



CHARGE Accounts

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.

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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

Back to School? More Questions than Answers

There 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.

Remote Learning Resources

Starting the school year remotely? Visit the [CHARGE Syndrome Foundation](#) and [FAVI Deaf-Blind Collaborative](#) websites for resources and activities.



Masks, Face Shields and Gloves, Oh MY!

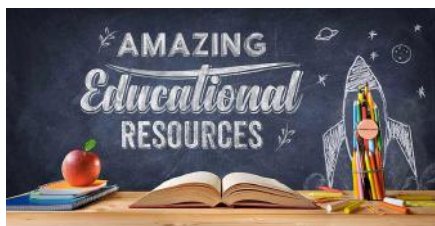
Written by Tara [no last name], a speech/language pathologist who specializes in autism.

[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?



Although geared toward the autism population, the University of North Carolina School of Education website resource [Supporting Individuals with Autism Through Uncertain Times](#) includes strategies and information regarding COVID-19, Coping and Calming Skills, Building and Maintaining Routines, and Behavior Supports, all of which might be helpful for families living with CHARGE.



This free resource sharing site currently has over 1,524 resources in their searchable, accessible database. The site is always looking to add more, so if you have one you think others could benefit from, you can submit it. [Click here.](#)

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



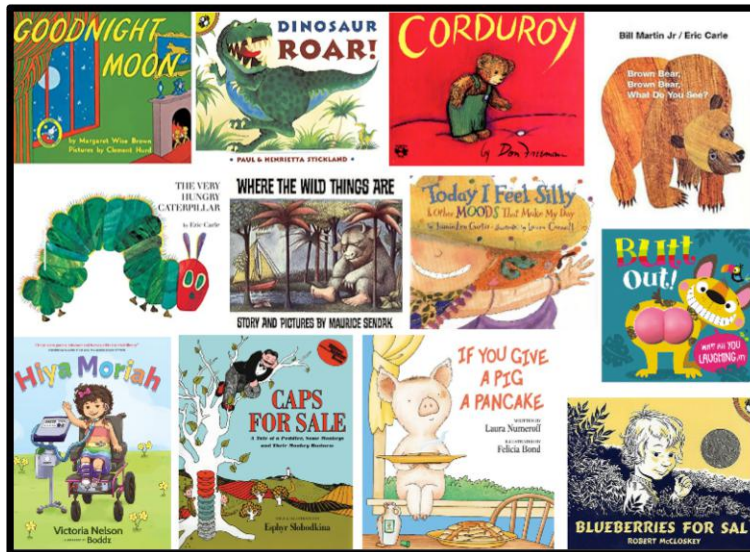
Have you ever wanted to visit Paris, Mars or a Farm but couldn't? [This link](#) is for you! With links to more than 30 virtual Field Trips, you can visit a zoo, a national park or an aquarium.

Have fun and safe travels!!!

Accessible Story Time!

by Lily Slavin

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 bummed (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 take-aways 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.

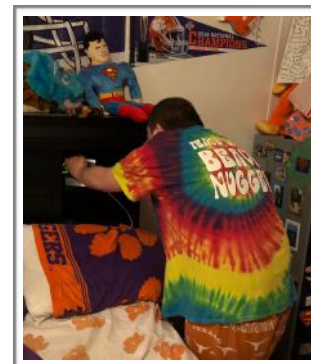
Jodie Beavers: Nolan does better wearing a mask than we do and complains a lot less. He really, really misses school and having his usual routine. He keeps asking when Coronavirus is going away. Wish we knew, Buddy!



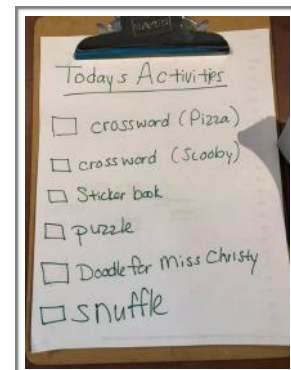
Minnie Lee Lambert: I love to tuck Andrew in then head to my room to listen to him on the monitor. One of the very first things I hear is him opening the shelf on his headboard to set his

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](#)

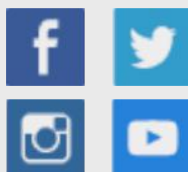
IF YOU ARE IN THE POSITION TO HELP SUPPORT THIS DIRECT ASSISTANCE INITIATIVE,
[PLEASE CONSIDER DONATING](#)

**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.



KEEP UP WITH OUR STORIES AND POSTS

FOLLOW US ON SOCIAL MEDIA

SUBSCRIBE TO OUR YOU TUBE CHANNEL

Focus on Fundraising



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, Robbin – 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

amazonsmile
You shop. Amazon gives.

AMAZON SMILE NOW AVAILABLE IN THE APP!

How to use Amazon Smile

Focus on Fundraising



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.

Ahmed Elamrani	Emma Sweeney	Lisa Michelle
Alissa Garcia-Hobson	Eric Klug	Lori Biondo
Allie Lachman	Eric Mack	Lorne Littlejohn
Amanda L. Ward	Erica Reeves	Lura Kirby
Amara Robles	Eugenia Guillén	Mackenzie Colp
Amrit Mehta	Havens Journey	Macy Ayala
Amy Chaps	Filip Johansson	Maggie Eubanks Poole
Amy Pratt	Freya Chandler	Makayla Williams
Amy Trainer	Gail Stout	Marcella Rebecca Collins
Angeline Rabary	Ingrid and Anna Lobaugh	Marilyn Fox
Anita Ross	J Vaclav	Mark Dynes
Anna Floyd	Jacob Gray	Mary Hutchison
Antonia Santiago Roberson	Jamie Strong	Mathieu Van Waes
Anysa Green	Janay Mohamed	Matt Brand
April Crandall	Jane Von Dohre	Maureen Marsolan
Ashley Mikayla	Janice Bridgewater	Meghan Bryant
Ashley Gallop	Jasmine Mangan	Melissa Sikora
Ashley Sue Lester	Jeanne Rutan	Michael Saruski
Ashley Rae Schell	Jeff Snyder	Michaela Hackett
Barbara Lambert Player	Jennifer Herron Gillett	Michelle D'Agostino
Bennie Harris	Jennifer McIntire Davis	Michelle Touceda
Bayley Webb	Jennifer Peterson	Mike J. Mohler
Bennettreesecampbellmelsam Stalter	Jenny Van Waes	Mike Vyn
Bianca Pubill	Jered Calvin Southwick	Minnie Lee Lambert
Billie Watson	Jeremy Kitlinski	Missy Capozza Gulley
Bonnie V Maka	Jerry Cowling	Moira Saunders
Bryan Alston	Jessica Cahill	Monica Farthing Hieb
Callie Sutcliffe	Jessy Nilsen	Monica Villa Guzman
Camila Arsenault	Jika MK	Nancy Remspear
Catherine Leanna Laswell	Jill Barthe	Naptown Bourbon Club/Jason Fruits
Cathie Josephson	Jillana Reuter	Neil Proctor
Celeste Nycole	Joanne Sclafani Lent	Nic Adams
Char Warner	JoLea Urrutia	Nick Krull
Chelsea Premo	Jordan Lively	Onward Podcast & Onward Movement
Cheyenne Ball	Joseph Hill	Paige Krebs
Chip Dixon	Kaitlin Longano	Pam Pace
Chloe Wild	Karina Jazmín Guerra	Pamela Weimer
Christine Kalaway Huff	Kathi Barksdale	Patrick Ames
Christopher H. Hudson	Kathy Moscato Farese	Paul Gilman
Cindy Ruark-trainer	Kathleen Hill	Payton Black
Claire Schramm Boudon	Kathryn Williams	Racheal Stephens
Claudia Eargle Kirkland	Katie Reding	RazZae Klean Maree DeGeest
Cornelia McPherson	Katie Rye	Rebecca Cliffe
Daniel Hansen	Kayla Fairchild	Rebecca Hood
Darlene Norman	Kelly Hagen Pedersen	Rebecca Jenkins
David Brown	Kerri Hoffman Cochran	Rebecca Leigh Ingram
David Sanders	Kim-Kristina Bergner	Reyina Rosa Luevano
Dawn Webb	Kimberly Hollister	Robert Patrick Paulson
Debbie Dukes Smallwood	Kristin Markley	Ron Galloway
Dee Allaway	Kristy Benston	Ronalda Russell Smith
Destiny Chinnici	Lara Baggs	Ryan Scott
Devlin Michel	Laurie Beth O'Daniel	Sammy Sunshine
Donia Shirley Douglas	Lily Slavin	Sandra H Campos
Emily Hermus	Lisa Belyea Campbell	

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Sarah Gardner
Sergio Reyes
Shannon Perdue
Sharon Hargis Chatham
Shawn Short
Shawna Myers Hyslope
Shelby Anderson
Stacie Holder
Starlette Pace

Steph Preuss
Stephanie Nai
Tedi Kramer
Teri Christensen
Teri Woodward Radke
Terry Smith
Theresa Buelman
Tracy Allred
Tracy Baumann

Tranique QueenShyt Gordon
Tristin McInteer
Valerie Ross
Victoria K Points
Vikki Kujacznski Locke
Viktoriya Schatz
Walter Touceda
Wendy Pickwoad-Lemaire
Zmaja Babic

Create Your Facebook Fundraiser to support the CHARGE Syndrome Foundation. It's easy!



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
Laurie Suter
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](#)

