Blyth Lord Oral History.

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Biography

Ms. Blyth Lord is the founder and Executive Director of Courageous Parents Network, a not-for-profit focused on improving the experience of parents caring for children with life-limiting illness through education, advocacy and parent-to-parent support. Ms. Lord's daughter, Cameron, and nephew, Hayden, died of Tay-Sachs disease in 2001. In the years since their deaths, Ms. Lord has overseen the Lord Foundation’s funding of pediatric palliative care research and program development. She has also promoted the needs of families caring for children with serious illness and how providers can best meet these needs. Drawing on more than 20 years of experience as a television producer at ABC News, Medical News Network, and WGBH, she produced the award-winning film, Cameron’s Arc with the American Academy of Pediatrics. The purpose of this film was to educate healthcare professionals working with families from the time of their child’s diagnosis through end-of-life care. Cameron’s Arc has been distributed nationally as a teaching tool to pediatric residency programs across the United States. She also produced The Parenting a Child with Life-Limiting Illness video with the National Tay-Sachs and Allied Diseases organization, as a resource for parents and the providers who work with them.

These successes inspired the inclusion of parent and provider story-telling and videos that are central to Courageous Parents Network, which she founded in 2013. A growing number of parents work with Ms. Lord and the staff in contributing to the Network and in continuously evolving its value to families.

Ms. Lord is an affiliate member of the American Academy of Pediatrics Section on Hospice and Palliative Medicine. Ms. Lord is the Board Chair of the patient-disease and advocacy group National Tay-Sachs and Allied Disease and until recently served on the Board of The Children’s Room, the Arlington, MA-based organization that provides bereavement support to families who have lost parents/siblings/children. She has a Master’s in Education and lives in Newton, Massachusetts with her husband and two daughters.

Interview Abstract for Interview #1

Ms. Lord begins the interview by recalling her early experience with her daughter and nephew who were both diagnosed with Tay-Sachs disease, but experienced very different types of end-of-life care. Ms. Lord, her husband, and her daughter had a pediatrician that was willing to work and assemble a care team for the family and ultimately provide a rewarding end-of-life experience. Ms. Lord’s nephew’s pediatrician was not similarly equipped and his family experienced stresses, particularly at his end of life, because of that. After reflecting on her daughter’s journey, Ms. Lord wanted the level of care she experienced to be accessible for anyone with Tach-Sachs, thus began her career in advocacy.

Ms. Lord then describes how she and her husband and brother- and-sister-in-law were able to bring all of their familial support together to develop the non-profit, The Lord Foundation, to fund research of Tay-Sachs and the advancement of pediatric palliative care.
Ms. Lord’s background in television and video production then aided her in completing two multimedia projects, *Cameron’s Arc*, a project with the American Academy of Pediatrics about delivering palliative care from a community-based pediatrician, and *Parenting a Child with a Life-threatening Illness*, a resource for families affected by Tay-Sachs, GM1, Sandhoff and Canavan disease. Ms. Lord was motivated by positive feedback from clinicians using these movies to teach the new generation of clinicians. She soon left her job to focus full time on developing the Courageous Parents Network (CPN). Ms. Lord says the scope of CPN was initially just for parents, to promote palliative care and help parents hear from other parents through videos, but it has since grown into a large and reputable educational platform for parents and clinicians alike.

Ms. Lord then goes on to describe that one of the primary goals of Courageous Parents Network is to orient and empower families of children with life-threatening diseases as advocates and decision-makers for their child, and to promote palliative care as critical to helping make that possible.

Ms. Lord concludes the interview by describing a series of goals she has; for other parents and families, to know that they always have options and they are not alone; for clinicians, to foster the skillset of palliative care to be a holistic provider.
### Glossary of Acronyms

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<td>ABC</td>
<td>American Broadcasting Company</td>
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<td>CPN</td>
<td>Courageous Parents Network</td>
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<tr>
<td>GI</td>
<td>Gastrointestinal</td>
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<td>HEXA</td>
<td>Hexosaminidase; an enzyme</td>
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<td>NTSAD</td>
<td>National Tay-Sachs and Allied Diseases</td>
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<td>PACT</td>
<td>Pediatric Advanced Care Team</td>
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Interview Roadmap for Interview #1

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Today is July 11th, 2019. I am Bryan Sisk and I'm in Saint Louis, Missouri interviewing Ms. Blyth Lord over the telephone for the Pediatric Palliative Care Oral History Project. Ms. Lord is in Newtown. Newtown or Newton?

Blyth Lord: Newton, N-E-W-T-O-N.

Bryan Sisk: Thank you Newton, Massachusetts. So, thank you Ms. Lord for joining me today. To get us started, could you just tell me when you first became aware of pediatric palliative care?

Blyth Lord: My husband and I became aware of pediatric palliative care in 2000, I would say it was late 2001 as we had experienced pediatric palliative care during our daughter Cameron's life. What happened is, if I may jump right into it, is that our nephew—I had our first-born daughter Taylor and then my second daughter Cameron was born in May of 1999. And at the time that she was born, my husband's identical twin who had married my roommate from college, their first born, Hayden, was just one and he had just been diagnosed with cerebral palsy. He had not been developing typically. He wasn't sitting up on his own and he wasn't rolling over. So a little later than usual, because his parents were sort reluctant to dig into it because they kept being hopeful, but by the time he was one they had taken Hayden to be assessed and they were told that their son had cerebral palsy.

Fast forward to where Cameron is now five months old and Hayden is 17 months old. Cameron has just been given a glowing bill of health from her pediatrician. She has beautiful gross motor skills and has hit her milestones thus far. She's five months old. Hayden, however, is going backwards and the physical therapist and occupational therapist who've been working with Hayden and his parents felt like this was not in fact cerebral palsy. It must be something else and it was at that point that Hayden was accurately diagnosed as having infantile Tay-Sachs disease.

And my husband is an identical twin, so we assumed that he too was a carrier of the mutation, at which point I went to get tested to see if I was a carrier and it came back that in fact I—for that they just did the enzyme assay to check on the level of HEXA [Hexosaminidase]. And I remember the genetic counselor had to bring them here in Boston saying "It's so statistically improbable that four parents in one family, that two siblings, that twins would marry women who are both carriers," especially because my husband's mutation had never been seen before. So how unlikely
that would be. Well, it turns out that I was in fact the carrier. First, it looked like maybe it was a false positive but then we did the DNA test and they also tested my daughter.

Turns out that I carried the Ashkenazi Jewish mutation or one of them because my grandmother was of Russian-Jewish descent, so in fact, I'm the only one in the four parents that carried a mutation that had thus far has been seen before. And we tested my daughter and she turned out her enzyme level was in the basement and we were called in to our pediatrician's office and he delivered the news that our daughter had Tay-Sachs. And at this point we've been living with Hayden's diagnosis for almost three weeks, so we knew enough about Tay-Sachs to know what this meant for our daughter as well.

And this is a story that I've told in different ways many times. First with the project that our pediatrician and we did with the American Academic of Pediatrics called Cameron's Arc, about how the primary care pediatrician works with the family for some form of diagnosis all the way to end-of-life and basically practiced palliative care.

The key I would say here is that, at the time that our pediatrician provided this exceptional palliative care, he was not calling it that. I'm not sure if he even knew that's what it was called. The field was very nascent. Pediatric palliative care was very, very nascent. It was only after our daughter had died and my nephew had died and we had the four grandparents—or the six grandparents and the four parents had started a family foundation called the Cameron and Hayden Lord Foundation. This is now in 2001 and we were thinking about what do we want to fund with the money raised. We concluded that we wanted to fund medical research for a treatment for Tay-Sachs and other lysosomal storage diseases. But that we also wanted to make it possible for families to receive the type of exceptional care that my husband and I and our daughter received during her life.

And we understood that how the type of care she and we received made an extraordinary difference in the eight months that we had from when we learned that she was going to die to when she died. And we were able to contrast that a little bit with the care that my brother and sister-in-law received for Hayden, who had a wonderful pediatrician who loved him and loved their family and took beautiful care of typical children, but did not know how to really care for a child with Tay-Sachs. And he didn't know ultimately what it meant to do care goal planning and have
conversations about medical orders. And at the very end, didn't know how to make recommendations for how to manage a child who is ultimately dying from pneumonia.

And in that gap of care, we saw that my brother and sister-in-law had to figure out a lot on their own. That was more traumatic than when we compared to what happened to us; we knew it needed to be. So, while they had to figure stuff out by hook and by crook, including calling people as their son was dying to find out what level of morphine he should be getting as he was dying, because he was being cared for at home.

We on the other hand had our pediatrician who helped find expertise pain and symptom management doctor at Boston Children's who helped us, who helped the nurses who were caring for her during her last week of life figure out what her morphine dosage should be.

So, the contrast is pretty striking. And it was for that reason that we said then alright we've got to help other families get what we got. I believe it was Laura Basili, our grief counselor, and somebody else who we were talking with, he said, "What you received was palliative care and from her primary care pediatrician. This is a growing field and you should talk to some people who are building it." And literally it was right as Joanne Wolfe and her team at Boston Children's Hospital with Dr. Joanna Breyer, and the nurse Janet Duncan, and the social worker Marsha. Oh my gosh I'm forgetting her name at the moment, but we're putting together, we're building one of the first PACT teams, palliative care team for children at Boston Children's Hospital. It was as that was coming online. And so that was really the beginning of my professional introduction to the field of pediatric palliative care and the beginning of becoming what we would call a professional parent advocate for palliative care.

What happened then is the Lord Foundation began funding pediatric palliative care programs and then research. And so we went back between funding programs and funding research. Through that I came to know, as a trustee who was involved in directly framing the request for proposals and thinking about the types of things we wanted to fund, that I came to know the leading people who were developing the field.

Joanne Wolfe Chris Feudtner, Sarah Friebert. I knew some. I learned of Justin Baker, but he was not quite there yet. The Lord foundation was one of the only small family foundations that was
specifically devoted to pediatric palliative care programming. They paid attention to what it was. They invited me to have conversations with them and I think they mentored me as helping me understand the provider perspective of the field. And I mentored them as a professional parent. And I feel that my family and especially I, have been part of laying the foundation for this field with me as representing the family perspective; one of the professional parents representing the family perspective to complement the provider perspective. Because at the end of the day it's a team effort; parents and providers caring for the child.

I should a pause here and say that our, the pediatrician who provided such exceptional care for Cameron, his name is Dr. Richard Goldstein. At the time he was in primary care private practice in Cambridge. He subsequently went on to be certified in pediatric palliative care, left his work in private practice, was part-time at Boston Medical Center, and then went full time to the PACT Team at Boston Children's Hospital. Until recently, when he left the palliative care team at Boston Children's Hospital, has been doing palliative care in other ways and his field of research at the moment is kids. He works doing a lot of work on grief research with a specialized focus on kids, or it's not even kids, studying unexpected deaths in children or whatever we're it calling it now. Anyway, that is a long explanation.

It's fascinating. What I love is seeing a couple of things. One is seeing a wonderful example of turning something that's pure grief into something really constructive that has a big impact on the world. And number two, people that are doing things that they probably never thought they would be doing. So how did you know how to do any of this when you decided to pursue Cameron's Arc and when you started the Cameron and Hayden Lord Foundation, how did you know how to do all that?

So, starting with Cameron and Hayden, Lord Foundation, that is a lot of families decide to start foundations in their children's name so the act itself is not unusual. But my husband and his twin brother, so my husband Charlie Lord and his twin brother Tim Lord, are both non-profit founders and executive directors of non-profits. Well, my husband isn't any more, but he had been. So both of them had expertise in running non-profits and working with foundations, so they were not intimidated. They understood what it took to—it's not hard to do the paperwork to start a foundation.

What was harder for us this focusing on the Lord Foundations was figuring out who to fund. And what we realized both from the
medical research group perspective, because none of us were experts in science, and in terms of pediatric palliative care was, rather than doing this ourselves, and we actually learned this the hard way, we as a small family foundation were going to be much more effective if we enabled work that was being done by a larger institution that already had an infrastructure and was part of the bigger initiative. In the earlier days were issuing $50,000 grants to originate something and run it. And $50,000 doesn't go very far if it isn't part of something bigger where there's already an infrastructure and where they're taking funds from others to round out the number for the project that they're initially doing. So ultimately we learned that it would be better to be a catalyst or an enabling grant for a project that was originating in a palliative care team at a hospital or palliative care researcher, a hospital-based palliative care researcher, so that we weren't the only funder and that there was already an infrastructure. So that's how we learned the philanthropy piece in terms of some of the work we started to do like Cameron's Arc, which then this actually ended up building into the development of Courageous Parents Network which is the non-profit that I founded and am currently the executive director of.

My background is in television and video production. I had worked in television news at ABC and then WGBH. At ABC and WGBH, I learned video production and basically documentary, I learned from documentary storytelling. At WGBH where I worked in lifestyle programming and then in children's television developing programming for PBS, I also learned about how to do outreach and to collaborate with other organizations that shared a vision and desired outcomes and how together you can do more, especially as non-profits. I had to learn how to write grants which is a very important skill set for a non-profit director to have. And another area of professional expertise that I had was, I had worked for a number of years in between my time at ABC and WGBH, I worked for this distance learning company, which is no longer, called VIS, which is no longer, but I learned how to do web delivered communications and corporate communication during orientation courses for people delivered over the web. So, I learned web design. I myself didn’t learn how to code but I learned how to oversee a team of developers and video production for the web. This is right as the internet was coming online and a lot of companies were making fast delivery of video available over the internet.
So I had video production experience, I had distance learning, web design, and then outreach experience, and I put it all together to create Courageous Parents Network.

The way we come to Courageous Parents Network is that, the Lord Foundation was started in 2001 and between 2001 and 2013, the Lord Foundation was, until I mean through today, ongoing, was funding medical research in pediatric palliative care programs and research. What I was learning was that I was really, really interested in the field of pediatric palliative care. As an aside, I wanted to do something professionally that allowed me to take the professional skills that I had, video production, distance learning, and my growing expertise in pediatric palliative care and my understanding of the needs of families—of course, through my own experience of my daughter Cameron and nephew Hayden, but also through the communities that I was getting to know through the National Tay-Sachs Association where I was meeting a lot of families affected by Tay-Sachs, GM1, Sandhoff and Canavan disease.

I was seeing these patterns in what families need and when their child is living with a fatal diagnosis and I wanted to make what helped my husband and me, available for families going through it now. And the first step was producing ‘Cameron’s Arc through the American Academy Pediatrics where—that was a video produced to teach community-based pediatricians, primary care doctors understand how they could provide palliative care, everything short of pain and symptom management. So it was really around the communications, goal setting, shared decision making and how a pediatrician could do that with the family.

Working on that project, I was reminded of how much I love taking my video production skills and directing it towards something that I cared about personally that was mission-directed. That inspired me to then work with the National Tay-Sachs Association, with a grant from Genzyme, to produce a DVD project called Parenting a Child with a Life-threatening Illness\(^1\), which we did for the National Tay-Sachs Association so that families whose children had been diagnosed with one of the diseases Sandhoff, GM1, Canavan or Tay-Sachs, could hear from other parents about the psychological and emotional issues that families often face. And also some sort of tips and guidance around caring for the other siblings, making difficult decisions around

medical interventions like feeding tubes, and then transitioning to end of life.

And the goal of that project *Parenting a Child with a Life-threatening Illness¹*, was to reduce the isolation that families feel by bringing video to them so they could hear from other parents, to help with decision making, and to really let families know that number one, they were not alone, but number two, that if these people on these videos can do, you can do it too. And if you’re stuck with a decision, perhaps hearing from other families who may had to wrestle with similar decisions will help you find your way.

So that DVD project was a gratifying one to work with. What I learned from that was, that not only is helpful for families, but medical providers were using it to teach residents in hospitals. Specifically, Dr. Pat O’Malley at MassGeneral Hospital for Children said, “I’m using the videos in this DVD with trainees here with residents here at the hospital.” And I was like, “Wow, the voices and experiences of families can be used, not just only to help other families, but it can be used to train providers in the family experience in what families need.”

All of which motivated me several years later to leave my job at WGBH and found Courageous Parents Network, which is a non-profit whose mission it is to empower and support and orient families caring for children with serious illness and to help provide training resources or medical providers who work with these families. It —launched in 2014 and ’it represents the evolution of everything that began with my daughter Cameron receiving palliative care and then everything I learned with the Lord Foundation and the providers we were funding and the successes we were having in what came out of ’Cameron’s Arc and the Parenting a Child with a Life-threatening Illness¹’. And so, it was the culmination of all of that and now it’s an ongoing concern. It all makes sense now.

[Bryan Sisk: 
Looking back connecting the dots.

Blyth Lord: 
Yep.

Bryan Sisk: 
So, I would love to move back a little bit and before you started these foundations, talk a little more about the experience of you, but also the experience of other parents that you met. It sounds the Dr. Goldstein working with you guys was just a phenomenal
physician and without knowing that it was palliative care, was providing, high quality palliative care.

**Blyth Lord:** Yes.

**Blyth Lord:** What types of things was he doing that you’re defining now as palliative care?

**Blyth Lord:** Well, first of all as a point of reference, I would encourage you and whoever reads this to find ‘Cameron’s Arc,’ which was a DVD that the AP distributed, but ‘is about to be made available for free online, and Bryan remind me to send you a link to it when the AP puts it up on their website. Because ‘Cameron’s Arc’ really explains the type of care that Cameron’s pediatrician delivered. Can you just hold one moment please? Just one sec.

**Blyth Lord:** So the way I would categorize it is, first of all, how he delivered the diagnosis, how he prepared for delivering the diagnosis, and then how he supported what he said, how he said it. Then how he did anticipatory guidance with us. Framing where things were going to be going and the types of decisions that we were going to have to make, but letting us know that we had plenty of time to make those decisions and that there would be no rush, and that there would be no right or wrong decision. So created this space, he framed this space in the type of decisions we would be making. Then he accompanied us as we ran along and then he had very explicit conversations with us over time about what our care goals and values were.

Everything from, “We do not want our daughter to be hospitalized,” which means when she gets the pneumonias, he has to understand we’re coming, this is how we want to treat her pneumonias at home. And he said, “I will do everything in my power to make that possible so that she can be treated at home.” Seizures were going to be a big deal and we knew that there would be grand mal seizures and how can we treat those grand mal seizures at home so she does not need to be hospitalized for seizures. And then ultimately when the time came, we were doing the medical conversation about medical orders including the do not resuscitate form with my husband. And ultimately when the time came and he diagnosed her as having another pneumonia and my husband and I who had been doing so much work as a couple both with Dr. Goldstein and with a grief counselor, Laura Basili, and I really want to stress the importance of this counseling from
diagnosis onward, we at that point understood that we were not going to treat that last pneumonia because we felt that her quality of life was very, very poor and that she would not want to come back from that last pneumonia. We felt we understood what she wanted for her life. And when we discussed it for Dr. Goldstein, he came to the house and said, “Yes, she has pneumonia.” And we looked and he said, “I can go back to the hospital and I can go back to the office and get her medicine,” And we looked at him and said, “No.” And this was not easy for him, but he did it.

He supported us in that decision, at which point it was purely about making comfortable, ensuring Cameron was comfortable at her end-of-life which ultimately was five days from diagnosis. I mean from—when he—it four days. She had a second birthday on May 4th. On May 5th he said she has pneumonia and she died on May 9th. He worked hard to find the expertise required to keep her comfortable at home, which was a doctor who specialized in pain management from Boston Children’s Hospital, Dr. Chuck Berde.

He and Chuck Berde figured out how much morphine Cameron would need based on her size and age to keep her comfortable because she did not have hospice but she did have nursing. That dosing was communicated to the nurses who helped us keep Cameron comfortable at home.

And then when she died, he came to our home and he pronounced her and then he helped us find who would help who could do some grief counselling. Well actually he didn’t do that. I will tell you going backwards right after diagnosis, our first concern was for our older daughter Taylor who at that time was two. And he helped us find somebody who could, a psychologist who could help us understand what our daughter would need.

And I think another pivotal moment in his care of us is, we let him know that we were not going—we knew from the Tay-Sachs trajectory that ultimately children with Tay-Sachs begin to lose the ability to swallow and they begin to aspirate, and aspiration pneumonias begin happening, and were we going to want a feeding tube? And first, he had talked at length with my brother and sister-in-law who were going through this with their son Hayden who was a year older and therefore they were coming to these decisions before we were, but we were having conversations about them together, so by the time came for Cameron, we had already talked at length about what we wanted for Cameron because we had been talking to Tim and Allison about what they wanted for Hayden.
And Hayden was really the leader for the way it was going to go for Cameron and that was very unusual. You know most families don’t have somebody leading the way with whom they’re so close to their parents.

So, we were very fortunate in our unfortunate situation, that’s two children in one family, we were very fortunate because we could be talking with my brother and sister-in-law at length about what it was that we wanted for our children. We had like-values and we had an intimacy and we had tremendous trust because we were related to each other and we liked each other and we loved each other. And because Hayden was a year older and the shit was hitting the fan for Hayden, we were able to see “well that did not work well for Hayden so let’s not do that.” And the most immediate example of that was that Hayden was hospitalized for his first pneumonia and it was really traumatic for this little boy with Tay-Sachs to be hospitalized.

And we learned, Tim and I also learned that “we will never hospitalize him again.” And that told us that we would never want to hospitalize Cameron, and we went to Dr. Goldstein and said “Listen, we know from Hayden that we don’t ever want to hospitalize Cameron, can you help make that happen?” And he understood that, and he did. And similarly, Hayden’s end-of-life was very, very peaceful at home. But for Tim and Allison, it required a lot of back channeling to figure out, as I had said, about pain management and symptom management for the pneumonia at home because their pediatrician didn’t know how to do that.

So, we were able to go to our pediatrician, Dr. Goldstein, and say, “You have to help us do this.” And he was like, “Yes, I can help you do that.” So that it wasn’t going to be like it was for Tim and Allison with Hayden. So, we benefited from the fact that we had a foresight because what was happening with Hayden and because we had a pediatrician who stepped up to do that with us.

I’m assuming that you got to meet a lot of parents through—well, continually but especially through your earlier work. Did you get the sense that the care you received was the norm or the rare exception?

It was certainly the rare exception. ''What started was a rare exception and because it was a rare exception, I wanted to make families in the National Tay-Sachs Community aware of palliative care. And so, what I did that activated National Tay-Sachs and Allied Diseases has an annual family conference with
programming for families. And I was very involved with NTSAD [National Tay-Sachs and Allied Diseases] and I went to their director of family services and said, “We need to have a session that introduces palliative care to families, helps them understand what palliative care is, how it helps, how it’s not just about end-of—life, it’s not hospice. Hospice is the tail-end of palliative care. This is how palliative care can make a difference. I want to educate families so that they seek it out for their children.”

And over the course of two years, we came up with this concept of finding a Philosophy of Care and we began to run sessions at the conference called Finding the Philosophy of Care and Educating Families About Palliative Care, telling them “This is what it is, this is where you can, you can ask for palliative care. And even ‘if you cannot find a palliative care specialist, somebody who’s specializes in palliative care—“ because ’certainly this is true ten years ago, they weren’t very many of them, “—these are the types of communication that you can be seeking to have—types of conversations you can be seeking to have with your child’s primary care doctor. Go get ‘Cameron’s Arc and watch it and then give it to your pediatrician.” So, because I was still involved with National Tay-Sachs, the American Academy of Pediatrics gave copies of ‘Cameron’s Arc to National Tay-Sachs. And every time a new family was diagnosed, and National Tay-Sachs knew about them, they would send a copy of ‘Cameron’s Arc to that family for them to watch to see what they might hope to have as a relationship with their child’s pediatrician.

Fast forward to where we are today and at the most recent family conference that I went to in April 2019. I go every year and I’m listening to families and some families are getting exceptional care from their child’s pediatrician, some families are not. Some families are getting palliative care in their community depending on where they live. So, if you live in the state of Massachusetts or in the area around Raleigh-Durham, North Carolina or in parts of California or parts of Vermont or parts of Pennsylvania, you can be getting community-based palliative care where child life specialists or nurses or massage therapists come into your home and offer complimentary palliative care at home in addition to whatever palliative care that your child might be getting when they are inpatient in the hospital.

The problem is most of these children are not inpatient because they’re living with a chronic complex condition that is progressively worse but often with periods of stability at home. And what sort of support are these families getting at home, the
primary sources of support are whatever their primary care doctor is doing with them, whatever their neurologist or pulmonologist might be doing—actually, not pulmonologist so much, but neurologist might be doing with them. So those are the specialists. Might be a GI [Gastrointestinal] specialist as well and then what sort of support can be coming into the house. What I’m learning when I spend time with families, is that some neurologists and GI docs and primary care pediatricians are doing the work of palliative care.

I started recording again. You were saying that what you were learning is that some neurologists were practicing palliative care.

Yes, some specialists are bringing the communications and goal setting pieces and relationship building pieces, some of the fundamental principles of palliative care, to the families. But a lot of them aren’t and that’s where the opportunity is. From where I sit as a parent advocate for palliative care I believe, and I don’t think there’s anyone who disagrees with this, that while it is very differently important to build an army of palliative care specialists, it is equally important to develop some of the communication and goal setting skillsets in sub specialties and primary care so that you do not need a palliative care specialist to receive palliative care. Because there will never be enough palliative care specialists to take care of all the children living with complex chronic and life threatening conditions. So why not train and empower the specialist and the primary care doctors and nurses and social workers to deliver that care because at the end of the day it’s just good care.

\'Having been able to have a conversation with a patient or a parent about what their care goals are, is just good care. Let’s not just treat the symptoms. Let’s not just treat the disease. Let’s talk about what it is you want. Your emotional well-being, your psychological well-being and what quality of life means to you. Treating a disease in the absence of focusing on quality of life is, towards what end are we treating this condition if it’s not in the context of quality of life. So, I believe that that’s just good care and I believe that people who are primary care pediatricians are particularly well positioned to deliver palliative care, not including the specialization around pain medication which I appreciate is beyond the purview of primary care pediatrics .

I believe a primary care pediatrician should be able to have a conversation, a serious illness conversation, to talk about what it is
you think of most important—I “what if” conversation. The “in the event of, what matters to most to you” conversation. That is because the foundation of being a primary care pediatrician is relationship. You meet that family when that child is first born. You know that child in the context of their siblings, because typically you’re caring for the other siblings as well. You know what the family network is, the family system. You know what pressures that family is under. You know how realistic it is for a family to be going into the hospital all the time for appointments with specialists. Is that a realistic thing to ask that family that lives an hour away from the best hospital? Maybe not, maybe they should be getting better care in their community rather than asking them to traipse in to be poked and prodded at the hospital where parking is difficult and especially if you’re typically running late. Why are we putting that additional level of stress on parents when some of this care can be done somewhere else? This is just an example. I could go on.

Before we started recording today, we were talking briefly about suffering and about how there’s kind of the lower order suffering which is the symptoms or the insults. Then there’s higher order suffering which were really comes to tag on what gives your life meaning and what goes your life purpose and that could be for the patient, parent, clinician. Early on, from your perspective, when parents were experiencing lack of the care that you’re talking about, what type of care was most lacking? Was it the symptoms, was it the psychological, the social, these more existential needs? What was the ground reality then?

Can you hear me?

I have to take a brief pause for about one minute so just keep. So, I think the types of support that families were missing was processing anticipatory grief, recognizing that even though their child was alive, they’re experiencing significant grief as they think about the losses that lie ahead, including just the realization that their child is not going to live a typical life with a typical lifespan, which is a devastating prospect for families. So help with anticipatory grief. I would say helping families—be very aware and meta cognitive about goals of care in a context of a philosophy of care. And what falls out from that as an activity is decision making around medical interventions. What I was seeing is families wanting to—parents becoming experts in their child’s
disease progression but not having a guide or framework for how to be empowered as decision makers in their child’s care.

And what I was seeing happening which was distressing to me was families being put on a conveyor belt for treat, treat, treat, fix, fix, fix, when for a lot of these conditions there aren’t treatments available and the condition can’t be fixed. What it really is, is about management and how you want to manage this and towards what end.

And for me the most salient example was families who were being told, “Your child needs a swallow study. They’re having trouble swallowing and now they need a swallow study.” Now, if you’re going for a swallow study and your child has a condition like Tay-Sachs, you’re automatically going to discover that your child is aspirating. And the average swallow study technician and person following a swallow study is going to recommend a feeding tube; “Your child is struggling with swallowing, they’re aspirating, allow us to schedule a feeding tube surgery.”

Now, feeding tubes make a lot of sense for a lot of conditions and they may even make sense for Tay-Sachs if the family’s goal for that child is length of life for as long as possible. Because feeding tubes extend lives significantly for children living with lysosomal storage diseases. However, for some families, they may conclude that the neurological devastation that cannot be stopped, at least as of the time of this recording July 2019, it has been so great that extension of life is not what they want because their child is already so neurologically compromised and so much has been taken from them that, accept that quantity does not equal quality and therefore you do not wish to have a feeding tube.

My husband and I, that is what we decided and our doctor never put pressure on us to have a swallow study or a feeding tube because we had already had these conversations with my brother and sister-in-law and other families in the National Tay-Sachs Community who came up to us at our first conference. So, we went to our first family conference, this is shortly after Cameron and Hayden were diagnosed. And we went, and there were families who came back and said, “There are many ways you can go with medical interventions and none of them are wrong and none of them are right. You will find what’s right for you. If you decide that the more intensive direction is not for you, you can come talk to us.”
And what I have found is that families find their people who are most like them based on the decisions they think resonate for them and with their child. And I see this at the Tay-Sachs conferences I go to, is there are families that instinctively know that they’re going to want to do every medical intervention possible to keep their child alive for as long as possible and they find the families who made those decisions and they support each other and it’s a beautiful thing. And then there are the families like my husband and me who feel that they really want to do minimal medical interventions and they find the families like them who support them and it’s a beautiful thing. And what was upsetting me, x number of years ago, was that was not explicit and there were families who were getting swallowed up without realizing that they had a choice.

And two years ago, I was at the family conference and I met a mother whose son had Tay-Sachs. She lived in Northern California in a very popular city and her son had recently received a feeding tube. And it was her first time at the conference, and she decided to come to the Finding Your Philosophy of Care Session that I was co-leading, and I was talking about goals of care and I gave an example of a feeding tube. She said to me, “Wait, wait, you mean the feeding tube was optional?” And I said, “Yes, you didn’t need to give your son a feeding tube. You may well have believed that ultimately that this is the best thing for your son, but it was not a mandatory intervention.”

And you could see that all of a sudden there was this struggle happening inside of her because she resented the fact that she had not been given a choice and choice is really important to parents. As a parent, decision making is one of the ways that we parent our children and taking away the ability to make the decision for our child, if the child can’t make it for themselves, it’s still a part of the parent’s role. So, you could see that she was quietly devastated by that. And then she was quietly devastated by suddenly wondering if she had made the right decision that hadn’t even been a choice. Now I hope and believe that she ultimately made peace with it, because parents fortunately and mercifully do find a way to feel like the decisions they’re making are in the best interest of their child. But what you want is for that to be part of a process not retroactive peacemaking with something that you didn’t realize you’re even doing.

And for me a goal is how can we make much of this explicit and meta so that parents can do it thoughtfully, intentionally with full awareness—whether they’re doing it as a couple or co-parenting
with the other parent of the child or whether they’re doing it with the child if the child were cognitively able to do that work together. Because it is true that intentionality and that deliberateness that you feel that you made the best decision for the child, or that the child made the best decision for themselves, it is to that, that there’s peace so that when the end comes, if the child ultimately dies, there is minimal regret.

And I have seen and with all my work at Courageous Parents Network and parents who’ve cared for children with neurological conditions, chromosomal disorders, pediatric cancers, brain tumors—that a big, big, a big ingredient in what the grief looks like after and whether it’s complicated or less complicated or uncomplicated or whether it’s clean pain—what I call “clean pain” versus “dirty pain,” because there’s going to be pain no matter what; but the pain can be clean or it can be dirty—is what level of regret does the parent have about the decisions that were made in that child’s illness trajectory. And the less regret we can have, the better the pain and the grief.

And a big piece of a big variable or determinant in the level of regret to me is agency around decision making and now we’re living right now the space of shared decision making. I think I like that. I don’t think all parents make good decisions independently. I think it needs to be done in a healthy trusting relationship through good communication with the child’s medical team and that’s palliative care. That’s what palliative care does so perfectly.

I would love to switch gears a little bit and now think about your role as a professional parent and advocate. As you were starting these different adventures, what were the biggest challenges you were facing?

Okay. I do have to flag to you Bryan, that I only have about 20 minutes and then we can always schedule a follow-up.

Sure, perfect.

Okay.

I’ve got about a handful of questions after this and then you can just let me when you need to go.

I need to go at 11:40 my time so 10:40 your time, so if you can help me watch the clock for that. What were challenges starting the foundation I mean the nonprofit Courageous Parents Network?
Bryan Sisk: Yeah as you were building it and growing it over time, did you run into notable challenges?

Blyth Lord: You know it’s interesting. I’m going to answer that in the opposite, in the affirmative. I started Courageous Parents Network because I wanted to bring what had helped my husband and me during Cameron’s life, to parents who were going through it today. And I wanted to do that work full time. I remember sitting with Dr. Goldstein, we had just given a presentation of Cameron’s Arc to, I think it too was the American Academy of Pediatrics annual assembly or maybe it was a National Hospice and Palliative Care Organization, and we were flying back on an airplane. I was working at WGBH at that time and I said, “—I feel like I’m called to do this work full time, but I don’t know how to do it.” And he said, “Look at the cards you’re holding and play the hand you’ve been dealt.” And I said, “Okay, well let me see what I’ve got.” And I looked at it and I said, “Well, okay I’ve got video production, I’ve got distance learning, I’ve got web design, I’ve got outreach, I’ve got pediatric palliative care, and I’ve got a community of parents who I know whose children are living with life-threatening conditions or have died, and I have my own personal experience.”

—So I literally out of thin air put most of all those things together and I conceived a web and mobile platform that would harness the power of digital media and distance learning to bring the voices and experiences of parents and providers to families going through it today to reduce the isolation they experience and give them guidance and insight to help them make decisions and cope. And there would be no editorial agenda in terms of what those decisions should be, but what we would show is that there’s no right or wrong decision. There are a spectrum of ways you can go. We’re going to help you understand anticipatory grief. We’re going to help you understand what it means to work with your child’s medical team in a healthy constructive way. We’re going to help you think about what means to work with your child’s medical team in a healthy constructive way. We’re going to help you think about what goals of care are. We’re going to help you think about issues related to spirituality, fear of regret, all of these things. We’re also going to help you look at end-of-life by hearing some other parents whose children have died, and think about, and hear what their child end-of-life looked like, and what their transition was, and whether they wanted their child to die at home or in the hospital. So we’re going to cut. And then you’re going to hear from parents who are bereaved about what it has been like after their child has died and what their identity is as a parent is. And we’re going to help you share that, how it changes their
marriage, whether their marriage survived or not and how they cared for the other children going through it.

But the one thing we’re going to be very, very, very explicit about is the value of palliative care. So, we had no editorial agenda other than to talk about a wide spectrum of things with no judgement except we were going to promote palliative care as a form of care that helps you do all of this. And so, it was an experiment. I founded the non-profit. That’s not very hard. You work with a lawyer. You fill the paperwork to found 501c3. Got recognition from the IRS from the State of Massachusetts. We were incorporated as 501c3. I had a business plan for what I was going to need to do, what it was going to look like and then I put together professional advisory board. They gave me some very really good advice about how I needed to do a little more research. I sort of did that because I was very impatient to get going. I designed the website. I designed the platform. I found a develop to build it. The developer’s wife designed it. I went out and I found some parents to interview. I found them through the professional advisory board and my own network through the National Tay-Sachs Association and I built a proof of concept.

And the proof of—and then I sort of took it to providers and parents and got feedback about the proof of concept and evolved it from there. Then—I won a Social Innovation award from an organization called the Social Innovation Forum Organization which brought in-kind consulting services to help me take Courageous Parents Network to the next level, which was to professionalize the board, to do a real business plan, to do a real budget, to learn some best practices around fundraising and budget development and board development. And with that accelerator, grant, I was able to take CPN to the next level which was then the board. The board has been incredible at helping me grow the organization and set goals for growth and organizational development.

And I’ve also had an incredible provider advisory board that has helped figure out the best way to reach providers and understand how to make Courageous Parents Network available to them as a resource. Then concurrently, have put together an incredible staff which is some full-time staff and some part time contractors on retainer. I staff are parents, the contractors, some of the contractors are parents who’ve been there. Other religious were just people with extraordinary compassion and huge hearts and emotional intelligence and professional expertise around communication and
marketing, or data analytics, and digital marketing and technology and development to figure out how to grow.

So, it’s really gone from an experiment to something that is now trusted by providers and is being increasingly used by palliative care teams and specialists in hospitals around the country, as well as patient disease groups as a resource that they can recommend to families in their community. And organically to parents who are finding us through organic searches or social media and telling us, “Yes thank God we’re able to hear from parents like us. You’re helping us feel not as alone. You’re helping us consider decisions such as spinal fusion surgery.“

So, it’s been really—it was a startup and like any startup it had a proof of concept that we’ve iterated. We’ve thrown stuff out and we’ve added stuff and we’re learning all the time. What I would say is the hardest part is knowing how to pace ourselves and really knowing what to do next, because I always feel my background as a producer is to make stuff and knowing what the need is, I want to do everything all at once. I want to meet all the needs all the time but that’s not how you grow an effective organization. So for me the hardest thing has been prioritization.

I will say the, probably one of the most gratifying things that happened in Courageous Parents Network is that when I originally built it, my conception was that it was entirely for parents. But what we’ve learned is that providers, it’s proving to be a very effective and helpful platform and tool for training, because providers who train both for self-education, because watching the videos or reading the blogs to better understand what the lived family experiences are for self-education, or using the videos to train residents or other trainees in how parents then feel, what parents say they need, and using that as a jumping off point for training—whether it’s palliative care training or communication training or anything like that.

The other thing that has been hard is the growth piece, the marketing piece. It is absolutely true that just because you built it doesn’t mean they will come and how you get minds there of parents who don’t know about you and providers who are very, very busy. And so really promoting Courageous Parents Network as this resource that helps you, mom and dad, or helps you doctor, nurse, social worker, help the families you care for, that’s not easy. There’s a reason marketing communication budgets are one of the biggest ‘line items in a company’s budget. And it’s honestly no different in non-profit.
Lastly, I would love for you to dream aloud for me. If budget, politics, and cost, and interest, and all of those things we’re talking about, if none of those were an obstacle, why would you want care for these children to look like ideally in another ten years?

My goal would be that every pediatric provider who works with children that are living with severe medical complexity or serious illness, has been trained in and has the skills to do goals of care conversation, medical decision making conversation, advance care planning work, so that it becomes a common standard of care. So that you don’t have “the haves” and “the have nots” for people who are lucky because their pediatrician can do it or they’re lucky because they live in Massachusetts where there’s a community based palliative care network. So that no matter where you are or where you live, —the care your child is receiving knows how to do that work for you.

I don’t expect every provider to be able to do pain medication and symptom management for these children. That is a type of expertise that —requires technical training. That’s technical training. But knowing how to communicate and have goals of care conversations is something that I would like to see begin in med school, certainly with intention with residency, and be a standard of care in the specialties that touch these children. That is what I would like to see. Yeah that’s what I would like to see, and I believe it’s possible. I don’t believe you go into medicine, clinical care, and doing direct care of children if you don’t somewhere and your being recognize that’s part of the care you should provide. And if you’re an oncologist and you are not doing that type of work with a family, then I think you belong in the lab.

Agreed, amazing. Well, those are all the questions that I had. Is there any other important part of this history from your perspective that we haven’t hit on or that you think I need to dig in more deeply in the future?

Oh my God. Well I think I probably tired you out. I think I have certainly tired myself out in this moment. I think what I want to stress is that, this work is hard. From a provider perspective I recognize that this work is really hard because there’s no formula for how it goes in children, for what palliative care looks like because there’s no formula for how—or it’s not like there’s no formula. ‘It’s not simple because pediatric illness it’s so very indifferent and there’s certainly different types of ways for children to be sick. There are so many different disease
trajectories. There are so many different family compositions. And so, there’s, it’s definitely much more an art than a science. It’s also really intimidating and hard because it’s upsetting. This work is hard. Watching children be sick and watching children die and watching the grief of parents and siblings and children is really hard. So, I believe that there is nobody more noble than the person who has stepped up professionally to do this type of care. And for me, once you’ve stepped up to do this type of care, you’ve already declared yourself as somebody who wants to be the emotional intelligent or is already the emotional intelligent noble person. ‘—You’re already inclined to want to do this, let’s help you go the last mile, or in my opinion for me it’s like the last half of the journey is the staff that isn’t about pain and symptom management, it’s about communication via trust relationship development. So, like that’s why I have so much hope is because this is what these people signed up when they chose the specialty they’ve gone into in the first place. I also think it’s really gratifying to know you’ve made such a difference in a child and a family’s journey. And I believe that it’s a form of self-care for a provider in a field where it’s really hard, and physician burnout and provider burnout is high because the work is difficult—that this is a way to counter program burnout, is to help people do this work well. And yeah, I think I’ve lost the thread. I’m talked out.

Blyth Lord: Okay, I think that one of the next frontiers in pediatric palliative care is going to be involving parents as colleagues in the development and growth of the field because there is no more effective ambassador for private care than the beneficiary. And parents, not just as educators, the parents as fellow learners and fellow—well parents as educators, learners and ambassadors can help advance the field. And not just as subjects for the research but working with as fellow PIs in the research.

Bryan Sisk: Phenomenal. Anything else?

Blyth Lord: No, that’s it.

[End of Recording]