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

Assets
- Cash and Cash Equivalents $2,574,930
- Prepaid Expenses
  - Total Assets $2,579,826

Liabilities and Net Assets
- Accounts Payable 6,454
- PPP Loan Payable 17,690
  - Total Liabilities 24,144

Net Assets
- Without Donor Restriction 2,555,682
  - Total Net Assets 2,555,682

Total Liabilities and Net Assets $2,579,826

Statement of Activities
- Individual and Group Donors $ 899,164
- Donations via Partnerships 256,772
- Special Event Revenue 174,284
  - Total Revenue 1,330,220

- Program Services 104,250
- Management and General 33,664
- Fundraising 24,063
  - Total Expenses 161,977

- Change in Net Assets 1,168,243
- Net Assets, Beginning 1,387,439
  - Net Assets, Ending $2,555,682
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
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Marc Kaplan
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Josh Bickerstaff
Mike Hoover
The Don Allen Foundation
Olyvia Gogorek
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

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National Christian Foundation
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Alexander Smith
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Charity Beats
A Cure For Adri

Recurring Donors
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