



We care for parents caring for their children who are seriously ill



**Sarah, Steve and Emerson celebrate Emerson's first birthday**

*In January, CPN member Sarah joined Executive Director, Blyth Lord to give Pediatric Grand Rounds at University of Vermont's Children Hospital.*

*Sarah spoke eloquently about the role CPN played in their journey with Emerson, who died at age 16 months from Gaucher Type 2.*

*"We will be forever grateful for the way that CPN, along with access to palliative care, helped our family, to not only survive, but to actually thrive."*



YOUR GIFT HELPED HER FEEL LESS ALONE

## A Mother Finds Community, the Words, and Learns about Pediatric Palliative Care

As Sarah and Steve considered their baby daughter Emerson's fatal diagnosis, they felt, in Sarah's words, "utterly and completely alone and isolated."

*"As you can imagine, our world had been completely shattered. Our hearts were broken. All we could think of was that our beautiful, funny, sweet daughter was going to die, and that we had to make sure, she didn't suffer."*

A social worker on their palliative care team recommended Sarah visit Courageous Parents Network. She had some trepidation about joining what she thought was an online support group. Was she ready for that level of interaction or commitment? It felt burdensome. But Sarah learned she could access the stories, sage advice, and tools at her own pace, in privacy and with no obligation to interact.

**And so, Sarah viewed CPN's videos. Immediately she felt less alone.** The parents she saw in CPN videos shared her feelings of fear, sadness and uncertainty – in short, they understood – articulating feelings Sarah didn't yet have the words to express. Through CPN, she learned about anticipatory grief. "That's just what I'm feeling." She wondered how could she cope with looking into to her happy, babbling 8-month-old child's twinkling eyes and simultaneously anticipate her death? Sarah also gained a greater understanding of palliative care through the CPN website. It comforted her to know that palliative care is more about living well than a good death and so she sought it out. In her first meeting with a palliative care physician, they explored what quality of life would mean for Emerson.

*"We talked about the delicate balance between helping Emerson to live as long a life as possible (knowing that no matter what we did, it was going to be short), while also maintaining quality of life."*

The Network helped Sarah grapple with decisions about optional medical intervention and the CPN videos, blog posts and live Parent Education Series were key tools through which she learned how other parents found hope in the face of serious illness, and even the death of their children. Maybe she could do that too and embrace Emerson's life just as it was. Support from CPN allowed Sarah and Steve to be "the best parents we could be for Emerson – to be the parents she deserved."



## Medical providers also benefit from COURAGEOUS PARENTS NETWORK.

Providers value CPN as a trusted extra layer of support for their families, like Sarah, Steve and Emerson. But they themselves are also learning from CPN's parent voices.

In a recent CPN blog post, pediatric palliative care doctor Dr. Jon Mullin writes:

*"[CPN] videos are a gift to providers as they give us a small window into the experience of children and their families, and allow us to hear – in retrospect – how the care we provide impacts all those involved."*

This year with support from donors, CPN hopes to develop a Provider Toolkit to train clinicians in how to effectively use CPN with the families they serve and to train colleagues.

# Thank You!

Your contribution is making a difference.  
*But there's more to do.*

### WAYS TO EXTEND YOUR PAST SUPPORT

- Become a monthly donor. Spread your generosity throughout the year. You have no idea how helpful this is!
- Sign up online [courageousparentsnetwork.org/donate](http://courageousparentsnetwork.org/donate)
- Take advantage of employer matching gift programs.
- Renew your support.



### OTHER WAYS TO HELP

- We are new and novel. Help spread the word by following us on Facebook, Twitter, and Pinterest and share our posts with your followers.
- Tell your children's pediatrician and your providers about Courageous Parents Network.
- Let us know how to keep you informed by completing the surveys we send – no more than 1/year.



## Listen to our new podcast series featuring, more stories from families and friends and produced in association with StoryCorps.®


"These podcasts are an invaluable resource for families who are seeking support to cope with their child's illness, but they can also help extended family members and friends understand the experience on a much deeper level. To hear Kerri tell her story in her own words, in her own voice, was at once clarifying and cathartic. I am grateful for the insight her words provided and because her story will help me, and anyone else who listens to it, to cope and heal."

Ann-Margaret  
Aunt & Courageous Parents Network donor

VISIT [courageousparentsnetwork.org/podcasts](http://courageousparentsnetwork.org/podcasts)

## OUR REACH IN THE PAST 3 MONTHS

  
**12,790**  
unique visitors

  
**4,695**  
video views

  
**534**  
podcast listens

  
**9**  
original blog posts

**THIS IS A LOT OF COMMUNITY ENGAGEMENT!**



**COURAGEOUS  
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