



# Courageous Parents Network



**FOUNDED:** 2013  
**CURRENT ORGANIZATION BUDGET:** \$215,236  
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## Investment Opportunity

Courageous Parents Network seeks to raise \$1 million over the next two and a half years to support the expansion of its innovative model of virtual community and supportive resources for parents and families of children with serious illness. The organization will produce new digital content and mobile engagement tools for parents and healthcare providers and build its audience base through marketing and outreach. In order to grow, CPN must diversify its funding, plan for organizational sustainability, engage new board members, and hire additional staff.

Courageous Parents Network (CPN) provides parents and families of children living with serious illness with expert guidance and virtual community to promote coping and resiliency and to lessen the isolation they experience.

Approximately 53,000 children die each year in the United States and an additional 500,000 children suffer from life-threatening illnesses. For each of these children, there are parents, siblings, and families who experience grief, anxiety, and isolation. While the disease-directed medical needs of these sick children are attended to by providers, the psycho-social and emotional needs of millions of their parents—and by extension their siblings—are often inadequately met, especially outside major children’s hospitals.

Research has shown grieving parents to be at increased risk of anger, guilt, intrusive memories, social isolation, loneliness, marital and relationship problems, financial hardship, and increased mortality from natural and unnatural causes. Given that the primary predictor of child well-being is parent well-being, it is critical to find ways to support these parents. It is also important that this support be accessible, free, and responsive to the needs of parents.

## Two-Year Goals

- Expand reach to serve 250,000 parents and 183 children’s hospitals
- Produce 100 new original videos and diversify content to include podcasts
- Produce Spanish-language content
- Optimize site for mobile use
- Build organizational capacity; grow board membership to 10 and staff to three
- Diversify and expand fundraising efforts to ensure sustainability

## Ways to Invest

### FINANCIAL

- \$50,000 funds the production of Spanish videos and a Spanish track on the CPN site
- \$25,000 funds the development of parent engagement tools for mobile devices
- \$6,000 funds the filming of three new parent stories and production of related videos

### IN-KIND

- Hosting a fundraising event
- Providing office space for five staff
- Referring a friend in need to [courageousparentsnetwork.org](http://courageousparentsnetwork.org)



## Leadership & Governance

Executive Director Blyth Lord founded Courageous Parents Network in 2013, following more than 20 years as a television producer and her own experience as a bereaved parent.

CPN's board of directors is led by Steven Segal, Executive-in-Residence at Boston University's School of Management and Special Limited Partner of J.W. Childs Associates. A six-member advisory board provides strategic guidance and content expertise.

### Advisory Board

Patricia O'Malley, MD, *Mass. General Hospital for Children*

Richard Goldstein, MD, *Boston Children's Hospital & Dana-Farber Cancer Institute*

Jennifer Bates, EdM, *MA Dept. of Public Health*

Sandy Clancy, PhD, *Mass. General Hospital for Children*

Mary Summers, *Federation for Children with Special Needs*

Brita Gill-Austern, PhD, *Professor of Pastoral Theology, Andover-Newton Theological School*

## THE COURAGEOUS PARENTS NETWORK MODEL



### PARENT-TO-PARENT VIDEOS AND PODCASTS

Parents of children with serious illness benefit significantly from hearing from other parents who have gone through similar experiences, but other parents are hard to find. Courageous Parents Network's website features over 200 short videos of parents sharing their experiences caring for a child with a serious illness. These videos provide parents and providers with insights into some of the most difficult topics (e.g., self-care, marriage, spirituality, difficult decisions, transitioning to end-of-life) from the parent perspective—with professional guidance interspersed—in simple and honest terms. Watching another family in a similar situation helps parents feel less alone and can help them face the challenges of caring for a child with a serious illness. The videos and all of the CPN resources are available 24/7, and parents can access them wherever and whenever they need them, including in the middle of the night or from their child's bedside. The videos also help providers prompt important but difficult conversations with families. CPN plans to add audio podcasts in 2016 and develop a Spanish-language version of the website in 2017.

### EXPERT GUIDANCE

Parenting a child with serious illness is a journey unlike any other. Courageous Parents Network shines a light on the darkest parts of this journey, helping parents to navigate it, equipped with the knowledge that they can get through. In addition to the video and audio content, the CPN website has practical, expert-reviewed resources and information. CPN offers guidance on how to think about difficult decisions, tools to help families talk about what is important and set goals for their child's care, and advice on working with medical providers effectively.





**This is information that needs to be available to every family who is facing such difficult issues for their child.**

JEAN

Mother of Rachel

**Sharing a topic-specific video is a gentle way to start difficult conversations with a family. The videos are also a valuable teaching tool with residents and interns, as they deepen our understanding of the family experience.**

PATRICIA O'MALLEY, MD

Pediatric Palliative Care,  
MassGeneral Hospital for Children



### Partners

- AMERICAN ACADEMY OF PEDIATRICS
- AMERICAN CANCER SOCIETY'S "QUALITY OF LIFE" INITIATIVE
- CENTER TO ADVANCE PALLIATIVE CARE
- CHILDREN'S HOSPITAL BOSTON
- MASSACHUSETTS GENERAL HOSPITAL FOR CHILDREN

## PEDIATRIC PALLIATIVE CARE AWARENESS

Courageous Parents Network educates parents and providers about the value of palliative care through its online content and advocacy efforts. Pediatric palliative care is specialized care for children with serious illness that focuses on providing relief from the symptoms, pain, and stress of a serious illness—whatever the diagnosis. It includes the physical, emotional, social, and spiritual elements of care, with the goal of improving quality of life for both the child and the family.

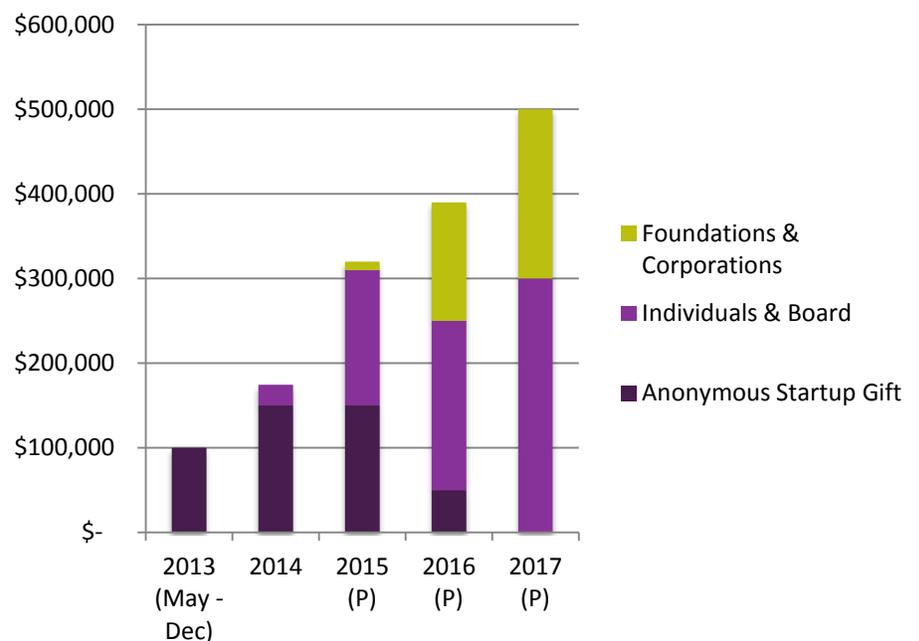
Hospitals and communities are only beginning to recognize the value of pediatric palliative care, and its presence is uneven, often non-existent outside of the major urban medical centers. Many physicians and specialists do not fully understand its value (or confuse it with hospice care) and fail to refer families to these services. By educating both parents and providers, CPN seeks to ensure that physicians inform parents of available services and that more parents receive and accept referrals for palliative care.

CPN's executive director, Blyth Lord, is a vocal advocate for pediatric palliative care, co-chairs the Parent Advisory Group for the American Academy of Pediatrics' Section on Hospice and Palliative Medicine, and presents to professional audiences about the impact of this care on families.

## FINANCIAL SUSTAINABILITY

Launched in 2013 with an anonymous three-year startup donation of \$450,000, CPN plans to ensure its sustainability by engaging new individual, foundation, and corporate supporters and investigating opportunities to develop a revenue stream through paid content for healthcare providers.

Revenue by Source



## Blyth's Story

In 1999, Blyth Lord's six-month-old daughter Cameron was diagnosed with Tay-Sachs one month after Cameron's cousin Hayden was diagnosed with the same fatal illness.

Blyth, her husband Charlie, and Charlie's brother and sister-in-law were traveling together on the devastating road towards their respective children's deaths; but they were also traveling the distance together to figure out how to cope. They vowed to give their children the best lives possible and then prepare to give them the best deaths possible.

Despite the profound sadness of watching their daughter lose all cognitive and physical abilities, Blyth and Charlie were able to live fully into her short life, and, following her death in 2001, emerge from the dark fog of grief with no regrets.

Blyth credits the palliative care practiced by Cameron's pediatrician and the fellowship of going through this experience with her in-laws for helping Charlie and her to cope effectively and to heal. This experience was the seed for Courageous Parents Network.



## PROGRAM PERFORMANCE AND ORGANIZATIONAL HEALTH

Below is a summary of the key measures that Courageous Parents Network will track to demonstrate progress, capture lessons learned, and make course corrections as needed. Note: Fiscal year January 1–December 31.

	FY 2015 (P)	FY 2016 (P)	FY 2017 (P)
<b>PROGRAM PERFORMANCE</b>			
Parent videos (cumulative total)	220	250	280
Expert guidance videos for parents (cuml.)	2	8	12
Audio podcasts	Pilot	8	20
Palliative care educational videos for providers (cuml.)	-	Plan	10
Spanish-language videos for parents (cuml.)	Plan	Pilot	4
Spanish version of website	Plan	Develop	Launch
Marketing outreach to children's hospital programs	40	50	63
<b>ORGANIZATIONAL HEALTH/CAPACITY-BUILDING</b>			
Number of organizational staff	1.75 FTE	3.75 FTE	4.75 FTE
Number of board members	6	8	10
Develop and implement strategic marketing and fundraising plans	Develop and launch	Assess and refine	Update plan
Total revenue	\$320,000	\$390,000	\$500,000

## SOCIAL IMPACT

Having launched online in April 2014, CPN is focused on measuring reach and engagement, understanding the user experience, and collecting feedback in order to refine and strengthen its innovative model and develop content parents and providers seek. In the future, CPN seeks an evaluation partner to support more robust outcome measurement, particularly around how CPN contributes to its ultimate desired outcomes of maximum healing, minimal regret, and resilience in families of children with life-threatening illnesses.

INDICATOR	2014
Total website visits	7,802
Unique website visits	5,280
Average site visit duration (minutes)	2:46
Total video views	6,100
Network membership (Facebook and website communities)	700
Site user data and feedback collection <ul style="list-style-type: none"> <li>• User type (parent, provider)</li> <li>• Referral source</li> <li>• Most frequently accessed content</li> <li>• User self-report on feeling less dread, more able to cope, etc.</li> </ul>	Develop & implement plan in 2015

