CHARLOTTE'S HOPE
FOUNDATION

NEWSLETTER

Fall 2023

Dad carefully hooks up the nutrition bag for his infant foster baby boy's Gastrostomy-Tube (G-Tube) feeding. Mom sways with his twin sister in her arms while looking over sheet music. The couple came to play in the band for today's event where Emily K. Whiting is the keynote speaker. After Emily's talk, Mom approaches Emily, teary-eyed. Mom shares how these beautiful babies born prematurely have already faced immense medical challenges, with more to come. The women embrace, cry and laugh together, sharing the unique connection between parents of children with medical complexities. Emily gives Mom a copy of the book *She is Charlotte*, a journal and an *Empowered by Hope* podcast flier.

Several months later, Mom reaches out to Emily saying, "I've been listening to the *Empowered by Hope* podcast and have read Emily's book. These resources have made such an impact on my life and my ability to parent these precious little babies…thank you for being there when we needed to know we weren't alone."

Being there for her and countless other parents and caregivers, THAT is the mission of Charlotte's Hope Foundation, Inc. (CHF) and we are so grateful for your part in furthering that mission.

HELLO!

It is amazing how some of life's most difficult and scary experiences lead us to life-changing opportunities. Each of us having babies with medical complexities is directly responsible for the creation of CHF, and oh, what incredible things are resulting from this nonprofit since its official inception April 2022!

In our inaugural newsletter to supporters, partners, friends and family, we share the incredible wins toward fulfilling our mission, projects in progress, events to look forward to, and an introduction to the incredible people serving on the CHF Board.

The success and growth of CHF is largely due to your support and encouragement. For that we are humbled and full of gratitude.

ashlyn emily

Ashlyn Thompson and Emily K. Whiting
Co-Founders & Executive Hope Directors

Emery, daughter of Ashlyn, has endured two harrowing surgeries in her short two years, but, oh, how she has soared. Her first surgery closed her abdomen where the bladder was visible and vulnerable, as well as reset her hips. She was a mere seven-weeks-old at the time of that surgery and she was placed in traction, which meant she could not be held for four weeks. She rebound quickly, but it did not solve the long-term complication of highly probable life-long incontinence.

Unwilling to accept this fate, Ashlyn found a skilled surgeon in the United Kingdom who performs a bladder/urinary system reconstruction procedure not offered in the United States. After copious amounts of research and virtual discussions with the surgeon, it became apparent his years of experience and successful track record were proof enough this was the next step in Emery's care. The Thompson family packed their bags and journeyed to London this Spring, where Emery became a medical tourist just before her second birthday. After a grueling five-week recovery, they traveled home. Emery's prognosis is excellent!

LIFE UPDATE FROM THE GIRLS WHO INSPIRE THIS MISSION

Five-year-old Charlotte has finally received a diagnosis! The Cleveland Clinic Children's Genetics team used the Whole Genome Sequence (WGS) to identify her condition as MED12 Hardikar Syndrome (HS). Ultra-rare is an understatement. Less than ten cases are documented world-wide, though through the work of CHF, more surface weekly!

For the first time ever, her mother Emily says, “we've found other families who can relate to our journey in a very practical, lived way.”

Charlotte recovered from her 17th procedure this Spring, with upwards of ten more anticipated in her future. But “our beautiful little girl continues to beat the odds and do so with joy and resiliency,” says Emily.

OUR MISSION:

Charlotte's Hope Foundation exists to support, encourage and educate parents and caregivers of children with medical complexities, embracing each family's reality with an outlook of hope and empowering them as capable advocates for their child's optimal quality of life.

TOP THREE 2023 PRIORITIES:

To be the first touchpoint for families upon receiving diagnosis—be the lighthouse for the parent and caregiver caught in the medical storm:

1. Foster partnerships with other parent support organizations.
2. Develop and drive podcast content.
3. Book keynote speaking engagements.

EMPOWERED BY HOPE PODCAST HITS THE AIRWAYS

With the goal of reaching parents and caregivers in their time of need, a podcast seems the most fitting form of media. Parents and caregivers are on the go between outpatient appointments, hospitalizations and at-home caregiving needs. Thus, the inception of the *Empowered by Hope* podcast, which can be listened to from anywhere, on any device, from any podcast platform.

Board member Ben Krueger is founder and owner of Cashflow Podcasting, a podcast launch service and production company. With Ben and his team's expert advice and guidance, the *Empowered by Hope* podcast is a growing success!

Since posting the first episode in December 2022, the show has surpassed 1,500 downloads and more than 30 episodes aired.

Topics range from "Your Child's Diagnosis is NOT Your Fault" to "How to Handle Insurance and Medical Bills with Confidence." Nearly one-third of the episodes feature guests ranging from seasoned moms and dads to medical professionals and other parent support organization leaders.

Rack card fliers promoting the podcast are currently distributed in Cleveland Clinic Maternal Fetal Medicine offices, NICUs and PICUs, as well as Ronald McDonald House Cincinnati, and are already making an impact.

If you haven't tuned in to an episode yet, we invite you to do so. And, don't forget to subscribe for the latest content!

SHE IS CHARLOTTE TOUCHES HEARTS

The book *She is Charlotte: A Mother's Physical, Emotional, and Spiritual Journey with Her Child with Medical Complexities* hit #1 New Release in Pediatrics Books within the first 24-hours of availability on Amazon and maintains a 5-star rating from every customer review. Here's what a couple readers are saying:

"This is a story you need to know:
She is Charlotte is one of those rare books that inspires, challenges, captivates and gives hope, regardless of the reader's own life experiences thus far... *She is Charlotte* is more than a book, it is an experience with the potential to positively change one's perspective and provide hope, even when all hope feels completely lost."

"What a beacon of hope and inspiration:
Her (Emily's) writing is gut wrenching and so real, that you come to more closely understand what a mother goes through, all the ups and downs of caring and navigating the medical web for such a child, while testing her trust in God through it all... You feel as if you are there with her every step of the way. One cannot put this book down for the writing is truly amazing and awe inspiring."

Get your copy if you haven't already (available on Amazon.com and CharlottesHopeFoundation.org)! If you have read the book, thank you! We would love to hear your thoughts via a review on Amazon.

Our focus now turns to bulk book sales for larger distribution, selling books at speaking opportunities, conferences, hospitals, etc., because the more people have access to the book, the more parents and caregivers CHF can support.

MEDIA EXPOSURE LEADS PARENTS TO CHF

A girl named Charlotté

Charlotte Whiting works with some toys to keep her busy as she listens to her mom, Emily, talk about her life.
MIKE SCHENK/THE DAILY RECORD

Family coping with child's many health issues

Linda Hall
Special to Wooster Daily Record

A Doylestown woman and her husband received shattering news in July of 2017 at the 20-week ultrasound of their unborn child.

Emily and Dan Whiting were looking forward to a happy occasion, learning from an ultrasound whether their child would be a boy or a girl during what they thought would be a routine appointment.

They found out they were going to have a girl, but their moment of elation was short-lived. They didn't foresee hearing she had multiple medical issues, literally from head to toe, involving multiple organs. Nor did they anticipate asking the question, if she survived delivery, what would her prognosis be?

"Will we have two minutes, two days, two years, or 20 years?" Whiting recalled asking, discovering the answers changed "minute by minute."

She could not have envisioned God leading her on a path to becoming a future advocate, not just for Charlotte, but for other struggling families, through a book, a podcast, and a nonprofit foundation.

Who decides on 'quality of life'?

Terminating the pregnancy "was never an option for us," Whiting said. "My husband and I were very blessed to really know and value the dignity of life. It wasn't up to us to end it," she said. "Do we even know what quality of life means? Who are we to decide?"

However, she clarified, she gained an "immense amount of empathy and love for parents who find themselves in a similar position and don't feel confident to keep the pregnancy. I can see what a difficult position that has to be."

She does not support it, "but I understand how it is a thing," she said.

It's why she has made it her goal to come alongside other families whose children are combating complex medical conditions and "help them feel equipped that they can do it."

While doctors care for the children, "there is a huge gap for taking care of the parents."

Many tests and evaluations later, Charlotte's specific condition was just recently specifically diagnosed using the Whole Genome Sequence. Here is one of only nine other documented cases worldwide of MEDEI Hardikar Syndrome.

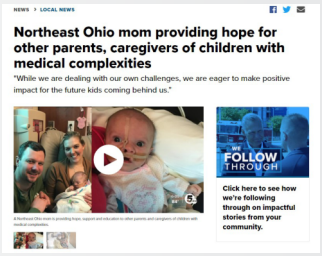
An ultra-rare disorder, it encompasses cleft lip and pallet, bile duct abnormalities, liver disease, intestinal malrotation, pigmentation of the retina, narrowing of the aorta and vascular anomalies, kidney and bladder irregularities, and more.

Whiting's book, "She is Charlotte, A Mother's Physical, Emotional and Spiritual Journey with Her Child With Medical Complexities," published in January, narrates the beginning of their medical journey, encompassing the remainder of Whiting's pregnancy through Charlotte's birth in November 2017 and the nearly three months she spent in Cleveland Clinic's neonatal intensive care unit.

Whiting's book chronicles the unrelenting fatigue and overwhelming emotions she and her husband experienced as Charlotte's condition fluctuated between medical milestones and defeating setbacks.

See CHARLOTTE, Page 2A

"I've now listened to the diagnosis podcast (episode 21), and I cried the whole time. In ten years, nobody has ever related with what we are and have been through with my daughter." Ashley



NEWS > LOCAL NEWS

Northeast Ohio mom providing hope for other parents, caregivers of children with medical complexities

"While we are dealing with our own challenges, we are eager to make positive impact for the future kids coming behind us."

This is one mother's comment among several, after she searched for her child's diagnosis online and discovered News Channel 5 Cleveland's story about Charlotte's journey and CHF.

Another parent said, "I saw your news story on your daughter's diagnosis with Hardikar Syndrome. My daughter is seven-months-old and was diagnosed with Hardikar as well. We have felt really alone with it as you know how rare it is and how they don't know much about the syndrome." Laura

CHF was also the feature story in The Daily Record, Times Gazette and Columbus Dispatch newspapers. This coverage continues to help parents and caregivers discover CHF when they need us most.

SPREADING THE WORD

While focused on the parents, caregivers and families of children with medical complexities, bringing awareness to the medical professionals and students is also part of our mission. Understanding the unique challenges these patients face allows health professionals to provide better care and ensure optimal outcomes.

Speaking to leaders in the pediatric medical community is a top priority. The following are just a couple examples, with many more in the works:

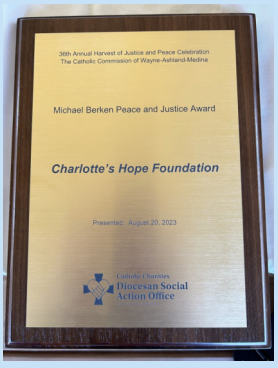
Emily guest lectured at the University of Mississippi Department of Communication Sciences and Disorders Speech Pathology Graduate Class. All students were required to read Emily's book *She is Charlotte* as part of the syllabus. Many students commented after the lecture, that "this was the best guest lecturer they've ever heard," and "this class was so impactful," helping them understand the important role they play in each and every patient's outcome.

Ashlyn is working with Dr. Imran Mushtaq, Consultant Pediatric Urologist at Great Ormond Street Hospital (GOSH) and Senior Lecturer at The Institute of Child Health, London, England, to develop a series of videos that explain the continence surgery he performed on Emery. This procedure has a very high success rate across his patient panel and is currently not offered in the US. Dr. Mushtaq is one of the UK's leading laparoscopic surgeons.

Emily is the keynote speaker at the Parent to Parent USA Leadership Institute this Fall with the talk title, "The #1 Tool to Combat the 'Epidemic of Isolation'." Parent to Parent is a nationwide nonprofit that works to ensure parents of children with special needs find support in other parents who've been there.

ACCOLADES: CHF RECEIVES PEACE AND JUSTICE AWARD

CHF is the recipient of the 2023 Michael Berken Peace and Justice Award. Presented by the Catholic Commission of Wayne, Ashland, and Medina, this award goes to one organization each year which pursues justice and peace in their local communities and beyond.
What a humbling honor and reminder of CHF's significant impact!



MEET THE BOARD OF ADVISORS

In addition to Ashlyn and Emily, there is an incredibly talented team advising the growth and impact of CHF.

Tamela Grabb

As Emery's maternal grandmother, Tamela is personally passionate about the work of CHF. She's played an integral role in Emery's healing. Advocating and caregiving have always been part of her life as the sister of a sibling born with severe brain injuries. Professionally, her background is in Marketing and Communications.

Dr. Rick Rodriguez, MD

Dr. Rick is a well-known and beloved neonatologist who lovingly warns his patient families that he will remain in their lives as their 'uncle' long after the baby graduates from the Neonatal Intensive Care Unit (NICU). Dr. Rick was Charlotte's neonatologist and continues to serve hundreds and thousands of sick babies and their families.

Terrie Koch, RN

Terrie was there that fateful day when Emily went in for her 20-week anatomy scan while pregnant with Charlotte. As a nurse specializing in maternal fetal medicine, Terrie witnesses the devastation families experience when they receive diagnoses for their babies. Terrie lives the mission of CHF every single day.

Ben Krueger

Podcast extraordinaire, marketing guru, entrepreneur mastermind, world-traveler. These are just a few descriptors that come to mind when thinking of Ben. He also happens to be Emily's brother and a steadfast support throughout Charlotte's medical journey, going so far as to fly home for her time in the NICU and for post-operative recoveries since.

Danielle Matter

The woman who brought Emily and Ashlyn together long before either had children, Danielle embodies the concept that hope fosters healing. As an adult who has lived with a childhood-onset disease, Danielle embraces the challenges her medical complications present and she presses on as an accomplished event-planner. She contributes her many talents to the advancement of CHF's mission.

THERE ARE MANY WAYS YOU CAN JOIN THE MISSION.

Pray:

For the families we serve and for the CHF team. Praying might be one small line on this page, but it's hands-down the most impactful thing you can do.

Share:

- Pass this newsletter to someone who might love the mission as much as you do.
- If you are in a book club, suggest *She is Charlotte*.
- Suggest Emily as a professional speaker for relevant organizations and events.
- Share CHF social media posts and subscribe to our weekly podcast emails via our website.
- Host a Facebook social fundraiser for CHF.
- If you know of somewhere the podcast fliers should be shared (for example: a doctor's office waiting room), reach out to us and we will ship them to you for free!

Volunteer:

We are seeking individuals who have a passion for the mission and desire to contribute your incredible talents. Specific skills we are seeking include:

- Social media experience/passion
- Website design and development
- Copywriting
- CPA/treasury experience
- Public relations and media experience

And beyond! If you have a talent you'd like to contribute, please reach out to us!

Donate:

Every dollar makes a BIG difference. CHF is currently 100% donation funded and our goal is to raise $27,000 to cover the next six-months expenses. We are so grateful to all our donors who make this mission possible!
You can give via:

- CharlottesHopeFoundation.org, scroll down the page to the Donate Today section and enter the amount you choose.
- PayPal or Zelle
- Check written to Charlotte's Hope Foundation and sent to P.O. Box 225, Doylestown, Ohio 44230
- Company matches and/or recurring monthly donations.
- If you or a company you know is interested in being a sponsor for our upcoming Celebration of Hope (see details on page 7), reach out to us for details!

How donated dollars have been put to use so far:

- Legal costs to set-up a 501(c)(3)
- Nonprofit liability and directors and officers insurance
- Brand design and development
- Website development
- Marketing materials
- Podcast equipment
- Administrative costs
- Team meeting expenses

However you choose to join us,
we are deeply grateful for your support!

mark your Calendar

MAY 4, 2024

Save the date! On May 4, 2024, we will host our first-ever Celebration of Hope at the stunning Quailcrest Farms in Wooster, Ohio. This event will celebrate the incredible scientifically proven power of hope for parents and caregivers as they raise their children with medical complexities, and the hope we offer them through CHF. We would love nothing more than to celebrate with you!

This event has three primary goals:

1. Celebrate the countless children, parents, caregivers, families, and medical staff positively impacted by this mission and set the vision for CHF's future impact.

2. Build the CHF Community by bringing supporters together and personally engaging them.

3. Fundraise via this opportunity for our community to support this great cause.

We hope you will join us! Stay tuned for an official invitation.

This newsletter is fully sponsored by an anonymous donor.

We are so grateful for their generosity!

CHARLOTTE'S HOPE
FOUNDATION

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