

# PROJECT / ALIVE

A Hunter Syndrome Research  
& Advocacy Foundation

## 2024 Strategic Plan

[www.projectalive.org](http://www.projectalive.org)

2024



2024



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# Vision and Mission

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## Mission

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

## Vision

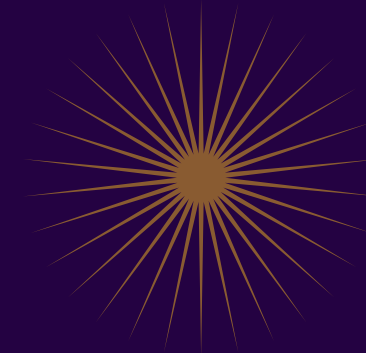
Project Alive is a powerful voice for children and adults with Hunter Syndrome, bringing together families and advocates with researchers, industry, and regulators. The organization funds promising curative research, assists researchers and industry with designing research studies for our community, 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.

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# Our Promise

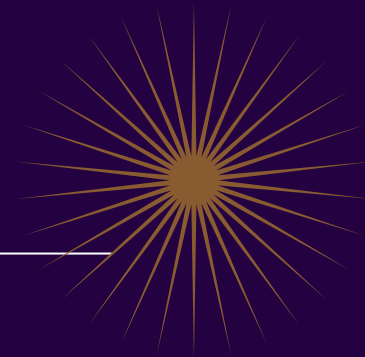
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- Funding MPS II research
- Supporting families and people with MPS II
- MPS II studies & literature
- Advocacy



# Objective 1



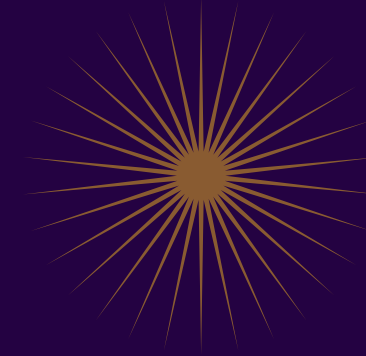
## Objective:

Support, empower, and educate those directly affected by MPS II through programs and community resources.



- Webinars and workshops
  - Host 3 webinars or workshops by the end of 2024.
- Toolkits and resources
  - Develop a comprehensive list of nationwide nonprofit organizations offering useful resources for the Hunter syndrome community outside of Project Alive's purview.
  - Develop state specific social services, medicaid information, and other resources for 5 states (CA, OH, IL, NC, PA) by the end of 2024.
  - Develop a list of state specific nonprofit organizations offering useful resources for the Hunter syndrome community outside of Project Alive's purview for at least 5 states (CA, OH, IL, NC, PA) by the end of 2024.
  - Create 1 toolkit for providers (i.e. OT, PT, SLP) to provide MPS II specific education by the end of 2024.
- Support groups
  - Host 4 virtual support group sessions by the end of 2024.
- Mentor/buddy program
  - Develop a community mentor/buddy program and register 10 community members by the end of 2024.
- Hunter Syndrome Community Conference and Family Fair
  - Increase 2024 Hunter Syndrome Community Conference and Hunter Syndrome Family Fair attendance by 5%.
- Translations
  - Obtain Spanish translations of the MPS II Active Clinical Trials resource page from 4 pharmaceutical companies by end of 2024.
  - Provide Spanish translations for 3 pages of Project Alive's website by the end of 2024.
- IEP Advocate
  - Provide individual IEP advocate services to 3 families by the end of 2024.
- Spending
  - Spend \$200,000 on community programs and associated program director by the end of 2024.

# Objective 2



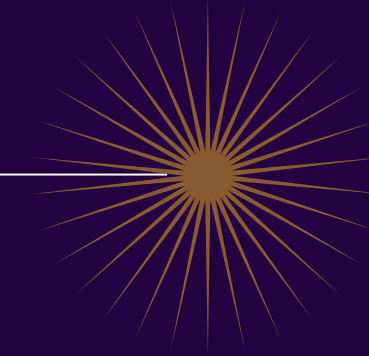
## Objective:

Develop new streams of revenue through fundraising campaigns, donor initiatives, grants, and events and conferences.

- MPS Awareness Day
  - Raise \$25,000 for MPS Awareness Day in 2024.
- Giving Tuesday
  - Raise \$50,000 for Giving Tuesday in 2024 and enlist 3 donors to provide matching funds.
- HSCC
  - Bring in revenue of \$80,000 for 2024 Hunter Syndrome Community Conference.
- Family Fair
  - Bring in revenue of \$100,000 for 2024 Hunter Syndrome Family Fair.
- Additional Fundraising
  - Raise \$20,000 with additional fundraising campaigns and events by the end of 2024.
- Donor Initiatives, other foundations
  - Bring in \$275,000 of revenue through general donations and partnerships with foundations and other organizations by the end of 2024.
- Provide 4 donor specific newsletters by the end of 2024 to promote donor retention.
- Applying for grants: programs, events, general funds
  - Apply for 10 grants to fund programs, events, or general funds by the end of 2024.



# Objective 3



## Objective:

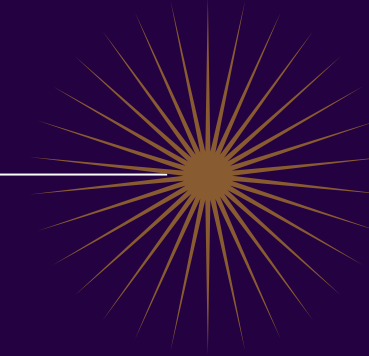
Support MPS II research by offering research grants, participating in research and scientific publications, and publishing the MPS II standard of care paper.



- Promote research grants program
  - Enlist PR firm to publish a notice of Project Alive's research grant program in 2 scientific or medical journals by the end of 2024.
  - Publish Project Alive's research grants program on 2 grant search engines.
- Fund research grants, present to community
  - Fund \$100,000 in research grants by the end of 2024.
  - Have 1 Project Alive funded research study presented to the community by the end of 2024.
- Fund and participate in the planning of 1 consensus meeting by the end of 2024.
- Publish the MPS II standard of care paper by the end of 2024



# Objective 4



## Objective:

Support Hunter syndrome clinical trials through advocacy and program development.

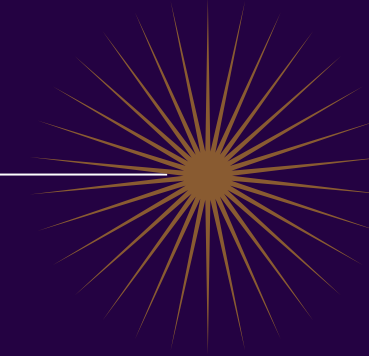


- FDA
  - Obtain an active role in FDA advocacy efforts in 2024.
- Relocation
  - Develop clinical trial relocation support program and create internal tracking system by the end of April 2024.
  - Provide relocation support services to 3 families by the end of 2024.
  - Work with 4 pharmaceutical companies with active MPS II clinical trials to ensure all non English speaking families receive translated written materials pertinent to their clinical trial by the end of 2024.
  - Work with 4 pharmaceutical companies with active MPS II clinical trials to ensure all non English speaking families receive an interpreter within the provided travel coordinator agency and the hospital site by the end of 2024.
- Engaging community in studies and trials
  - Develop a webpage for MPS II studies within the community resources page by the end of 2024.





# Objective 5



## Objective:

Lead and support Hunter syndrome advocacy efforts.



- Newborn screening state by state
  - Develop a newborn screening toolkit in partnership with MPS Center by the end of 2024.
  - Continue the partnership with the EveryLife Foundation in their Newborn Screening Task Force in 2024.
- Educating providers in MPS II
  - Participate in 2 educational presentations or conferences for medical students or active providers addressing MPS II by the end of 2024.
- Identifying areas of concern for community and initiating advocacy efforts around them
  - Release 1 community survey with focus on identifying gaps in the community by the end of 2024.
  - Have 1 member of Project Alive attend Capitol Hill advocacy days by the end of 2024.

