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Genetics

A Network for Courageous Parents Offers New Views, Advice on Grief

Having Company Helps in Worst of Times

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Sitting next to her husband in their Palm City, Florida, living room, Oralea Marquardt describes the last few moments of her 8-year-old son William's life. Displayed prominently behind the Marquardts are photographs of William, who died in February from GM1 — a genetic disorder that causes a progressive loss of cognitive and motor functions. [Click for more Genetics stories.](#)

"He simply exhaled, and he had all his family in and around him at home," Marquardt, 38, tells the camera, her voice solemn but steady. "And I think every scenario I played in my head was much worse than that moment for us."

The Marquardts share their story, from diagnosis through bereavement, in more than a dozen segments featured on the [Courageous Parents Network](#). The brainchild of longtime television producer Blyth Lord, CPN is a new, video-centric resource site for parents whose children have received a terminal diagnosis of any kind.

Since it went live in April, more than 180 original, television-quality videos have been posted on CPN. In various segments, most of them between 90 seconds and seven minutes long, parents speak candidly about how caring for a critically ill child [impacted their marriage](#); they talk about [choosing comfort care](#) over life-extending treatments and, poignantly, about [the fear of being left with an empty crib](#).

There are also interviews with therapists, physicians and hospital chaplains. The experts provide primers on topics such as palliative care and anticipatory grief, and even the pros and cons of finding support on social media. (Pro: It's easy to connect with those facing similar struggles. Con: Some feel burdened by the pressure to post constant updates.)

For Lord, 46, the project is deeply personal. In 1999, her 6-month-old daughter, Cameron, was diagnosed with Tay-Sachs, a degenerative disease that in its classic infantile form claims most victims by age 4. That devastating news came just three weeks after Hayden, the one-year-old son of her husband's identical twin brother, was found to have the same terminal illness. Before the family had a chance to process one diagnosis, "we found out that two beautiful children in one family were going to die sometime in the next one to three years," said Lord.

Hayden died in December 2000; Cameron died five months later.

Genetic mutations that cause Tay-Sachs — an autosomal recessive disorder in which two carrier parents have a 1 in 4 chance of having an affected child — are disproportionately prevalent among Ashkenazi Jews. As many as 1 in 25 people in this population carry a Tay-Sachs mutation; in the general population, the risk is thought to be between 1 in 250 and 1 in 300, according to the Jewish Genetic Disease Consortium. Thanks to widespread genetic screening among Ashkenazi Jews, the number of children born with Tay-Sachs has plummeted in recent decades; today, however, the disease long associated with Jewish genetics is more commonly found among non-Jews, who are less likely to have been screened for the mutation.

Hayden's and Cameron's parents are not Jewish, though Lord suspects her own mutation was passed down through a grandmother with Jewish ancestry.

The Lord families founded the [Cameron and Hayden Lord Foundation](#) in 2001 to build awareness of pediatric palliative care, in which symptom management and a family's care goals help guide a child's treatment. The foundation also funds medical research and bereavement services.

But Blyth Lord was determined to take her activism a step further. So last year, Lord — who had also partnered with the National Tay-Sachs and Allied Disease Association to make an educational film about parenting a terminally ill child — left her job at Boston's WGBH to start the Courageous Parents Network.

The goal of CPN is to address a few key questions, she explained: "What can we do to give parents confidence that they can survive this? What can we do to help them understand what is happening to them, to begin to tell their child's story, to lessen the dread they feel about their child's end of life, to free them up to be more present with their child?"

While parents of critically ill children have long been going online for information and support, many sites geared toward this group are disease-specific, with a focus on research and symptom management; others serve mainly as peer-to-peer support networks. The Courageous Parents Network, however, transcends diagnosis, includes a mix of personal stories and professional perspectives and is unique in its focus on building a comprehensive video library for this audience.

The effort has been buoyed by an unusually large anonymous donation of \$450,000 over three years. Even Lord does not know who provided the cash infusion.

That funding has permitted Lord, together with a film crew, to travel across the country to produce the site's videos. It also enabled her to hire Nancy Frumer Styron, a Boston-area pediatric psychologist who is featured in many of the videos, as the site's content director.

Plans are also underway to host a series of topical webinars and live chats with grief counselors and other special guests.

Oralea Marquardt said she went public with her story to ease the sense of isolation other parents feel. There's an aversion to talking about death — specifically the death of a child, she told the Forward, and that can make families of terminally ill children "feel not normal and alone in this process." "You get people making comments, like 'At least you have two other children' and others who just remove themselves entirely from your life," the mother of three said.

Jennifer and Joe Salazar, of San Antonio, Texas, also agreed to be interviewed for the website. As they talk to the camera — on subjects ranging from their early denial to making time for their well children — their wheelchair-bound daughter, Mallory, sits between them.

Mallory, 7, suffers from juvenile Tay-Sachs, the rarest form of that disease. (NTSAD estimates that, nationwide, there are 12–15 new cases a year of infantile Tay-Sachs, 3–5 new cases of late onset Tay-Sachs, and 1–3 new cases of juvenile Tay-Sachs, which is diagnosed in early childhood.) What many who haven't been there don't understand "is that the diagnosis itself comes with a certain amount of grief," leaving parents bereaved even while their child is still alive, Jennifer Salazar, 36, told the Forward.

Lord said she understands that the digital model for the Courageous Parents Network has its limitations: It's one-directional, and there's no guarantee that virtual support will be helpful in real life. Still, she sees in it tremendous potential. She is particularly intent on highlighting how the benefits of palliative care and grief counseling during the course of the child's illness could help "minimize regret and maximize healing" later on.

"When a child is dying, parents may not be in a situation where they can leave home or the hospital, or they are just not going to seek out help," said Frumer Styron, who is also the clinical director at the [Children's Room](#), a bereavement center in Arlington, Massachusetts. "Going online is a mixed bag, but it's an important resource, and one that's available to many people when they can't or don't want to access resources in any other way."

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