



Project Alive
2021 Annual
Report



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Message from the President

2021 has been an amazing and challenging year for so many of us. It makes me so happy to be able to say more boys than ever before are now participating in clinical trials. And we are pushing the boundaries with the inclusion criteria to make sure that those who for so long did not qualify for a trial – older boys, those with complicated diagnoses, those who are attenuated, and those that went through BMT – are now being considered for treatment. Advocating works. I believe we are getting close to a world where our boys will have options for treatment and will have a chance to grow up.

We owe so much to our large community of supporters, donors, friends, and families. It is because of you that we have been able to continue the great work of finding treatments, advocating for better trials and outcome measures, and pushing research.

Kim Stephens
President

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

First Annual Hunter Syndrome Community Conference

2021 was the inaugural year for HSCC. Project Alive was able to connect families from all over the country by hosting a virtual conference that highlighted updates from industry, informative sessions from the medical community, breakout sessions, and the opportunity to socialize with other families.

Clinical Trial Moves to UNC

As the gene therapy trial was moved from NCH to UNC successfully, Project Alive continued to work with UNC to finalize plans. As more information becomes available, the community will be updated on progress.



Community Outreach

Project Alive continued to support the community by providing gift cards for those who needed a little assistance while spending time in the hospital or dealing with an emergency. Project Alive also began a program that planted a tree for those who have passed as a symbol of remembrance.

MPS II Multi-Disciplinary Paper

The Medical Advisory Board of Project Alive began to work on a paper that will address the many symptoms, issues, and treatments that come with MPS II. This paper will be published so that it can educate physicians in multiple disciplines on how to better care for boys with MPS II.

Statement of Financial Position

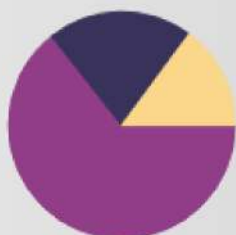
For Year End December 31, 2021

Revenue



- Ind. and Grp. Donors - 68%
- Donations via Partnerships - 19%
- Special Events - 13%

Title



- Program Services - 64%
- Management and General - 21%
- Fundraising - 15%

Assets

Cash and Cash Equivalents	\$ 2,574,930
Prepaid Expenses	4,896

Total Assets	<u>\$ 2,579,826</u>
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Liabilities and Net Assets

Accounts Payable	6,454
PPP Loan Payable	17,690

Total Liabilities	<u>24,144</u>
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Net Assets

Without Donor Restriction	<u>2,555,682</u>
Total Net Assets	<u>2,555,682</u>

Total Liabilities and Net Assets	<u>\$2,579,826</u>
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Statement of Activities

Individual and Group Donors	\$ 899,164
Donations via Partnerships	256,772
Special Event Revenue	<u>174,284</u>

Total Revenue	1,330,220
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Program Services	104,250
Management and General	33,664
Fundraising	<u>24,063</u>

Total Expenses	<u>161,977</u>
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Change in Net Assets	1,168,243
Net Assets, Beginning	<u>1,387,439</u>

Net Assets, Ending	<u>\$ 2,555,682</u>
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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

Jill Chaffee
Bernard Brust
Nicholas Baum
Sarah Mitchell
Carol Mitchell
Betsy Hemby
Chris Smith
Stephen Caserta
Alexa Hansen
Reina McRae
Sean Ascher
Vogel Family Foundation
Marie Edwards
Marc Kaplan
Angela Hoover
Josh Bickerstaff
Mike Hoover
The Don Allen Foundation
Olyvia Gegorek
Lindsay Austin
Heather Boening
Amanda Hoffman
Natalie Kanney

\$5000 - \$9999

The Carolyn Smith Foundation
Vanguard Charitable
Katey and Andrew Hoffman
Mr. and Mrs. Ralph Edwards

\$10,000 and Up

Windhover Foundation
National Christian Foundation
Orlando
Alexander Smith
Help Extinguish Hunter Syndrome
Charity Beats
A Cure For Adri

Recurring Donors

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

