FEBRUARY 2023 VOL. 3, ISSUE 2

BEST NEWS

Blind Early Services TN - Newsletter for Caregivers and Providers

FEBRUARY 28 IS RARE DISEASE DAY

Rare Disease Day is a global advocacy movement for those living with rare diseases, working towards equity in social opportunity, healthcare, and access to diagnosis, therapies and other services. Since its start in 2008, Rare Disease Day has helped to build an international community that reaches numerous disease diagnoses and brings together people from around the world united in the same mission - to advance advocacy work for the community on local, national and international levels. Rare Disease Day is observed every year on February 28th (or the 29th in leap years), the rarest day of the year.

Through Rare Disease Day, individuals, families, caregivers, healthcare professionals, researchers, clinicians, policy makers, industry representatives and the general public are encouraged to participate in raising awareness and taking action on behalf of a vulnerable population. Using social media, wearing the Rare Disease Day colors, attending or holding events, sharing experiences, and by calling on policy makers, you can help to shine a light on and improve the lives and access to support services for people living with a rare disease, estimated to be 300 million people worldwide.

MARK YOUR CALENDAR!

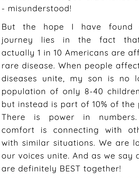
NOW AVAILABLE
VICTORIA WATTS CYR.U.S. SYSTEM BEST TOGETHER PODCAST

FEBRUARY 28
7:00PM CT
NFB TN PARENT DIVISION MEETING

MARCH 1
6:30PM-7:30PM CT
PARENT CONNECT VIRTUAL SUPPORT GROUP MONTHLY MEETING

MARCH 9
11:30AM CT
BEST ADVOCATE QUARTERLY IEP TRANSITION TRAINING LUNCH & LEARN

BEST is proud to support Rare Disease Day - 70% of rare diseases start in childhood and impact many of the children we serve. We believe strongly that low incidence should never mean left out, left behind or left to fall through the cracks. We encourage you to wear the Rare Disease Day colors on February 28th (green, blue, pink and purple) and share to social media to help spread the word about this important date and population. Visit the link below to learn more about the day and how to support the mission.



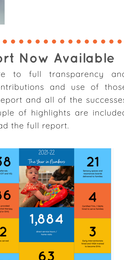
Rare Disease Day Hits Home

by BEST Co-Founder, Stacy Cornwall

The emotional toil surrounding my youngest son, Nathaniel's, rare disease diagnosis is not completely unlike the emotional strain surrounding his diagnosis of optic nerve atrophy. The uncertainty. The isolation. The desperation.

A rare disease is defined in the US as one affecting less than 200,000 Americans or approximately 1 in 1,500 people. Nathaniel's genetic condition, called Malignant Infantile OsteoPETrosis (MIOP), affects only between 8-40 children in the United States each year - making it technically an "ultra-rare" condition. Through a gruelingly long but blessedly successful bone marrow transplant, Nathaniel is actually cured of the genetic condition. But the affects of disorder, one that left uncured is incompatible with life, are still marked on his body in the form of damaged optic nerves, a VP shunt, a g-tube and scars from his former Hickman line and port.

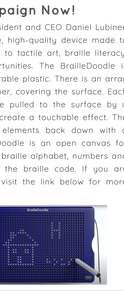
I don't always offer to people the fact that his disorder is ultra-rare. Sometimes it's misunderstood as may being competitive or wearing "ultra-rare" like some badge of honor. That is another feeling to add to the list of what you experience as a parent of a child with a rare disease - misunderstood!



But the hope I have found along the journey lies in the fact that together actually 1 in 10 Americans are affected by a rare disease. When people affected by rare diseases unite, my son is no longer in a population of only 8-40 children in the US but instead is part of 10% of the population. There is power in numbers. There is comfort is connecting with other people with similar situations. We are louder when our voices unite. And as we say at BEST, we are definitely BEST together!

Join BEST Advocate's Quarterly Lunch & Learn March 9th

The BEST Advocate program has scheduled its next quarterly parent training session for March 9th at 11:30 AM CT. Grab your lunch, hop online and join us! We know how overwhelming transitions can be and how many questions come with them. As you prepare for your child to age out of early intervention and into the school system or other environment, we invite you to join our training led by Disability Policy Advocate, attorney and parent, Erin Richardson. We will cover the IFSP to IEP process, program options specific to Tennessee including the new early intervention extension option, as well as an optional segment for parents of children with blindness or low vision. All parents of children in TEIS are welcome!



WonderBaby's New Article Focuses On Developing Multisensory Skills

Wonderbaby.org is a wonderful website with endless resources for parents of children who are blind, low vision or who have multiple disabilities. The website was started in 2006 by Amber Bobnar when her son, Ivan, was only one year old and diagnosed with Lober Congenital Amaurosis (LCA), a rare retinal disorder. Searching for support and answers, she curated everything she found into one place for other families to access. Last month, Amber wrote a new article for Wonderbaby on how to develop multisensory skills in babies who are blind. Be sure to check it out at the link below.

BEST 2022 Annual Report Now Available

As a nonprofit organization, we adhere to full transparency and accountability regarding our financial contributions and use of those funds. BEST is proud to share our annual report and all of the successes we have achieved during last fiscal year. A couple of highlights are included below. Please visit the link below to download the full report.

Reminder: Support the BrailleDoodle Kickstarter Campaign Now!

The TouchPad Pro Foundation, led by President and CEO Daniel Lubiner, has developed the BrailleDoodle, a simple, high-quality device made to expose those who are blind or low vision to tactile art, braille literacy, technology, and other educational opportunities. The BrailleDoodle is about the size of an iPad and made in durable plastic. There is an array of hundreds of holes, placed tightly together, covering the surface. Each hole contains a tiny element that can be pulled to the surface by a magnetic stylus and locked into place to create a touchable effect. The user erases a creation by pushing the elements back down with a satisfying "pop." One side of the BrailleDoodle is an open canvas for creating, while the other side features the braille alphabet, numbers and contractions for teaching and practicing the braille code. If you are interested in purchasing a BrailleDoodle visit the link below for more information.

WHAT WE'RE LOVING THIS MONTH!

The bilibo is a great tool for children look for sensory input and movement. It is a fun wobbly, spinning seat but can also encourage creativity as it can become anything a child can imagine: sand scooper, bucket, helmet, stool, stepping stone, cradle, or snow mold. The bilibo supports gross motor skills, active and imaginative play, critical-thinking, and problem-solving. Great for open-ended play, indoors and out!