



**Project Alive**  
**2023 Annual**  
**Report**

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# Message from the President/ Executive Director

Dear Project Alive community,

We had an exciting year in 2023 that has sparked growth for 2024. We announced an update to our mission statement which has allowed us to expand our community support services. After receiving so many helpful responses through our community survey, we were able to get a few new programs up and running based on community need. We provided a free IEP advocate to families, introduced our caregiver support group virtual chats, and hosted two workshops. These programs will continue on in 2024 with new additions to look forward to.

Our annual Hunter Syndrome Community Conference had a growth in attendance as we have adjusted the event to fit the ever changing needs of our community. Most excitingly, we added our first annual in-person event: The Hunter Syndrome Family Fair. It was amazing to see so many families and children with Hunter syndrome all in the same room. We may have set a record! Eleven families received travel scholarships to attend, with over half receiving the opportunity to attend their first conference or the first one in over five years. Our planning committee is looking forward to announcing the plans for our 2024 Family Fair.

We recharged our mission towards research, expanding that to encompass all Hunter syndrome research. We developed a Scientific Advisory Board and launched our research grants program. We have included an annual budget of \$250,000 for research and awarded our first grant. We are working to market our grants to garner more interest in performing MPS II research.

Project Alive also saw new corporate interest in our mission along with the continued support of many dedicated donors. Our families enjoyed creating their own story pages on our website as a fundraising and awareness tool that we launched around Giving Tuesday. It is inspiring to see so many people rally around our mission and our amazing Hunter syndrome community.

In the fourth quarter of 2023, we released our Strategic Plan for 2024. Our staff and board are all eager to share our progress throughout the year. We hope you will join us in making a bigger impact on the Hunter syndrome community!

Thank you,

*Kristin McKay*

## Our Mission and Vision

Project Alive exists to find a cure for Hunter syndrome through research and advocacy, and provide education and resources to the Hunter syndrome community.

# Key Achievements

## Overview

### **Project Alive Updates the Mission**

Since Project Alive began as Saving Case and Friends, the mission was to fund a cure that would save those affected by Hunter syndrome. The parents who started on this journey spent numerous hours and hard work to raise funds to make this happen. As we learned at the end of 2023 that this would now be more challenging than anticipated and losing financial backing, we made the difficult decision to focus our fight in other ways. As heartbreaking as this news was, we look forward to supporting existing clinical trials as they strive for FDA approval, offering our community support by providing more resources, education, and research opportunities that will benefit the families and those affected.

### **Research Grant Funding**

The need for continued research is integral to one day finding a cure for Hunter syndrome. The goal is to support research that fills critical gaps in the current knowledge of Hunter syndrome across basic science, critical care, and translational therapeutics that could lead to improved lives for the affected and their families.

### **First Annual Family Fair and Casino Night**

In 2023, we held our first in-person event! The Hunter Syndrome Family Fair brought together a strong community of support for families impacted by Hunter syndrome. The Family Fair offered educational booths, table games for the kids, speakers, and the chance to meet other families from across the country. Casino Night offered charity casino games, bingo, and the chance to make meaningful connections. At Project Alive we understand the need for families to connect and will continue these events. Please join us in 2024 in Texas for another day of community building.

### **New Website Launched**

After months of hard work, we launched our new website that provides more information, education, and resources. The new site gives those who visit the chance to understand Hunter syndrome better, meet a few of the families from the community, and various ways to contact us for new programs and apply for grant funding. As Project Alive continues to grow, our website will continue to be an important resource for caregivers, affected, and those who want to know more and get involved.

# Key Achievements

## Data

### Research

Project Alive funded a \$50,000 research grant for the study titled: Transitioning from Pediatric to Adult Health Care in Lysosomal Diseases: The MPS Experience

### IEP Support

Project Alive introduced a free IEP support program. In 2023, we assisted 10 families by providing a free IEP advocate.

### Conference Scholarships

Project Alive provided travel scholarships to 11 families to attend the Hunter Syndrome Family Fair. 7 families had never attended a conference.

### Education & Support

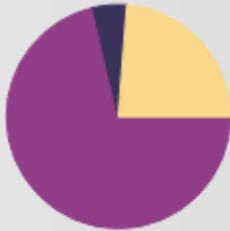
- Hosted an IEP workshop
- Developed and hosted a How to Tell Your Story Workshop
- Hosted 3 Caregiver Chat support groups



# Statement of Financial Position

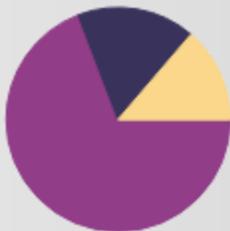
For Year End December 31, 2022

## Revenue



- Ind. and Grp. Donors - 71%
- Donations via Partnerships - 5%
- Special Events - 24%

## Statement of Activities



- Program Services - 69%
- Management and General - 17%
- Fundraising - 14%

### Assets

Cash and Cash Equivalents	\$ 2,661,436
Accounts Receivable	17,620

Total Assets	<u>\$ 2,679,056</u>
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### Liabilities and Net Assets

Accounts Payable	6,194
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Total Liabilities	<u>6,194</u>
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### Net Assets

Without Donor Restriction	2,672,862
Total Net Assets	<u>2,672,862</u>

Total Liabilities and Net Assets	<u>\$2,679,056</u>
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### Statement of Activities

Individual and Group Donors	\$ 259,867
Donations via Partnerships	17,690
Special Event Revenue	<u>86,622</u>

Total Revenue	364,179
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Program Services	170,932
Management and General	42,134
Fundraising	<u>33,932</u>

Total Expenses	<u>246,998</u>
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Change in Net Assets	117,181
Net Assets, Beginning	<u>2,555,681</u>

Net Assets, Ending	<u>\$ 2,672,862</u>
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# Thank You to our Donors

Donor support is key to the success of Project Alive. Each donation received allows us to provide continued support for the Hunter syndrome community. As we have broadened our mission, contributions will help us create new programs, add resources, fund needed research, and continue to advocate and ensure all boys with Hunter syndrome will one day be treated. We have such gratitude for each person who has made a donation to Project Alive, we could not do the work we do without you!

