertise the project
Diana Campbell, our extremely talented ASL Specialist/Storyteller
Helen Boucher, our fabulous ASL Interpreter
Sarah Sykes and Lily Slavin, current and former DB Central Summer Interns and CHARGE Lab Graduate Research Assistants, who spearheaded this project and helped with scheduling, closed captioning, advertising, editing, and general logistics.
What's something surprising that you learned about your child or your family during this pandemic?

**Laurie Suter:** Lacey wore a mask, which I didn’t think she would as she is so sensory defensive. Lacey doesn’t understand what Covid is, but she keeps her masks on even though she doesn’t understand why she is wearing it. I am so proud of her!!

Lacey has had some difficulties, though, because she doesn’t understand why she isn’t doing her usual routines and going to her adult day program and doing the things she likes, like horse back riding therapy, yoga, adaptive dance class, swimming, bowling, etc. She has been pinching and digging at her skin and making marks on her skin and causing a lot of bruising (she is not mad when she does this), and pinching me more. Her PCP feels she is depressed, which makes sense. She is now taking a small dose of medicine and it has helped her.

As a family we are resilient!! We are very close, we have been strong and have earned not to be stressed and worry about things. Because we have a very strong faith, even COVID-19 can’t break up our spiritual routine and our happiness! So glad we have zoom! And I personally have learned to have lots and lots of patience.

**Katrina Michel Stevanovich:** I was surprised to see Lili make progress despite not attending therapies in person and having the option of getting teletherapies with only a few of her therapists, which really had me bummmed (she has so many therapies!). Sadly, the systems isn’t set up for things like this. Something else we discovered: the phenomenal virtual resources, webinars, trainings, etc. It is really great seeing educators from all walks of life, from around the world, teaching many different categories. I have really learned a lot and with that comes some really great takeaways to continue to strive at being the best possible parent, nurse, teacher (and the many other hats we CHARGE moms wear) to my sweet Lili.

**Jodie Beavers:** Nolan does better wearing a mask than we do and complains a lot less. He really, really misses school and having his usual routine. He keeps asking when Coronavirus is going away. Wish we knew, Buddy!

**Minnie Lee Lambert:** I love to tuck Andrew in then head to my room to listen to him on the monitor. One of the very first things I hear is him opening the shelf on his headboard to set his alarm clock. He sets and wakes to his alarm clock independently. That's one IEP goal we can mark as MASTERED when he goes back to school! Yes, he's on vacation and yes, he still gets up at the same time every morning. Before you judge - it's 10 am, 9:30 on Friday morning, and no alarms on the weekends!

What does Andrew do while I work? He is certainly NOT sitting on that phone or laptop all day! He chooses the activities and I create his list then he can decide what he does when!
Family Assistance Program Update

We’re happy to announce that the CHARGE Syndrome Foundation Family Assistance Program has helped over 100 families to date! 
Every qualified applicant received a financial award!

Thanks to the Berman and Schechter families and all WalkandRoll4CHARGE participants, we are continuing to accept applications for assistance.

This assistance is provided in the form of a check or a Walmart or Amazon Gift Card, to be used for bills, groceries and other expenses associated with self-isolation and quarantine.

IF YOU HAVE AN INDIVIDUAL WITH CHARGE IN YOUR HOUSEHOLD AND NEED HELP PAYING BILLS OR PURCHASING NECESSITIES DUE TO COVID-19, CLICK HERE TO APPLY

IF YOU ARE IN THE POSITION TO HELP SUPPORT THIS DIRECT ASSISTANCE INITIATIVE, PLEASE CONSIDER DONATING

On September 21, our CHARGE community will take A Day to Remember to honor those individuals with CHARGE who have passed away.

This year during this time of uncertainty, it is especially important for us to be kind and patient with each other. During the week leading up to September 21, we ask you to perform an act of kindness and share it with the Foundation on social media using the hashtag #adaytoremember.

Last year, our CHARGE community shared with us their many wonderful acts of kindness. From treating teachers and classmates to lunch or goodies, picking up trash in their town, or sending a note or e-mail of encouragement to a friend or stranger, there are so many ways we can be kind to each other. Please click on the video or link to get some ideas of how you can REMEMBER this year.

Visit our website here for grief support materials and information about the grief support group offered through the National Center on Deaf-Blindness.

SAVE THE DATE
A Day to Remember
SEPTEMBER 21, 2020
Our first virtual event was a success! On June 13, members of the CHARGE community around the country - and in Ireland - emerged from isolation and walked, rolled and strolled to raise awareness of CHARGE syndrome. More than 60 individuals and teams raised over $40,000 for the CHARGE Syndrome Foundation Family Assistance Program. Check out this video featuring walk participants. Thanks to all who participated and donated.

Barthe, Jill – Team Louisiana Let the Good Times Walk & Roll4CHARGE
Beavers, Mallorie – Miles for Michigan
Beavers, Jodie – Miles for Michigan
Bittelari, Lindsay – Perkins Deafblind Program
Bradshaw, Jill – Texas Chargers
Brown, Kelli
Bull, Robin – Team Kansas
Carlson, Kristin – Perkins Deafblind Program
Cheek, Cybill – Team Kentucky
Chen, Suzanne – NY CHARGE
Connaughton, Megan – Perkins Deafblind Program
Corn Collette, Lisa – Team Kansas
Covelli, Andrea – Perkins Deafblind Program
Cowling, Alison
Daigle, Ben & Katie – CT CHARGE
Dohl Menconi, Tina
Echols, Penni – Nevada CHARGE Syndrome
Espanet, Sara – Perkins Deafblind Program
Gallimore, Thornton – Team Illinois
Garrison, Megan – PNW CHARGE Families Together!
Gomez, Jamie – Walk4JOE
Hannan, Fran – Louisiana Let the Good Times WALK & ROLL4CHARGE
Hartshorne, Jake – Miles for Michigan
Herod, Heather – New Hampshire Families CHARGE ON
Herrick, Shawn – CHARGE on for Cole & Friends
Irving, David – Sam’s CHARGERS
Knutson, Kristin – South Dakota Prairie Chargers
Kurby, Sandy – Kurby Krew
Lambert, Minnie – Team SC!
Lauger, Kim & Roy – Arizonans Together in CHARGE
Leech, Deirdre – CHARGE Syndrome Ireland
Lent, Sarah
Lin, Michelle – New Hampshire Families CHARGE ON
Lindquist, Maria – Nebraska Walks and Rolls 4 CHARGE
Lonardo, Cristy – Perkins Deafblind Program
Manobanda Castro, Jelixa
Martin, Anna
McCall, Russell
Mehta, Amrit – Miles for Michigan
Merrill, Lydia – PNW CHARGE Families Together!
Michel, Katrina – Florida Friends!
Mohnkern, Bethany – Perkins Deafblind Program
Pell, Stephen – Perkins Deafblind Program
Penton, Amanda – Team Kalob
Petersen, Angela – Team Illinois
Premo, Chelsea – Miles for Michigan
Probst, Kristi – Team Kansas
Radke, Teri – Team Kalob
Rosinski, Kaitlin – Team Cassidy
Sadikot, Takrima – Team Kansas
Schmittel, Megan – Perkins Deafblind Program
Scholl, Courtney – Nebraska Walks and Rolls 4 CHARGE
Shirley-Douglas, Donia – Florida Friends!
Slavin, Lily – Miles for Michigan
Smith, Kate – On the Move in Missouri!
Solomon, Erika
Stanger, Sheri & Neal – NY CHARGE
Stelzer, Sharon – Perkins Deafblind Program
Suter, Laurie – New Hampshire Families CHARGE ON
Sykes, Sarah – Miles for Michigan
White, Carol
Wolfe, Jody & David – Team Illinois

Support the CHARGE Syndrome Foundation while you shop

AMAZON SMILE NOW AVAILABLE IN THE APP!
How to use Amazon Smile
Facebook Fundraisers Raise Over $27,000 so far in 2020!

Thanks to all who have supported the CHARGE Syndrome Foundation with a Facebook fundraiser, with special recognition to everyone who started a fundraiser during this COVID-19 pandemic. Your support and the generous donations of your family and friends are greatly appreciate.
Create Your Facebook Fundraiser to support the CHARGE Syndrome Foundation. It’s easy!

**CHARGE It For CHARGE**
Charge It for CHARGE is the online fundraising campaign of the CHARGE Syndrome Foundation
Every dollar donated helps fund research, outreach, and conferences, and provides assistance to our families

**Thank you to our fundraisers!**

- Melissa Coward
- Aubrey Williams
- Jayme Weinert
- Minnie Lambert
- Tracey Busby
- Jessie Beals
- Sabrina Landau
- Amy & Max McKinley
- Neal Stanger
- The Shikora Family
- Julie & Jay Brandrup
- Hollie St. Arnauld
- Tracy Roth
- Allie Jones
- David & Jody Wolfe

*Stay tuned for our next campaign, starting soon!*

---

NEW MASKS IN OUR AWARENESS STORE!

*Earloop Face Mask • Tie Face Mask • Clear Face Mask • Camo Face Mask*

Whether you wear a mask for your child, parent, sibling, friend or whole community, we all can do our part to protect our families and keep us healthy and safe.

**ORDER YOUR MASK HERE.**

Share your photos of you wearing your CHARGE mask on social media.
Use the hashtag #IWearMyMaskFor

**Click Here for Ideas to Help Individuals with Deafblindness Learn to Wear Masks**