



CONNECTIONS

We care for parents caring for their children



Emerson captured in a moment of splendor!

"Thank you for the work you are doing. We have been fortunate to have enormous support from Emerson's doctors. And yet my husband and I often feel quite isolated. The resources that CPN provides have made us feel less alone and have been very educational as we have started this journey."

SARAH ~ EMERSON'S MOTHER

EMERSON'S JOURNEY The Essence of Our Impact

When Emerson was tragically diagnosed with Gaucher disease, a life-limiting genetic condition, she was seen by Boston Children's Hospital and her parents began navigating the new world of hospital systems and procedures. Fortunately, the palliative care team at Boston Children's referred Emerson's parents, Sarah and Steve, to Courageous Parents Network last fall. With your support, CPN launched a pilot Parent Education Series this spring. Sarah participated – along with a virtual group of other parents over four weeks, each week a different theme, facilitated by our content director and psychologist Nancy Frumer Styron.

In June, Emerson died unexpectedly from complications related to Gaucher. Shortly after Emerson's death, Sarah expressed how you help parents like her with your generosity: "Thank you again for what you do with the Courageous Parents Network. You have no idea how much the blog, videos, articles shared on Facebook, and parent education group, did to help us not only get through – but to actually embrace Emerson's journey, as hard as it was at times. She really was the best :)"

That last bit about helping her parents "embrace Emerson's journey" is what Courageous Parents Network is about and essentially what you help make possible. Sarah and Steve asked that gifts in honor of Emerson be made to CPN and we have received nearly \$3000 to date from grateful friends.

REACHING OUT We helped this dad. Now he is helping others.

Greg reached out to us with his story. We interviewed Greg and Heidi so their story can help others experiencing similar emotions, challenges and hopes. Here's an excerpt from that interview.

Things were snowballing and Abby was getting worse. We don't know what tomorrow holds. We were grieving but for something we hadn't lost yet. I started doing Google research about "anticipatory grief" and found Courageous Parents Network. I saw the videos, I read the materials, and I thought, "That's us! That's exactly how I feel, what I'm going through. I'm looking at the palliative care materials and I said [to my wife], 'Heidi, this is exactly what Abby needs. We need something else to fill this void and pieces all the other doctors together to make sure Abby gets the best quality of life.' And that's when we found palliative care and it's been a Godsend."

In this moment, Abby is doing very well and Greg is on our Parent Advisory Board.



Greg and Heidi, with their children Tomas (age 4) and Abby (age 5).
Abby has been diagnosed with Leigh's Disease.



You Made a Difference this Past Year

Thank you for helping us provide emotional, psychological and practical support to parents like Sarah and Steve and Greg and Heidi. There are approximately 500,000 children living with life-threatening illness in the U.S. alone. CPN is here 24/7 to offer their parents community, perspective, and resources to help them get through. In past year, we've:

- Grown our monthly reach to 2500 unique visitors
- Added new families to the video library (270+ videos)
- Presented to 15 professional audiences, reaching 445 MDs, nurses, social workers, chaplains
- Developed partnerships with Massachusetts General Hospital for Children, Boston Children's Hospital, and UMass Memorial Medical Center.
- Given parents a voice via the CPN Blog
- Produced guides for parents
- Piloted our live virtual Parent Education Series
- Collaborated with StoryCorps to produce a podcast series (launching soon)
- Been named a Mass Challenge Finalist
- Received the Cydan Therapeutics Scholarship for Rare Diseases



Our Generous Donor Network

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Why We Give

BY CHRISTINE ANGELAKIS

Giving to CPN last year was without question the most important and heartfelt gift that Michael and I have ever felt so blessed to be able to make.

Our friends inspired us.



Our connection to one of CPN's most involved and supportive families, the Swoyers, goes back almost 30 years. Barb and John Swoyer are very dear college friends who we knew in a care-free phase of life. We were blessed to start our families at the same time, having children in the same years. However, their path as parents of a child with an extremely difficult and

life-limiting condition came early, came hard, and continues to this day as our respective sons turn 21 years old this year. Even as we do not live nearby, we stay as close as we possibly can, but it is always difficult to feel like we do enough to show them how much we truly care for their family and how much we respect their deep commitment to both of their sons, their marriage, and to the community of other families with terminally ill children in palliative care. In the 20 years that Jake has been ill and under round the clock care, Barb has ardently championed and supported other families in countless ways.

Last November, we reached out to Barb to see if there was a new way for us to make a donation that she and John would feel connected to and that would have immediate impact. Barb quickly responded with a full page report on CPN and the work its team was doing...and said that a gift to CPN would allow them to touch so many families who are all struggling with many of the same heartbreaking issues.

Knowing that Barb and John were so deeply connected to CPN was to feel the blessing of being able to share a connection of love and support with them. And, as I stay connected to CPN's mission, purpose, and the stories from other families, we continue to feel blessed to be a small part of something making a difference in their lives.



We are profoundly grateful to Christine and Michael Angelakis for responding and giving as generously as they have. Their dear friend, Barb, has been a wise advisor to CPN from the beginning. She and John and Jake are featured in our video library.

*And we are grateful to you. **THANK YOU!***



**COURAGEOUS
PARENTS
NETWORK**

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