

# PROJECT ALIVE NEWSLETTER



## FAMILY SPOTLIGHT

Meet the Blain Family. Cory and Jason Blain are the parents of Sawyer and Daxton, five and three years old respectively. They live in Michigan along with their dog, cat, and a dozen chickens. Their home is nestled on many acres of land, perfect for two young boys to adventure throughout.

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## Meet our New Executive Director

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# Meet our New Executive Director

The Project Alive Board is pleased to announce that Kristin Stockin has been hired as Executive Director of Project Alive. Kristin has served on the Board of Project Alive since January 2020. She has worked on several committees including Marketing, the Hunter Syndrome Community Conference Planning, and Fundraising. Kristin has served as Project Alive's Secretary this past year and has jumped headfirst into every challenge presented to her.

Kristin is a well-known and lifelong member of the Hunter syndrome community. Her late brother, Zachary, gave her the drive to spread awareness about MPS II from an early age. The diagnosis of her son just three years after the passing of her brother kickstarted her passion for fighting for a cure.

"We could not be more excited to have Kristin join our leadership and continue the great work of the Hunter syndrome community. Her unique experience as both a sibling of a boy with Hunter syndrome and the mother of a child with Hunter syndrome will bring tremendous depth to the role of Executive Director. In addition, her deep knowledge of project management and fundraising expertise align perfectly with Project Alive's mission to find better treatments and a cure for Hunter syndrome," said Dr. Kim Stephens, President of Project Alive.

Kristin has seen Hunter Syndrome through much of its medical development with her brother receiving ERT after 10 long years of a lack of available treatment, to her son receiving a stem cell transplant at four months old. "I am thrilled to join Project Alive's staff as the Executive Director and to be part of this groundbreaking time of clinical trials and exciting new developments in treatment. I plan to dedicate my time to finding more ways to serve our Hunter syndrome families while keeping our goal of finding a cure for Hunter Syndrome close to my heart," says Kristin. Kristin will have the full support of the Project Alive Board and will work closely with Kim Stephens, who will continue as Board President.

"I plan to dedicate my time to finding more ways to serve our Hunter syndrome families while keeping our goal of finding a cure for Hunter Syndrome close to my heart," says Kristin.



# PROJECT ALIVE SURVEY

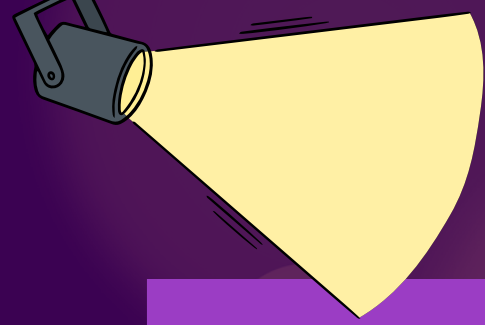
As we begin to plan for 2023, Project Alive is asking you to participate in our Community Survey to gather information needed to better serve our community.

The information you provide will better help us continue our fundraising efforts, plan events, and provide meaningful programs that you are looking for. We appreciate you taking a few moments to complete the survey. Please also note, all information collected will be used solely by Project Alive, nothing will be shared outside of the organization.

<https://tinyurl.com/pafamilysurvey>

Regenxbio is conducting a study of caregivers of those affected by MPS II and is currently holding interviews. The goal of the interview is to better understand, from the caregiver perspective, what might be a meaningful change in response to a treatment. The interviews will take approximately one hour, and caregivers will be given a visa gift card for their participation. Caregivers will be required to sign a confidentiality disclosure agreement and agree to be audio recorded to participate. The content generated from the interviews will be used to help us to interpret meaningful change in our current MPS II clinical trials.

If you would like to participate or know another family, please reach out to [patientadvocacy@regenxbio.com](mailto:patientadvocacy@regenxbio.com) for further details.



# FAMILY SPOTLIGHT

Meet the Blain Family. Cory and Jason Blain are the parents of Sawyer and Daxton, five and three years old respectively. They live in Michigan along with their dog, cat, and a dozen chickens. Their home is nestled on many acres of land, perfect for two young boys to adventure throughout.

Sawyer and Daxton were diagnosed with MPS II in early 2020, both have the neuronopathic form of the disease. Roughly two months post diagnosis, they began treatment and a year later, they were accepted into a clinical trial to begin a new treatment odyssey.

“Sawyer is my wanderlust boy. He is in his glory if he can just be free,” his mother describes. He loves music, a trait he shares with his mom, and getting as many snuggles as he can get from his family. Dax is the youngest of the family and has happily accepted his role as the “wild child” according to Cory. He likes to climb on anything and everything. When he’s not conquering a new height, he likes to watch Cocomelon and learn about farm animals. He gives the best hugs and has a contagious smile.

As a family, the Blains love to get outdoors. They have begun camping regularly as it has become a solace for them, away from the day-to-day of life and especially hospitals.

Since diagnosis, the family’s life has changed dramatically. Due to the frequent hospital and therapy visits required for each boy, Cory left her job to be a full-time caregiver for her kids. Jason, now being the sole financial provider, works long hours and often feels like he is missing out on quality time with his family. It hasn’t been easy for Cory and Jason, but they have found a way to make it work and provide all that they can for Sawyer and Dax. This is a struggle all too well understood by the MPS II community.

## THE BLAIN FAMILY



# THE BLAIN FAMILY

Both Sawyer and Dax are now in school where they receive occupational, physical, and speech therapy. They also receive services outside of the school system. Sawyer continues speech, OT, and PT privately, while Dax is currently receiving speech therapy privately. Dax may begin receiving ABA therapy soon as well. Cory is thrilled to see Dax making word approximations. She cherishes his sweet voice.

Cory and Jason have enjoyed getting involved in the MPS community. Cory has been excited about joining in advocacy efforts and recently began volunteering with Project Alive. Her passion currently lies with Newborn Screening.

The Blain Family, while often focused on clinical trial life, are dedicated to living in every moment. After receiving a terminal diagnosis for both of their children, time has become more valuable. They want to provide many happy moments for their family, while finding ways to make an impact in their community. Cory left us with her favorite quote, one she lives by, made by her own husband, Jason Blain, “you don’t have to live to old age to have a fulfilling life.”

Thank you to Jason, Cory, Sawyer, and Dax for sharing your story. Project Alive and the MPS II community are cheering you on!



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# UPCOMING



PLANNING HAS BEGUN AT PROJECT ALIVE FOR THE 2023 HUNTER SYNDROME COMMUNITY CONFERENCE! PLEASE MARK YOUR CALENDARS FOR MARCH 11-12, 2023, AND PLAN TO JOIN THE COMMUNITY FOR TWO DAYS OF INFORMATIVE CONTENT, AMAZING SPEAKERS AND FUN GAMES AND PRIZES. WE LOOK FORWARD TO SEEING YOU THERE!

MARCH 11-12, 2023

**HUNTER 100**

The National MPS Society and Project Alive have partnered with a research organization to conduct a study to explore the full spectrum of genetic changes in Hunter syndrome. Eligible participants will receive whole genome sequencing and a genetic counseling session at no cost, and a \$50 Amazon gift card. If you are a member of any support groups for Hunter Syndrome on Facebook or other platforms, you may have seen this study referred to as the "100 Patient Project." In this short video, Dr. Burton describes the impact and benefits of the study: [https://youtu.be/d\\_HH5MdymOk](https://youtu.be/d_HH5MdymOk)

We would love to have you be a part of the study. To enroll, please visit this website: <https://www.lunadna.com/hunter-syndrome-study/>

If you are having trouble signing up or linking your records, follow the link below to set a time to get assistance:

<https://calendly.com/huntersyndromestudy/30min?month=2022-09>