

SAVING CASE & FRIENDS
FUNDING A CURE FOR HUNTER SYNDROME

ALIVE

A PROJECT ALIVE DOCUMENTARY SERIES



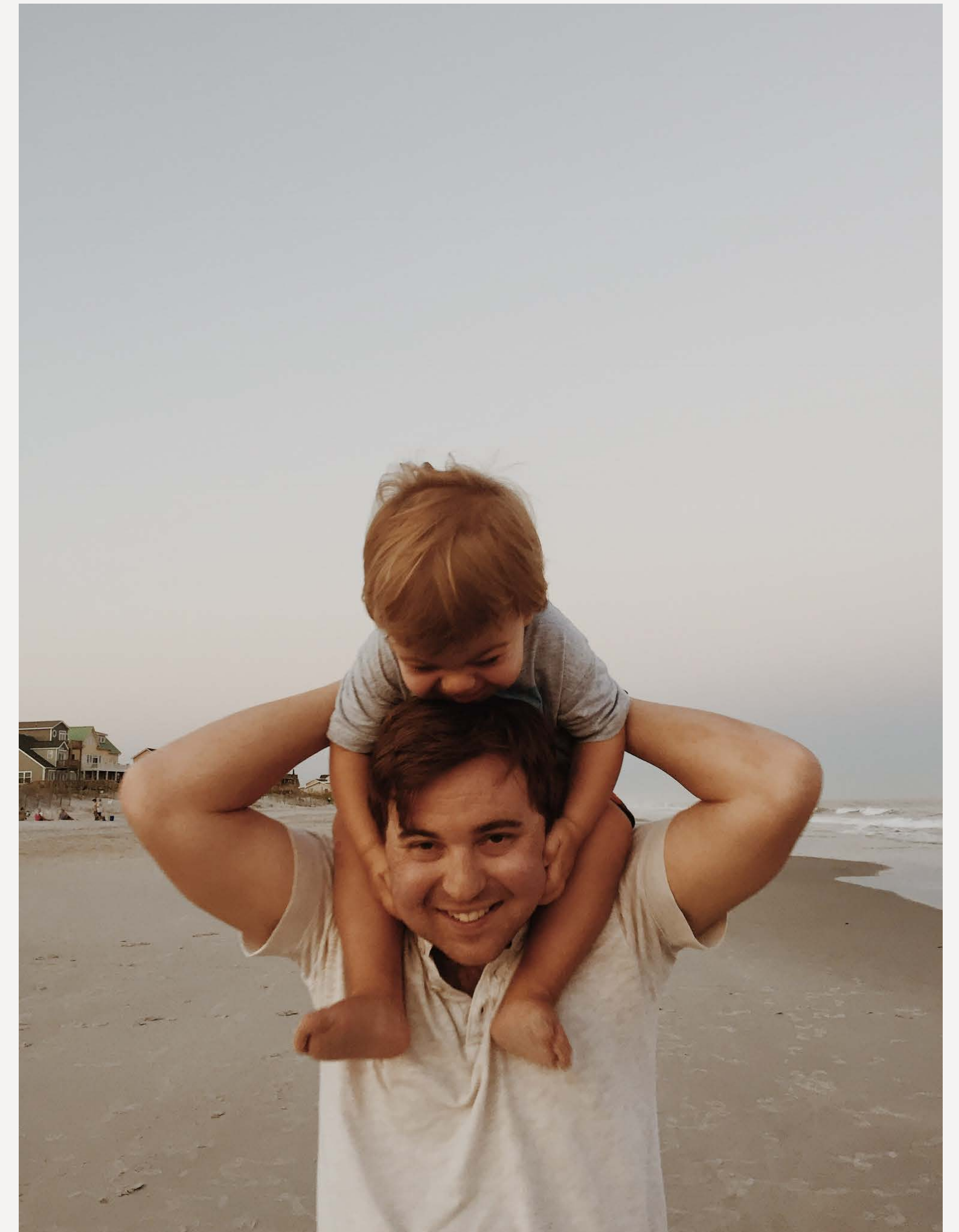
MARCH 2017

A NOTE FROM THE DIRECTOR

When I started Caravan in 2012, my goal was to tell beautiful and compelling stories. I never dreamed that one day, one of those stories would be my son's. In September 2016, my two-year-old son Finn was diagnosed with MPSII or Hunter Syndrome, a rare and terminal genetic condition with no cure. The only FDA-approved treatment available would keep Finn more "comfortable" while he slowly lost all of his physical and cognitive abilities. The thought of losing this precious child triggered a period of intense grief. I slowly came to a decision: I could let the darkness take over or choose to love and enjoy my sweet, fun-loving toddler that was standing right in front of me.

As I slowly started connecting with other parents of boys with Hunter Syndrome, I realized that although each of our stories was unique, we all were experiencing a common thread of grief and darkness born out of similar struggles. Our boys shared common treatment plans, therapies and challenges. Hunter Syndrome even causes them to develop similar facial features, resembling one another enough to be mistaken for brothers. The similarities in our children and our struggle created a deep sense in me that all these boys were my boys too. In the midst of my brokenness and shattered dreams for my own family, I somehow gained a new family: boys with joy and innocence and parents with boundless compassion only matched by their passion to save these children. This community with very little hope and too few numbers to attract much attention for research and funding has become my family. The desire to fight for them is how this project began. The ultimate goal is to raise 2.5 million dollars for a promising cure that could change the lives and family trees of thousands of families, now and for many years to come. Thank you for your time and consideration.

Jon Muedder
Founder & Director at Caravan



HUNTER SYNDROME



Mucopolysaccharidosis Type II (MPSII), also known as Hunter Syndrome, is a rare genetic disease that is progressively debilitating, life-limiting and without a cure. It occurs almost exclusively in males and currently affects approximately 500 boys in the U.S. and less than 2,000 worldwide. Individuals with Hunter Syndrome have a defect in the gene that cues the body to produce the enzyme iduronate-2-sulfatase (I2S), which is responsible for the breakdown of cellular waste called glycosaminoglycans or GAGs. Without that necessary enzyme, the accumulation of these GAGs leads to progressive damage throughout the entire body.

Though the disease is present at birth, symptoms become more apparent as the accumulation of GAGs builds within the body, triggering a diagnosis usually between 2 to 4 years old. Most boys with Hunter Syndrome continue to develop physically and cognitively

until between the ages 2 and 5 and then begin regressing. These boys gradually lose the ability to talk, walk and eat. Most do not live to see their teen years.

No cure exists for Hunter Syndrome. Currently, the only option for families after diagnosis is the one FDA-approved treatment on the market. Enzyme replacement therapy (ERT) consists of a weekly infusion of idursulfase (commercially known as Elaprase) to artificially inject the missing enzyme into the body. In most cases, it stabilizes many of the physical symptoms of Hunter Syndrome.

However, this treatment does not cross the blood-brain barrier, and thus, the cognitive regression continues. Though a patient may remain mobile longer, their cognitive abilities continue to decline to an infantile state.



A young child with dark hair, wearing a red long-sleeved shirt and blue jeans, is sitting on a red playground structure. The child is looking towards the camera with a slight smile. In the background, another child is visible, slightly out of focus, standing near some trees. The scene is outdoors with green foliage and tree trunks in the background.

GENE THERAPY



Gene therapy is a revolutionary approach to treating genetic diseases. It involves a one-time delivery of a normal copy of the defective gene with the aim of the body naturally producing the missing enzyme. It has been performed in other forms of MPS with positive results, and has been likened to “the cure” that these boys desperately need.

In 2013, a group of Hunter Syndrome families initiated a partnership with researchers at Nationwide Children’s Hospital in Columbus, Ohio to begin gene therapy research in Hunter Syndrome / MPSII. Now, the researchers are in the final stages of developing the first gene therapy clinical trial for boys with Hunter Syndrome. The only obstacle is the substantial funding required for such a trial. If the necessary funds are raised, the trial could begin as early as late 2017 or early 2018.

In the world of medicine, this treatment is considered an “orphan drug” because of the small patient population it seeks to treat. Few companies are willing to invest in research for such a population. In the US, an orphan drug is a treatment for a disease that affects less than 200,000 people. Drug companies fund much of the research for more common diseases because in developing a potential blockbuster drug for a large patient population, they also are more likely to make a profit.

In contrast, only an estimated 500 boys with Hunter Syndrome live in the United States. Without drug companies pursuing a cure for Hunter Syndrome, families tackled that lofty goal and have finally reached the point where a potential cure is ready and waiting with one obstacle: funding it.



*"We aren't supposed to lose our children.
But in the daily and painful act of losing, we gain a love that will never slip away."*

- Melissa Hogan





CONCEPT

Life is a cycle. The building blocks of this cycle are familiar to most of us. We are born, we grow physically, emotionally and intellectually, we find a partner, we bring forth new life, we watch our children grow and ultimately, we pass away after witnessing them create their own families. There are variants to this cycle, but ultimately, it's what we consider natural.



A man leans over the side of a bed. In the bed lays a woman. They are surrounded by commotion, by beeps and clicks, by doctors and nurses. The woman holds a newborn close to her chest as the man gently takes the baby's hand in his own and wonders at it's size and beauty. At this moment the noise fades, the man becomes a father, the woman becomes a mother. At this moment, the question "Will I outlive my son?" does not cross their minds.

This is a question that is so far removed from the cycle we are used to that it's almost impossible to grasp at. It is a complete re-arrangement of the order of things, the way things should be, the way they are for everyone else. This is the question that parents of children diagnosed with MPSII are having to ask themselves.

We intend to explore how families, whose reality has been irrevocably altered by MPSII, are able to rearrange the pieces and adjust for their disjointed, interrupted cycle. We want to see how they live and fight every day for their child.

These families have been dealt sadness, pain, and darkness; but the love for their children is as real as the pain, much stronger than the sadness, and a light in the darkness. We want to show others the reality that these families are facing, both the dark and the light. Life does not lose it's beauty. Laughter is still laughter and a family is still a family.



"Stories make us more alive, more human, more courageous, more loving."

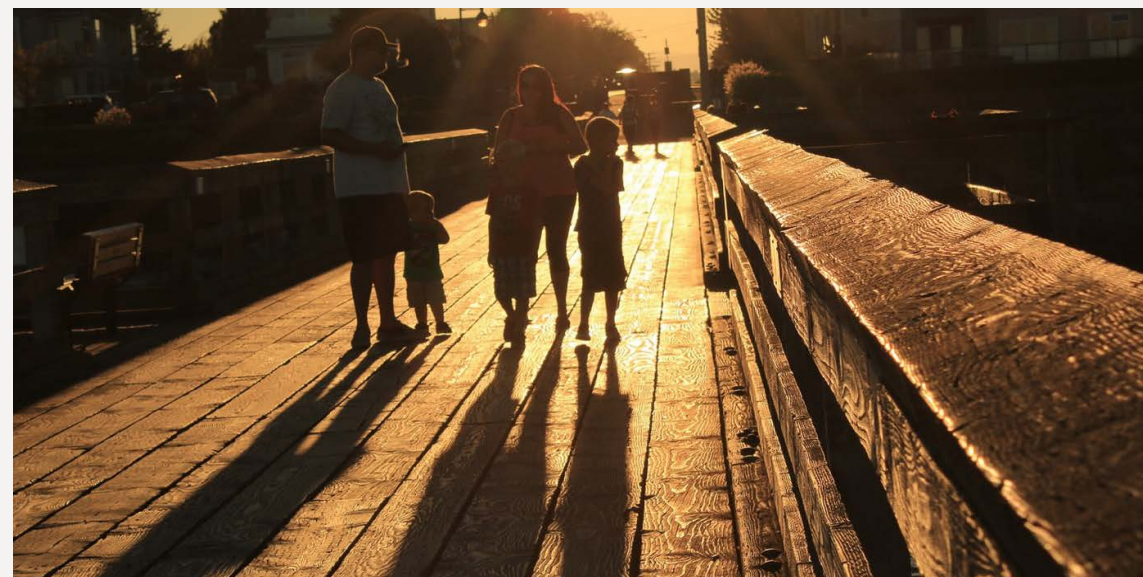
-Madeleine L'Engle





CREATIVE APPROACH

Stories have the power to inspire, inform and change people in a way that nothing else is able to. Stories transform complicated, abstract ideas or realities into emotional reactions and tangible connections. Only through stories can we get a glimpse into the fractured and delicate reality of a family whose son is dying slowly. Only through stories can we begin to understand their suffering, their love and their hope.



We will capture the stories of boys with MPSII and their families through a documentary lens. We'll show the devastating effects this disease has on the children, and the family as a whole, while also showing how they are able to find beauty in the darkest grief imaginable.

We will showcase stories from across the country. Boys with MPSII often develop very similar physical characteristics, coarse facial features, a large head, broad chest, thick hands and an enlarged abdomen. Our stories will explore the uniqueness of the boys and their families geographically, racially and culturally, as well as the bond that ties these stories and families together. Collectively these boys are fighting for the same thing, a chance at life.

Small crews will travel to different parts of the country to capture these stories in a cinematic, polished yet kinetic fashion. They will be crafted in the post production process to enable us to deliver a clear, concise and honest representation of their story, at once connecting with a wide audience visually and moving the individual viewer on a deeper emotional level to encourage them to share and support our cause.

Our goal is to create a series of short documentary films that capture the stories in an honest and tangible way in order to raise awareness of this disease and raise funds to move the gene therapy forward as a potential cure.





DELIVERABLES

- Project Alive Brand Identity
- Project Alive Website Re-Desifgn
- :90 Second Trailer/Concept Piece
- 3-5 Five minute Short Documentaries



MEET PROJECT ALIVE

Project Alive is an awareness and fundraising campaign of Saving Case & Friends, a 501(c)(3) non-profit dedicated to finding a cure for Hunter Syndrome. Over \$200,000 has been raised and contributed to gene therapy research.

MEET CARAVAN

Caravan is a full-service production agency based out of Charlotte, NC focused on commercial and documentary work. The company exists to tell stories that move people and bring those stories to life in a beautiful way. Each project is approached with passion and collaboration as the team continues to refine their techniques in animation, production and post-production. Clients of recent campaigns include: BMW, HBO, Pixar, Coca-Cola, and AirBNB.



GET INVOLVED



DONATE

Our goal is to raise \$2.5 million dollars needed to fund a clinical trial by the early fall of 2017. We are looking for early donors to help launch this campaign with noteworthy donations and matching challenges. If you are interested in either of these, please contact Jon Muedder (jon@wearecaravan.tv).

SHARE

Please share these films and project with friends, family, and media outlets. We believe that a groundswell of social media sharing, leading to national media, will capture the hearts and donations of many who have never heard of Hunter Syndrome.

COLLABORATE

Do you have a skill or platform that could contribute to the overall vision of this project? If so, we'd love to hear from you! We are looking for everything from administrative volunteers to producers who can connect us with influencers.

GET INVOLVED





CLOSING THOUGHTS

Families facing a Hunter Syndrome diagnosis start out just like a typical family. One day, it all changes. And while they struggle but are often successful in maintaining hope and joy into this new life, most of those changes are difficult and heartbreaking. But a gene therapy clinical trial offers hope of another day where it all changes. This time, that change could restore their family to a fuller and richer life where they get to watch their son grow up.

