Project Alive

2022 Annual Report

WWW.PROJECTALIVE.ORG

Table of Contents

Message from the Executive Director

2022 has been a year of excitement and success for Project Alive and our community. MPS II was added to the Federal newborn screening panel and we thank the National MPS Society for leading this effort. We are now working to bring testing to the state level and the community has stepped up to advocate in their states and make this a priority with legislators. There are now four clinical trials that are actively recruiting. Through many years of efforts to encourage research in MPS II, we are astonished at the number of trials in our space. Current President of Project Alive, Kim Stephens, has taken the role of Executive Director at the Muenzer MPS Center at UNC. This will be a space where new therapies, research, and therapeutic strategies will be offered for those affected by all forms of MPS. We also received a generous donation of $200,000 from fellow organization Action for Aidan. These funds will be used to help support programs at the newly established Muenzer MPS Center at UNC.

2023 will bring continued work on our work in advocacy and the search for a cure. We will also be bringing new programs and opportunities in research. And as always, we appreciate the support from our community and donors, without you, none of this could be possible.

Kristin McKay

Executive Director

Our Mission and Vision

Project Alive exists to find and fund a cure for Hunter Syndrome (also known as Mucopolysaccharidosis or MPS II) through research and advocacy.

Project Alive is a powerful voice for children and adults with Hunter Syndrome, bringing together families and advocates with researchers, industry, and regulators. The organization funds promising curative research, assists researchers and industry with designing research studies for our community, and advocates for the most effective and efficient system of clinical research, evaluation, and approval. Through its innovative campaigns and grassroots efforts, Project Alive has made significant advances in public awareness about Hunter Syndrome and its symptoms, the need for early diagnosis, and available treatments and clinical trials.

Key Achievements

Overview

Second Annual Hunter Syndrome Community Conference

2022 continued with the second annual virtual conference, held to allow families to connect and hear the latest updates from MPS II experts. Representatives from industry presented new and updated research and clinical trial updates. Drs. Burton, Muenzer, and Harmatz held a panel discussion as well as other sessions with medical professionals.This year's conference also gave attendees the opportunity to meet in breakout rooms, lots of fun games, entertainment and prizes.

MPS II Added to the RUSP

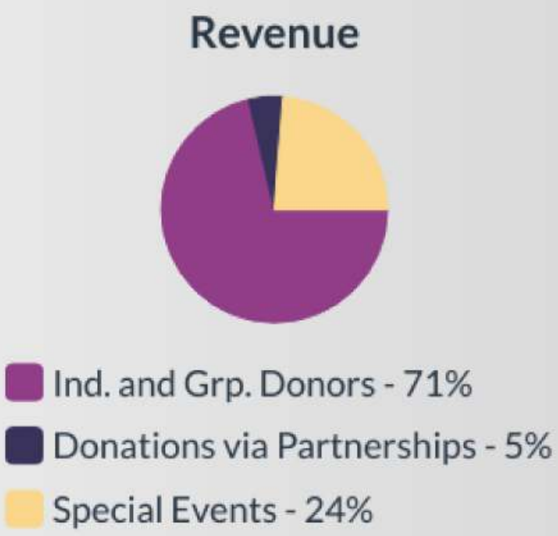
In August of 2022, MPS II was added to the Recommended Uniform Screening Panel (RUSP). This means that states can now add screening for MPS II to all newborn screenings, which means we now have a better chance at a faster diagnosis, allowing treatment to begin earlier. The work still needs to continue to ensure every state adopts this screening but the first major step has been accomplished. We thank the National MPS Society for leading this campaign and for all the hard work everyone involved contributed.

Action for Aidan

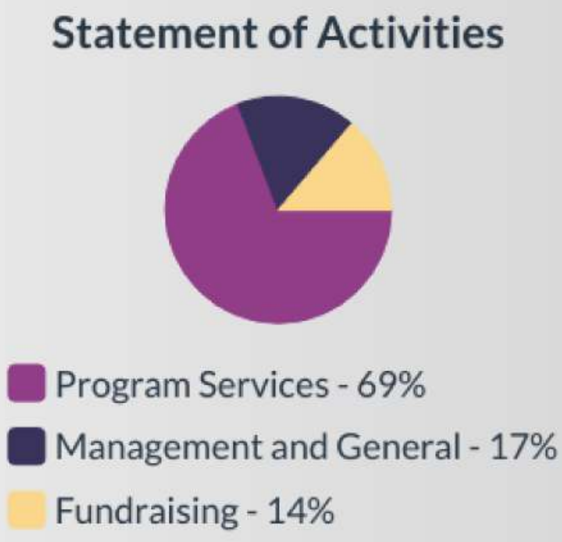
Aidan was diagnosed in 2009 with MPS II and like all parents, Jennifer and Tripp Brooks were not going to sit back and were not going to fight. They began Action for Aidan to raise funds to help find treatment and cure and over the last four years, their campaigns have proved successful. To help with Project Alive's mission, Action for Aidan donated $200,000 to enable us to get closer to the goal of funding more MPS II research. It is the work from these patient led organizations that help continue the research in MPS II.

Statement of Financial Position

For Year End December 31, 2021



Assets	
Cash and Cash Equivalents	$ 2,661,436
Accounts Receivable	17,620
Total Assets	$ 2,679,056
Liabilities and Net Assets	
Accounts Payable	6,194
Total Liabilities	6,194
Net Assets	
Without Donor Restriction	2,672.862
Total Net Assets	2,672,862
Total Liabilities and Net Assets	**$2,679,056**



Statement of Activities

Individual and Group Donors	$ 259,867
Donations via Partnerships	17,690
Special Event Revenue	86,622
Total Revenue	364,179
Program Services	170,932
Management and General	42,134
Fundraising	33,932
Total Expenses	246,998
Change in Net Assets	117,181
Net Assets, Beginning	2,555,681
Net Assets, Ending	**$ 2,672,862**

Thank You to our Donors

We would like to thank each donor who has contributed to the mission of Project Alive. Without your support, we would not be able to continue our work in the Hunter syndrome community.

$1000 - $4999

American Learning Systems, Inc.
Rod Miles
Bernard Brust
Anne Hoffman
Lake Arrowhead Rotary Foundation
Theresa Elgin
Leslie & Marilyn Kelman Charitable Gift Trust
Glenn Snyder
BriddleWood Facility Services
Jon & Allison Muedder
Alexa Hansen
Michael Elgin

$5000 - $9999

Amanda Hoffman
Luis & Courtney Coastales

Special Thanks

Action for Aidan

Recurring Donors

Tabbetha Langley
Anni McGee
James and Maryanne Lyons
Mindy Stout
Nicole Martinez
Jim and Myra Summers
Matthew Brown
Elizabeth Hawes