

# PROJECT ALIVE NEWSLETTER

Happy  
New  
Year

SEASONS GREETINGS FROM ALL OF US  
HERE AT PROJECT ALIVE! WE HOPE YOU  
ENJOY TIME WITH FAMILY AND FRIENDS  
THIS HOLIDAY SEASON. MAY THE NEW YEAR  
BRING YOU JOY AND PRECIOUS MEMORIES.

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## Meet our New Vice President

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# End of Year Report

## Project Alive Through The Year

Thank you for all you have done to help our Hunter syndrome community this year. 2022 has been a year of excitement and success for Project Alive and our community. As we look into the new year, let's reflect back at the changes brought about in 2022.

Our community saw MPS II added to the federal newborn screening panel. We owe a special thank you to the MPS Society for leading this effort. We are working hard to bring testing to the state level, and we are going to be asking for everyone's help in making this a priority with our legislators.

The Hunter syndrome community now has four clinical trials actively recruiting. Through many years of efforts to encourage research in MPS II, we are astonished at the number of trials in our space. Our fight is not over until all MPS II patients have access to a lifesaving treatment.

Project Alive successfully negotiated the move of the gene therapy vector trial originally located at Nationwide Children's Hospital to UNC Chapel Hill this year. We hope to be able to share more details very soon. Along with that, our President, Dr. Kim Stephens, accepted a new role as Executive Director of the Dr. Joseph Muenzer MPS Research and Treatment Center at UNC. While Kim has remained on as Board President, Project Alive hired Kristin Stockin as staff Executive Director. Kristin works closely with Operations Manager, Karen Beatty to keep everything working well in the day-to-day activities of the organization.

Project Alive received generous donations this year from foundations to continue MPS II research. Notably, Action for Aidan donated \$200,000 earmarked for use at UNC.

Along with other contributions throughout the year, Project Alive looks forward to announcing new programs and research in the new year.

Looking into 2023, we have exciting announcements. Project Alive will begin offering research grants for research done involving MPS II. With that, a medical and scientific advisory board will be initiated to assist in grant proposal review. With the help of new Vice President, Kyle Underwood, Project Alive will launch an adult resources program. Specifics will be outlined in 2023. We will also plan to do more towards community outreach, including newly diagnosed families as newborn screening begins hitting the state level. All of these new programs will be featured on Project Alive's new website set to launch in late March or early April of 2023. Stay tuned for an exciting virtual open house event to introduce you to the new website. In the meantime, be sure to sign up for our community survey to receive the newsletter and additional outreach.

We are pleased to welcome new board members, Jeanette Henriquez, Cory Blain, and Jenn Estevez for 2023. We cannot thank enough the long-time board members who are rolling off the board this year – Jamie Brooks, Jen Carter, and Katey Hoffman. These leaders have given so much to our community, and we know they will continue to make a tremendous difference in the Hunter syndrome community.

We wish you well into 2023 and look forward to seeing you all at our third annual Hunter Syndrome Community Conference on March 11-12, 2023.



# Meet Our New Vice President

Project Alive is pleased to announce that Kyle Underwood has accepted the role of Vice President starting in the new year. Kyle has served as a tremendous addition to the Board of Directors and will continue that work in his new officer position. His dedication and patient perspective will bring a new light to Project Alive. Kyle will join the executive committee alongside Board President, Dr. Kim Stephens, Secretary, Julie Ferrullo, and Treasurer, Jon Muedder.

This past August, Julie Ferrullo was voted in as Secretary. She has joined several committees, particularly within HSCC planning. She is the chair of the merchandise and entertainment committee for HSCC. Project Alive is thrilled to have both Kyle and Julie jump into executive roles as newer additions to the board. They have both brought new perspectives and passion to our organization.

Kyle was diagnosed with Hunter syndrome when he was four years old. Throughout his childhood, he encountered multiple doctor appointments, surgeries, and weekly infusions that allowed him to see the healthcare system from the patient perspective. Taking his experience and desire to make a difference in the rare disease community, he decided to pursue educational and professional opportunities where he could be a voice for change.

He earned his Bachelor of Science in Public Health and minor in Business from the University of California, San Diego. Kyle went on to receive his Master of Health Administration from the University of Southern California. Kyle's previous experiences include working in operations, strategy, and business development for both large health systems and emerging telehealth companies.

# New Vice President Continued

Kyle frequently participates in patient advocacy opportunities, most recently speaking at the Living Rare Living Stronger NORD Patient and Family Forum. Kyle currently lives in Cleveland, Ohio, and works at the Cleveland Clinic as a Program Manager.

Kyle has served on the Project Alive board since 2021, and has worked on several committees including marketing and Hunter Syndrome Community Conference Planning. He also serves on the Rare Disease Legislative Advocates Committee and Young Adult Rare Representatives for the EveryLife Foundation and the Adult Resource Committee for the National MPS Society. Kyle is recognized as a prolific speaker in the rare disease and healthcare leadership community and can often be found sharing his story and raising awareness on stages across the country.

“I’m thankful and honored to be able to serve our Hunter Syndrome community as Vice President for Project Alive. Being a patient myself who lives with Hunter syndrome, I’m eager to build upon the great work already done and bring a new perspective to the table that fosters a spirit of awareness, engagement and discovery that touches all members of our community. I look forward to continuing to advocate for the importance of lifesaving treatment and groundbreaking research to find a cure for Hunter syndrome.”

With Kyle’s entrance, we would also like to thank outgoing Vice President, Andrew Hoffman, for the outstanding work he has done throughout his term. With Andrew’s help, Project Alive has seen many accomplishments and organizational growth. We are pleased that Andrew will remain on the board in 2023.

**"BEING A PATIENT MYSELF WHO LIVES WITH HUNTER SYNDROME. I LOOK FORWARD TO CONTINUING TO ADVOCATE FOR THE IMPORTANCE OF LIFESAVING TREATMENT AND GROUNDBREAKING RESEARCH TO FIND A CURE FOR HUNTER SYNDROME."**

# 2023 Board and Staff

## Officers



Dr. Kim Stephens  
Board President



Kyle Underwood  
Vice President



Julie Ferrullo  
Secretary



Jon Muedder  
Treasurer



Andrew Hoffman



Mario Estevez



Sarah Mitchell



Aywon Nguyen



Nathan Grant



Elizabeth Gosa



Dave Ferrullo



Jenn Estevez



Jeanette Henriquez



Cory Blain



Kristin Stockin  
Executive Director  
Staff



Karen Beatty  
Operations Manager  
Staff

# UPCOMING

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2  
3

## Hunter Syndrome Community Conference

MARCH 11-12, 2023



### SNEAK PEAK

- MPS II Parent Panel
- Living with MPS - Adult Journey
- Saving Ryan/Parents as Advocates
- Transplant in MPS II

## HUNTER 100

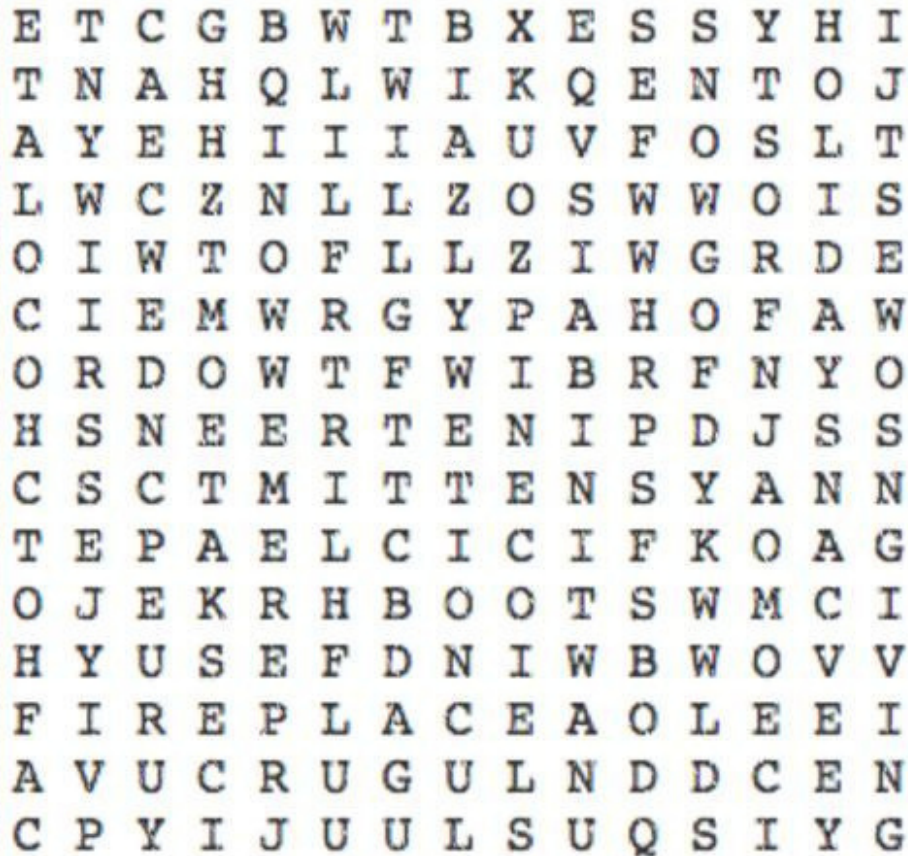
The National MPS Society and Project Alive have partnered with a research organization to conduct a study to explore the full spectrum of genetic changes in Hunter syndrome. Eligible participants will receive whole genome sequencing and a genetic counseling session at no cost, and a \$50 Amazon gift 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>

# WINTER WORD SEARCH



E T C G B W T B X E S S Y H I  
T N A H Q L W I K Q E N T O J  
A Y E H I I I A U V F O S L T  
L W C Z N L L Z O S W W O I S  
O I W T O F L L Z I W G R D E  
C I E M W R G Y P A H O F A W  
O R D O W T F W I B R F N Y O  
H S N E E R T E N I P D J S S  
C S C T M I T T E N S Y A N N  
T E P A E L C I C I F K O A G  
O J E K R H B O O T S W M C I  
H Y U S E F D N I W B W O V V  
F I R E P L A C E A O L E E I  
A V U C R U G U L N D D C E N  
C P Y I J U U L S U Q S I Y G

## WORDS TO FIND:

BLIZZARD	BOOTS	CHILLY
COLD	FIREPLACE	FROSTY
FROZEN	GIVING	GLOVES
HAT	HOLIDAYS	HOTCHOCOLATE
ICE	ICESKATE	ICICLE
MITTENS	PINETREE	SCARF
SNOW	SNOWBALL	SNOWFLAKE
SNOWMAN	SNOWSUIT	WIND
WINTER		