

Guide to CPN's Family Videos



Casey and Brian

Casey and Brian are the parents of Freddie, Bethie, Mary Frances, and Gus. Bethie was diagnosed in-utero with **heterotaxy syndrome** and died at the age of 14 months. Their videos touch upon decision-making and regret.

<https://courageousparentsnetwork.org/video-library/family/casey-and-brian>

Katherine and Nate

Katherine and Nate are the parents of Joey and Benjamin. Joey was diagnosed in-utero with **severe holoprosencephaly** (brain malformation) and died 2 weeks after birth. Their videos touch upon perinatal palliative care, decision-making, living with uncertainty, faith/spirituality, finding support, and grief.

<https://courageousparentsnetwork.org/video-library/family/nate-and-katherine>

Naomi

Naomi is the mother of Noah, who was born very premature and lives with multiple **complex medical conditions**. Her videos touch upon biases in the hospital setting, working with your medical team, palliative care, decision-making (trach), and faith/spirituality.

<https://courageousparentsnetwork.org/video-library/family/naomi>

Frank and Jeanette

Frank and Jeanette are the parents of Alex and Frankie Jr. Frankie has multiple progressive conditions including the **DNMT1 mutation**. Their videos touch upon advocating for your child, working with your medical team, quality of life, the marriage/partnership and supporting the siblings.

<https://courageousparentsnetwork.org/video-library/family/frank-and-jeanette>

Robin

Robin is the mother of David who had **leukemia**. Her videos touch upon childhood cancer, advocating for your child, palliative care, and end of life.

<https://courageousparentsnetwork.org/video-library/family/robin-k>

Sarita and Kareem

Sarita and Kareem are the parents of Jeff, Rian, Josiah, Jeremiah and Elijah. Elijah has **Trisomy 18**. Their videos touch up biases in the hospital setting, advocating for your child, working with your medical team, supporting siblings, and finding support.

<https://courageousparentsnetwork.org/video-library/family/sarita-and-kareem>

April

April is the mother of Jackson. Jackson had **Krabbe Disease**. Her videos touch upon the diagnosis journey, working with your medical team, palliative care, biases in the hospital setting, and grief.

<https://courageousparentsnetwork.org/video-library/family/april>

Ashley and Theron

Ashley and Theron are the parents of Rosa, Leo and Viggo. Viggo was diagnosed with **Trisomy 5p** shortly after birth and died at age 6 months. Their videos touch on the NICU experience, palliative care and decision-making.

<https://courageousparentsnetwork.org/video-library/family/ashley-and-theron>

Aubrey

Aubrey is the mother of De'Aubrey and his older sister. He was born extremely **premature** and lived with multiple complexities and diagnoses, including **epilepsy**. He passed away at age 14. Her videos touch upon anticipatory grief, advocating for your child, pain management, biases in the hospital setting, and bereavement.

<https://courageousparentsnetwork.org/video-library/family/aubrey>

Jazmyne

Jazmyne is the mother of Crimson. Crimson was diagnosed prenatally with **Congenital Diaphragmatic Hernia (CDH)** and lived her 5 months, deeply cherished, in the NICU. Her videos touch upon decision-making, advocating for your child, biases in the hospital setting, the NICU experience and bereavement.

<https://courageousparentsnetwork.org/video-library/family/jazmyne>

Crystal

Crystal is the mother of Sydney, who has severe **cerebral palsy**. Sydney is trached, on a ventilator, and fed via G-Tube. Her videos touch upon faith/spirituality, advocating for your child, biases in the hospital setting and palliative care.

<https://courageousparentsnetwork.org/video-library/family/crystal>

Matt and Myra

Matt and Myra are the parents of Havi, Kaia and Ezra. Havi died at age 2 from **infantile Tay-Sachs** disease. Their videos touch upon the diagnosis journey, role of extended family, grieving in relation to others, bereavement and writing as healing.

<https://courageousparentsnetwork.org/video-library/family/matt-and-myra>

Sarah

Dr. Sarah McCarthy, Ph.D., MPH, LP is a pediatric psychologist and mom to twin girls, Molly and Emma. Molly was diagnosed with the rare occurrence of two pediatric cancers - **Acute Lymphoblastic Leukemia** and **Neuroblastoma**. Her videos touch upon when the sibling is a twin, uncertainty and anxiety surrounding the cancer diagnosis, the need for self-care/taking a break and palliative care.

<https://courageousparentsnetwork.org/video-library/family/sarah-m>

Swati and Joseph

Swati and Joseph are the parents of Caleb and Canaan. Canaan died at 20 months from **Noonan Syndrome**. Their conversation touches upon faith/spirituality, regret, decision-making and supporting siblings.

<https://courageousparentsnetwork.org/video-library/family/swati-and-joseph>



Shawna and Mike

Shawna and Mike are the parents of Keenan, Kyle, Kashton and Karston. Keenan was born with **Microcephaly Capillary Syndrome**. Keenan died just before his third birthday. His siblings were born after. Their videos touch upon family planning, continuing bonds, hospital life, running a home PICU and grief.

<https://courageousparentsnetwork.org/video-library/family/shawna-and-mike>

Laura and Dave

Laura and Dave are parents to Hadley and Alden. Alden has **Polymicrogyria**. Their conversation touches upon advocating for your child, role of extended family, sharing the diagnosis, the marriage/partnership and decision-making (feeding tube).

<https://courageousparentsnetwork.org/video-library/family/laura-and-dave/>

Lynette

Lynette is the mother of Anderson "Andy," Zach and Jamie. Lynette is pregnant with Jamie at the time of this interview. Andy was born with **Marfan Syndrome** and died at age 3. Her videos touch upon pregnancy after child loss, decision-making (trach), baseline, end of life and grief.

<https://courageousparentsnetwork.org/video-library/family/lynette/>

Janna

Janna is the mother to Henley, who has had a heart transplant due to contracting **enterovirus myocarditis** which in rare instances can cause serious cardiac side effects. Her videos touch upon hospital life, finding support, family planning and the marriage/partnership.

<https://courageousparentsnetwork.org/video-library/family/janna/>

Sandy

Sandy is the mother of Jack and Ben. Jack was diagnosed with the rare blood disease **Kohlmeier-Degos** and died at the age of 5 – only 9 months after his diagnosis, most of which was spent in the ICU. Her videos touch upon hospital life, medical trauma, grief, decisional regret, the need for self-care/taking a break and continuing bonds.

<https://courageousparentsnetwork.org/video-library/family/sandy-clancy/>

Dawn

Dawn is the mother of Vayle, who has **Canavan Disease**. Her videos touch upon the clinical trial process as well as decision-making.

<https://courageousparentsnetwork.org/video-library/family/dawn/>

Megan

Megan is the mother of Isla and Jude and she is the Executive Director Sanfilippo Children's Foundation. Both Isla and Jude have **Sanfilippo Syndrome**. Her videos touch upon the clinical trial process as well as decision-making.

<https://courageousparentsnetwork.org/video-library/family/megan-donnell/>



Jenn

Jenn is the mother to Austin, Max, James and Norah. Austin and Max have **Duchenne Muscular Dystrophy**; and James has **Primary Immune Deficiency**. Jenn's videos touch upon the clinical trial process, the diagnosis journey and living life to the fullest with medically complex children.

<https://courageousparentsnetwork.org/video-library/family/jenn-mcnary/>

Michelle

Michelle is the mother of Alex and Julianna. Julianna had a severe form of **Charcot-Marie-Tooth** disease and died at age 5. Michelle's videos touch upon palliative care, decision-making (feeding tube), end of life, bereavement and supporting siblings.

<https://courageousparentsnetwork.org/video-library/family/michelle-m/>

Hannah and Eric

Hannah and Eric are the parents of Sage and older brother Gabriel. Sage was born with **Arteriovenous Malformation (AVM)** and died at age 3 months. Their conversation covers pregnancy after child loss, working with your medical team, advocating for your child, decision-making, the NICU experience and bereavement.

<https://courageousparentsnetwork.org/video-library/family/hannah-and-eric/>

June

June MSW, LICSW, ACHP-SW, is the mother to Alissa and Katie. Katie is medically complex and likely has **Rett Syndrome**. Her videos touch upon finding support, considering out-of-home placement, transitioning to adult care, guardianship and family planning.

<https://courageousparentsnetwork.org/video-library/family/june/>

Michelle and Joe

Michelle and Joe are the parents of Logan and Matthew. Matthew has **Batten Disease/CLN2** and was one of the first children in US to receive Enzyme Replacement Therapy beginning at age 4. Their videos touch upon the clinical trial process, supporting siblings, advocating for your child and the diagnosis journey.

<https://courageousparentsnetwork.org/video-library/family/michelle-joe-logan-and-matt/>

Brenda

Brenda is the mother of Sam, Simon and Solomon. Sam suffered a **stroke in-utero** and was medically complex from birth and died at the age of 15. Her videos cover the need for self-care/taking a break, decision-making (spinal fusion, trach), palliative care, anticipatory grief and bereavement.

<https://courageousparentsnetwork.org/video-library/family/brenda-murray/>

Mona

Mona is the single-mother of Owen, who has **Juvenile Tay-Sachs**. Her videos touch upon decision-making, being a single parent and finding support.

<https://courageousparentsnetwork.org/video-library/family/mona/>



Emily and Darren

Emily and Darren are the parents of Parker, Christopher and Jacob. Christopher has **Hurler Syndrome (MPS Type 1)** and has had a stem cell transplant. Their conversation touches upon the diagnosis journey, decision-making (stem cell transplant) and living with uncertainty.

<https://courageousparentsnetwork.org/video-library/family/emily-and-darren>

Oralea and Rod

Oralea and Rod are the parents of William, Kyla and John. William died at age 8 from **GM-1**. Their videos include a conversation with Kyla, William's sister, who shares her advice of spending as much time as you can with your sibling who has a serious illness. Oraclea and Rod touch upon supporting siblings, the need for self-care/taking a break, decision-making (feeding tube, trach), regret and bereavement.

<https://courageousparentsnetwork.org/video-library/family/oralea-and-rod-marquardt/>

Barb and John

Barb and John are the parents of Jake and Ryan. Jake has **Dravet Syndrome** and **Secondary Mitochondrial Dysfunction**. Their conversation touches upon the marriage/partnership, living with uncertainty, the need for self-care/taking a break and supporting siblings.

<https://courageousparentsnetwork.org/video-library/family/barb-and-john/>

LJ and Catherine

LJ and Catherine are the parents of Rachel, Alex, Caitlyn, Joshua, Abigail, Simeon and Michael. Rachel has **leukodystrophy**. Their videos touch upon a lot of topics including the marriage/partnership, goals of care, supporting siblings and faith/spirituality.

<https://courageousparentsnetwork.org/video-library/family/lj-and-catherine/>

Joy and Bruce

Joy and Bruce are the parents of Corinne (Cora), who has **Trisomy 18** and was 3 months at the time of this interview. Their videos touch upon living with uncertainty, advocating for your child, faith/spirituality and sharing the diagnosis.

<https://courageousparentsnetwork.org/video-library/family/joy-bruce-cora/>

Kate

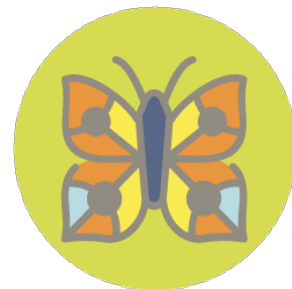
Kate is the mother of Brooke and older son Jake. Brooke had **infantile Tay-Sachs** and at the time of this interview was age 3. She has since passed away. Her conversation touches upon sharing the diagnosis and end of life.

<https://courageousparentsnetwork.org/video-library/family/kate/>

Jenn and Joe

Jenn and Joe are the parents of Mallory, Matthew and Melanie. Mallory has **Juvenile Tay-Sachs** and at the time of this interview was 6. Their conversation touches upon the marriage/partnership, supporting siblings, faith/spirituality, anticipatory grief and the need for self-care/taking a break.

<https://courageousparentsnetwork.org/video-library/family/jenn-joe/>



Haydee and Orlando

Haydee and Orlando are the parents of Kristie, Kimberly and Danny. Kristie died at the age of 16 from **leukemia**. Their conversation touches upon faith/spirituality, supporting siblings, the marriage/partnership, end of life and grief.

<https://courageousparentsnetwork.org/video-library/family/haydee-and-orlando/>

Lars and Elizabeth

Lars and Elizabeth are the parents of Adelaide, Charlotte and Levi. Adelaide has '**shrinking white matter**' disease and at the time of this interview she was 3. Their videos touch upon palliative care, supporting siblings, living with uncertainty and the marriage/partnership. Their videos also include a check-in conversation with Blyth providing an update about Adelaide that includes the diagnosis journey for her rare disease.

<https://courageousparentsnetwork.org/video-library/family/lars-and-elizabeth/>

Chad and Kristina

Chad and Kristina are the parents of Talon, Benjamin and Nicholas. Talon had a **peroxisomal disorder** and died shortly before his 2nd birthday. Their conversation includes end of life, supporting siblings, working with your medical team and bereavement.

<https://courageousparentsnetwork.org/video-library/family/chad-and-kristina/>

Sherri

Sherri is the mother of Rachel and Jessica. Rachel has **Canavan disease** and at the time of this interview was 16 and Jessica was 17. Her videos touch upon supporting siblings, faith/spirituality, decision-making and end of life. Her videos also include a check-in conversation with Blyth providing an update about Rachel where she talks about out-of-home placement.

<https://courageousparentsnetwork.org/video-library/family/sherri/>

Paula

Paula is the mother of Lydia and Luke. Lydia died at the age of 9 from **cancer**. Her videos touch upon the cruelty of cancer treatment options, faith/spirituality, supporting siblings, end of life and grief.

<https://courageousparentsnetwork.org/video-library/family/paula/>

Greg and Heidi

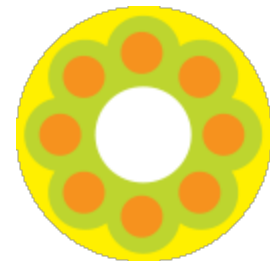
Greg and Heidi are the parents of Abby and Tomas. Abby has **Leigh's Disease**, a rare and life-limiting form of mitochondrial disease. Abby is receiving experimental therapy. Their videos touch upon the clinical trial process, palliative care, living with uncertainty, decision-making (G-tube) and advocating for your child.

<https://courageousparentsnetwork.org/video-library/family/greg-and-heidi/>

Janet and Brian

Janet and Brian are the parents of Michael, who died from **SMA**. Their videos touch upon decision-making (feeding tube, ventilator), the diagnosis journey, supporting siblings, end of life and grief.

<https://courageousparentsnetwork.org/video-library/family/janet-and-brian/>



Jenessa

Jenessa is the mother of Zach, Alex and Zoe. Alex has **SMA Type 1**. Her videos touch upon decision-making (tracheostomy, spinal fusion surgery), the diagnosis journey, traveling with a medically complex child, faith/spirituality and advocating for your child.

<https://courageousparentsnetwork.org/video-library/family/jenessa/>

Ben and Allison

Ben and Allison are the parents of Julia, Wilbur, Beckett and Clementine. Beckett and Clementine died at age 3 and 2 respectively from a rare **metabolic acidosis disorder**. Their conversation covers hospital life, palliative care, end of life and grief.

<https://courageousparentsnetwork.org/video-library/family/ben-and-allison/>

Spanish Speaking Families

Marilia

Madre de Daniel (5 años) y Diego. Diego nació con una afección **cardíaca congénita** y murió a los 7 años.

<https://courageousparentsnetwork.org/video-library/family/marilia>

Jesse

Madre de Kendall "Kenny" (2 1/2 años) Kenny tiene **dysplasia broncopulmonar, broncomalasia, y traquemalasia**.

<https://courageousparentsnetwork.org/video-library/family/jesse-martinez/>

Conversations with Extended Families

Sarah and Steve with Melissa (Sarah's mom)

Sarah and Steve are the parents of Emerson and Margot. Emerson died at the age of 16 months from **Gaucher Type 2**. Their videos touch upon the diagnosis journey, palliative care, decision-making, family planning, finding hope and bereavement. Their videos also include a conversation with Melissa, Sarah's mother and Emerson's grandmother. Melissa touches upon providing support to Sarah and Steve as they cared for Emerson.

<https://courageousparentsnetwork.org/video-library/family/sarah-and-steve/>

Blyth and Charlie with Tim (Charlie's twin brother)

Blyth and Charlie are the parents of Cameron, Taylor and Eliza. Cameron died at the age of 2 from **infantile Tay-Sachs** disease. Their conversation also includes Tim, who is Charlie's twin brother, and is the father of Hayden, Annie and Mary. Hayden died at the age of 2 from **infantile Tay-Sachs** disease. Their videos touch upon the diagnosis journey, palliative care, decision-making (feeding tube), end of life, anticipatory grief and bereavement.

<https://courageousparentsnetwork.org/video-library/family/blyth-and-charlie/>

Lindsay and Bear with Dani (Lyndsay's sister)

Lindsay and Bear are the parents of Quinlan and August. Quinlan died at the age of 2 of a rare genetic illness **BRAT1**. Their videos, which also include a conversation with Quinlan's aunt, touch upon the diagnosis journey, decision-making (feeding tube, trach), the role of extended family and friends, family planning and grief.

<https://courageousparentsnetwork.org/video-library/family/lindsay-and-bear>

Carla with Robin (Carla's mother)

Carla is the mother of Nathan, Audrey and Talia. Talia died at 23 months from **infantile Tay-Sachs**. Carla's conversation with her mother, Robin, includes the mother-daughter relationship in the face of Talia's diagnosis and illness. Their conversation also touches upon sharing the diagnosis, decision-making, faith/spirituality, end of life and the process of writing about their journey.

<https://courageousparentsnetwork.org/video-library/family/carla-and-robin/>

Jacob, Erin, Leah, Michael (Havi's aunts and uncles)

Erin and Leah are the two aunts and Jacob and Michael are the two uncles of Havi, who died at age 2 from **infantile Tay-Sachs**. They talk about how they showed up for Matt and Myra and the grief they felt as extended family.

<https://courageousparentsnetwork.org/video-library/family/jacob-erin-leah-michael>

Conversations with Clinicians

Jerris with Robert Macauley, MD (palliative care doctor)

Jerris is the father of Faith, who had **Osteosarcoma** with multiple complications and died at age 18. His videos include a conversation with Robert Macauley, MD who is the director of the Oregon Health & Science University Doernbecher Bridges program, where Dr. Macauley talks about working with the whole family and really listening to the patient. His conversation touches upon childhood cancer, pain management, advocating for your child, particularly as a father and working with your medical team.

<https://courageousparentsnetwork.org/video-library/family/jerris>

Amy with Erin Flanagan, MD (palliative care doctor)

A conversation between mom Amy, mother of four, including twins Lauren and Emma, and Erin Flanagan, MD, a palliative care doctor. Lauren was diagnosed with **rhabdomyosarcoma** at age 7 and died at age 10. Their conversation touches upon palliative care, advocating for your child, pain management, childhood cancer and end of life.

<https://courageousparentsnetwork.org/video-library/family/amy-g-mother-of-lauren-and-palliative-care-doctor-erin-f>

Natalie with Alyssa Siegel, MD (adult coordinated care)

Natalie is the mother of Emma, Avery and Lyla. Emma has been **medically complex** from birth. Her videos include a conversation with Alyssa Siegel, MD who is the Clinical Director for transition to adult coordinated care at Children's Hospital of Philadelphia. Their conversation touches mainly upon the transition to adult care for a medically complex child as well as decision-making (spinal surgery), what a good day looks like and traveling with a medically complex child.

<https://courageousparentsnetwork.org/video-library/family/natalie/>

Kate with Elizabeth Blume, MD (cardiac therapies)

Kate is the mother of Joseph, Jack and Grace. The boys have **familial cardiomyopathy**. Joseph died at the age of 6 and Jack received a heart transplant at the age of 4. Kate's videos include a conversation with Elizabeth Blume, M.D., who is the Medical Director of Advanced Cardiac Therapies at Boston Children's Hospital. Kate touches on the NICU experience, living with uncertainty, working with your medical team, family planning and decision-making (heart transplant).

<https://courageousparentsnetwork.org/video-library/family/kate-m/>

Jacqui with Kevin Callans, RN and Christopher Hartnick, MD (pediatric ENTs)

Jacqui is the mother of Tommy and Claire. Claire has **aspiration** and **sleep apnea**. Her videos include conversations with Kevin Callans, RN and Christopher Hartnick, MD both of whom are pediatric ENTs at MassGeneral Hospital for Children and Mass Eye and Ear. The videos mainly touch upon decision-making (feeding tube, CPAP, trach).

<https://courageousparentsnetwork.org/video-library/family/jacqui/>

Joanne and Lexi with Julie Hauer, MD (pediatrician)

Joanne is the mother of Brooke, Kristin, Lexi and Barry. Barry was **medically complex** and died at the age of 16. Joanne's videos include a conversation with Julie Hauer, MD who is a pediatrician. Within her videos is also a conversation with Joanne's daughter, Lexi, who talks about her special relationship with her brother Barry. Joanne's videos touch upon out-of-home placement, decision-making, supporting siblings and end of life.

<https://courageousparentsnetwork.org/video-library/family/joanne-and-lexi/>

Kerri with Nancy Frumer Styron, JD, PsyD (pediatric psychologist)

Kerri is the mother of Kai, who died from an **inoperable brain tumor** at the age of 2. Her videos include a conversation with Nancy Frumer Styron, JD, PsyD, a pediatric psychologist where they talk about anticipatory grief. Kerri's videos also touch upon palliative care, end of life, decision-making, the marriage/partnership and bereavement.

<https://courageousparentsnetwork.org/video-library/family/kerri/>

Jennifer and Stuart with Patricia O'Malley, MD (palliative care)

Jennifer and Stuart are the parents of Ben, Noah and Isabelle. Ben had **Sanfilippo Syndrome** and died at the age of 17. Their conversation touches upon palliative care, decision-making (feeding tube, spinal fusion surgery), the marriage/partnership, supporting siblings and end of life.

<https://courageousparentsnetwork.org/video-library/family/jennifer-and-stuart/>



Nicky with Janet Duncan, MSN, CPNP (palliative care)

Nicky is the mother of Janessa, Isaiah and Avery. Isaiah and Avery have **mitochondrial disease**. Her videos touch upon living with uncertainty, medical decision-making (spinal fusion surgery, trach), palliative care, the need for self-care/taking a break, faith/spirituality and the marriage/partnership.

<https://courageousparentsnetwork.org/video-library/family/nicky/>

Erin with Jay Barry, MD (general pediatrician) and John Emans, MD (pediatric orthopedic surgeon)

Erin is the mother of Will, age 17, who had spinal fusion therapy at age 14. In this video she is sitting with Dr. Jay Barry, General Pediatrician in the Complex Care Service at Boston Children's Hospital as well as Dr. John Emans a pediatric orthopedic surgeon as they discuss the decision-making process around spinal fusion surgery.

<https://courageousparentsnetwork.org/video-library/family/erin-ward>

Cari with Mary-Frances Garber (genetic counselor)

Cari is the mother of Dylan and Jessie. Jessie had **Sanfilippo Syndrome** and died at the age of 13. Her videos touch upon the diagnosis journey, faith/spirituality, supporting siblings, decision-making (feeding tube) and end of life. Her videos also include a conversation with Mary-Frances Garber a Licensed Genetic Counselor on the anxiety around family planning.

<https://courageousparentsnetwork.org/video-library/family/cari/>