

B Brave News

B Brave continues to provide care and relief to those who need it the most. Throughout the pandemic, B Brave Foundation has supported children, families and caregivers through grants, resources and referrals.

Help us keep this momentum as we provide for families, empower caregivers and deliver tools and perspectives to healthcare professionals that reduce suffering and improve the lives of children afflicted with rare incurable neurological illnesses.

With your help, we're building bridges to a brighter future.



Irish Eyes Smile on B Brave

Longtime friends and supporters of B Brave Josh & Melody Taylor (pictured above) completed their annual St. Patrick's Day's fundraiser for B Brave in March. This year they raised \$735, which will go directly to supporting families and our mission. We're grateful for the Taylors' efforts.



Java Junkies Get Their Fix

Our coffee-infused fundraiser is ongoing and picking up steam. It has a lot of perks, as everyone who's already donated or bought raffle tickets knows. We're in the final press to raise more before we filter though the results.

As a reminder, to win that delicious and practical coffee lovers' basket, simply make a one-time donation of \$5 (one entry), \$10 (three entries) or \$20 (eight entries) to win:

- · 2 B Brave mugs
- · 3 lbs of coffee from Goldie's Coffee Roasters
- · 2 Turkish hand towels
- · Ceramic coffee dripper
- · B Brave tote
- · Chocolate

We'll brew up the winning entry on May 16.

Donate Today



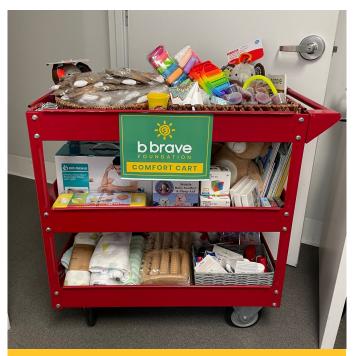
Your Support Changes Lives.

B Brave is wholeheartedly dedicated to the families and institutions we support. Every dollar we get helps improve lives. We recently helped several families through our Children & Families Assistance & Urgent Needs Funds. This allows B Brave to fill financial gaps for families of affected children by covering rent, paying utility bills, buying groceries and more.

Here's one way we helped a devastated family. Two of Mindi and Kyle's three children were afflicted with Tay-Sachs Disease. After the loss of their child Nikko in 2017, B Brave funded a trip to a retreat for bereaved parents for

Reaching Out to Caregivers and Supporting Families in Hospitals

Patients and families at Cleveland Clinic Children's often spend weeks or months in the hospital. To help them and their parents cope, B Brave created the Comfort Cart. It's filled with interactive toys, games, keepsake items, swaddle blankets, socks, books, lip balms, lotions, meal vouchers, gift cards and other goodies for children and parents to enjoy during their admission and beyond.



The Famous B Brave Comfort Cart is a big hit around the hospitals. It includes toys, blankets, and snacks for kids to brighten their day!

B Brave Foundation also celebrates compassionate and caring healthcare professionals who help children with rare, incurable neurological disorders and their families. Doctors, nurses and other professionals are partners who serve tirelessly and selflessly. Sharing difficult information and keeping families informed and empowered helps deliver the best care possible.

We partner with the pediatric palliative care teams at Cleveland Clinic Children's and Akron Children's to help give a voice to those who don't have one and a perspective that only parents know.

<u>The Caregiver Appreciation Program</u> is a gesture of thanks to those who do so much for affected children and families.

"It is a wonderful way for us to acknowledge the hard work of the staff who care for a very sick patient," said Dr. Christine Traul of Cleveland Clinic Children's Pediatric Palliative Care. "They are so pleased to get a small gift card and the recognition of their amazing hard work and care for patients and families."

More than 100 families and caregivers have benefitted from our Comfort Cart & Caregiver Appreciation programs so far this year.

Your support makes it all possible.



Cleveland Clinic Foundation Caregivers accepting their donations from B Brave Foundation. Due to COVID-19 everything is dropped off outside.

Project Rare

<u>Project Rare</u> is a collection of films created to educate, inspire and make a lasting difference for the rare disease community. These films feature families, caregivers and healthcare professionals wrestling with the complexities of grief, clinical trials and caring for loved ones with incurable diseases. B Brave is sharing these important and inspiring stories with the world.

The first docuseries featuring the Flysjo family is available on youtube.

This is an ongoing series and we're working on upcoming films now. Your generosity enables B Brave to educate a wider audience and inspire more people to participate in the transformation of the underfunded rare disease community.



Compassionate Caregivers Offer Perspectives

ICYMI – <u>three pediatricians speak to the challenges and limitations of medical</u> <u>care</u> and delivering hard news with grace & empathy.



Pediatric Neurologist Dr. Neil Friedman on Dealing with Devastating Diseases



Pediatric Pulmonologist Dr. John Carl on Compassionate Caregiving



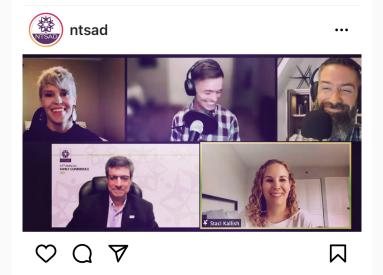
Pediatrician Dr. Skyler Kalady on Caring for Children with Complex Illnesses

B Brave Participates in NTSAD Conference

B Brave was a proud sponsor of <u>National Tay-Sachs and Allied Diseases</u> <u>Association's</u> 2021 Family conference. Being virtual allowed it to be the largest-ever gathering with more than 500 participants from 26 countries, including 140 families attending alongside researchers, industry members and academics.

Our own Sara Scaparotti participated in an inspiring panel discussion, helping remind the audience to live beyond circumstance, take care of themselves and their relationships even as they care for loved ones and to find hope and

purpose in the midst of their sadness. It was a moving event that brough B Brave's message to a bigger audience.



Giveaway Alert!

If you have not heard, the B Brave Foundation is a proud partner of the <u>Cleveland Crunch Professional Soccer Team</u>. The Crunch franchise, relaunched by Luciano Ruscitto and Eric Davis, is a blast from the past for many Northeast Ohioans who watched the original team win three National Premier Soccer League championships between 1994 and 1999 while bringing excitement to a passionate sports town.



The Brave Foundation along with <u>UN1TUS Athletic</u> <u>Wear</u> is pleased to offer Crunch fans a one of a kind water bottle as a thank you for this seasons support. The water bottle will be given to the first 50 fans at the Crunch's last home game of the season on May 22nd at 7:00pm at the North Olmstead Soccer Sportsplex. Tickets will be going on sale soon and seats are limited.

Please check out <u>https://www.theclevelandcrunch.com/home</u> to purchase tickets.

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Our Mission:

Improving the lives of children affected by rare incurable neurological disorders.

Donate Today

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