



# National MPS Society

Support for Families. Research for a Cure.





# Our Mission:

The National MPS Society exists to cure, support, and advocate for MPS and ML



**Lisa P. Todd**  
Chairman, Board of Directors



**Terri L. Klein**  
President and CEO

# Mucopolysaccharidosis and Mucopolipidosis II/III



**MPS I**

Hurler, Hurler Scheie, Scheie



**MPS II**

Hunter Syndrome



**MPS IIIA, IIIB, IIIC, IIID**

Sanfilippo Syndrome



**MPS IVA, IVB**

Morquio Syndrome



**MPS VI**

Maroteaux - Lamy Syndrome



**MPS VII**

Sly Syndrome



**ML II**

I-Cell Disease



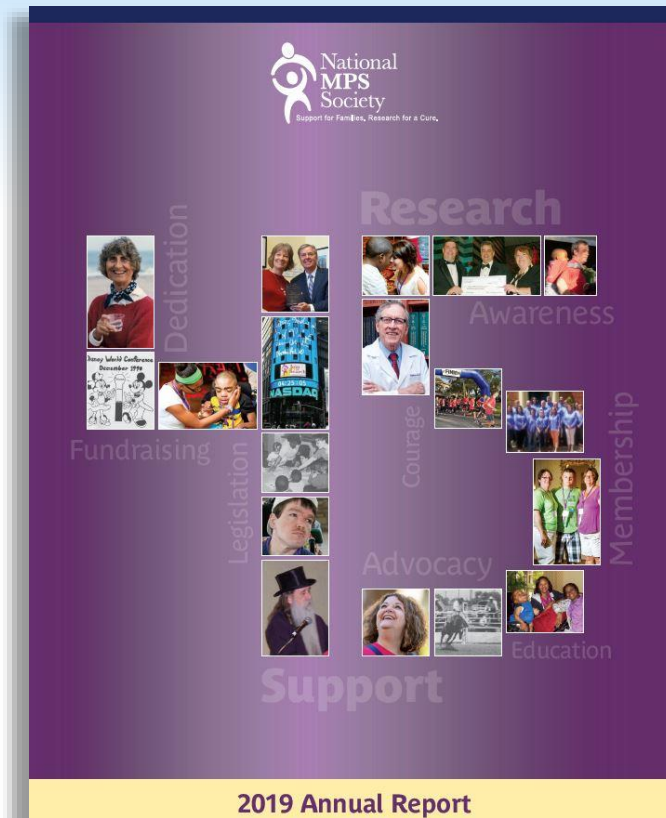
**ML III**

Pseudo-Hurler Polydystrophy



# Organizational Profile

- 45-year Patient Advocacy Organization
- Umbrella Organization for 11 syndromes
- **2100 active member households**
- Educational Resources
- Over \$12 million dollars in MPS/ML research
- Additional \$40 million in NIH funded research
- Over \$2 million in direct family support
- **Pathways – Newly Diagnosed Patient Program**
- 12 years supporting adults with SPIRIT & ARC
- **20 years Legislative Advocacy**
- Patient Registry - ConnectMPS



# Science and Research at the Society

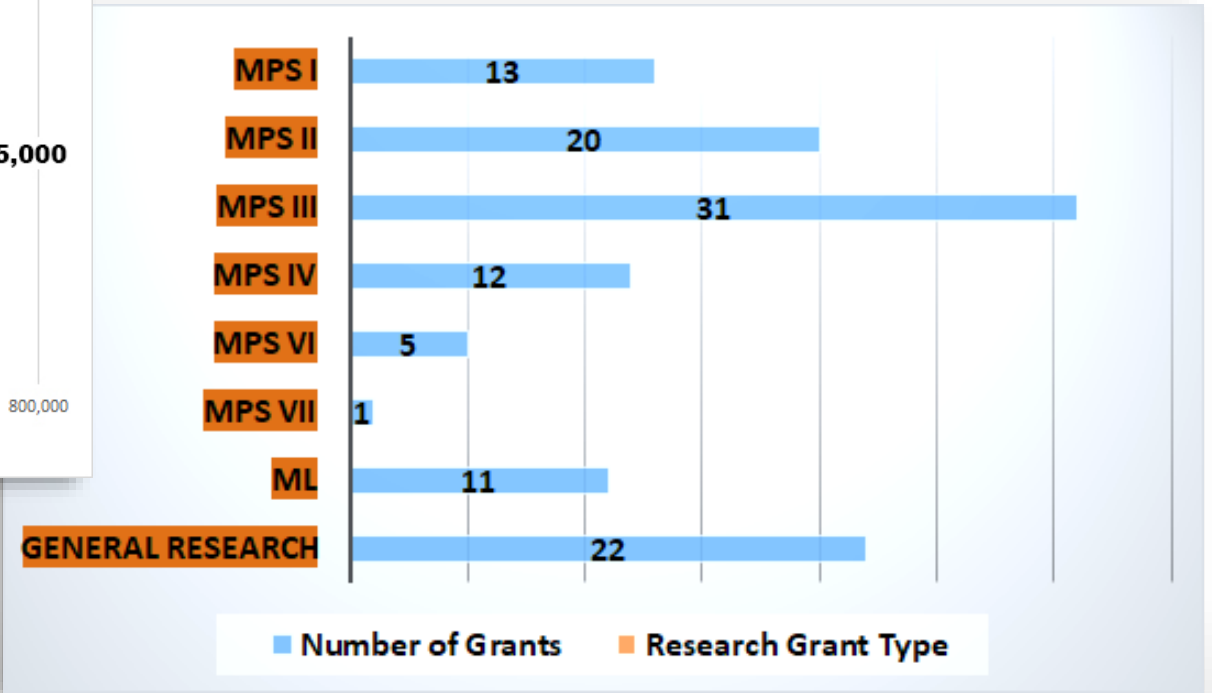
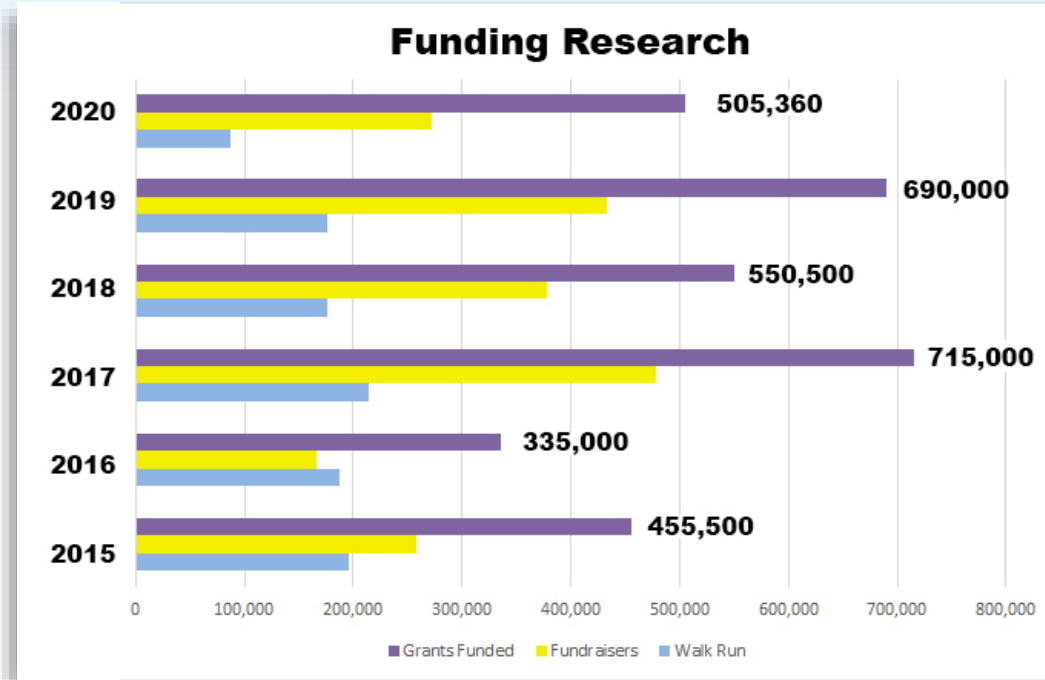
The National MPS Society supports Mucopolysaccharidosis and Mucopolipidosis research leading us to cures

## **Research Grant Program – Opens Feb. 15, 2021**

- MPS and ML grants
- \$50K - \$100K each
- Bench, investigative, and translational research
- Reviewer feedback
- Global funding
- One or two-year grants
- Publication support



# Science and Research at the Society



# Science and Research Resources

- **Chief Scientific Officer, Matthew Ellinwood, DVM, PhD**

- Oversight and administration of Sponsored Research
- Annual grants program
- Scientific liaison to industry, research, and public institutions
- Advancement of advocacy and applicable public health issues



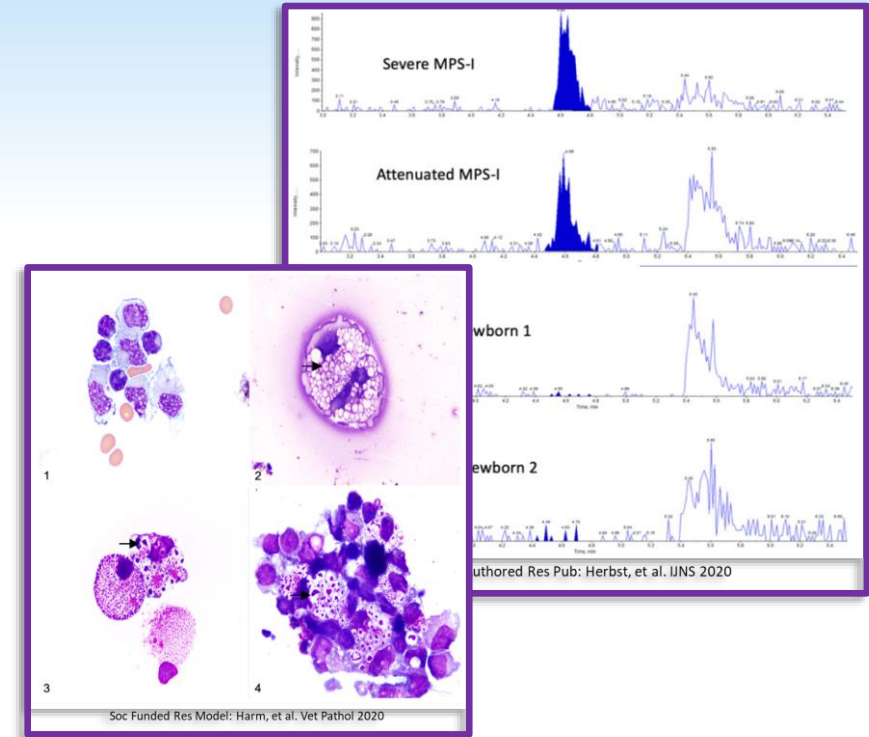
- **Scientific Advisory Board**

- Chair: Lynda Polgreen, MD, MS
- Over two dozen international experts in basic, translational, and clinical research on MPS and ML disorders
- Supports the Society's efforts in research and science



# Sponsored Research

- Two decades of sponsored research at the Society
  - A multimillion-dollar program
  - Over 100 funded research awards
- An international research portfolio
- Support for general MPS and ML research
- Support for syndrome research
- Fellowship and post-doctoral support
- Research support at the basic, translational, pre-clinical, and clinical level





# Science and Research Support Contacts

*Any questions?*

You can contact us at:

[matthew@mpsociety.org](mailto:matthew@mpsociety.org)

[grants@mpsociety.org](mailto:grants@mpsociety.org)

# Family Support Programs

## Grant Assistance:

- Bereavement Expense Program
- Extraordinary Experiences
- Family Assistance Program
- Journey Assistance Program
- Medical Travel Assistance Program
- Regional Social Events



**For more information, [visit us online!](#)**

# Family Support Programs

## Scholarship Programs:

- Family Conference Scholarships
- Continuing Education Scholarships
  - Individuals with MPS or ML
  - Parents, siblings, children
- Jeffrey Bardsley Scholarships



# Resources

The National MPS Society provides downloadable and publicly-accessible content to provide to patients and families. Please visit the following links on our website to access or download:

- [Syndrome-specific booklets and resources](#)
- [Fact Sheets](#)
- [General Membership Brochure](#)
- [Pathways Program Brochure](#)

For physical copies of brochures, booklets, and resources to keep in clinic or provide directly, please email your request to [info@mpsociety.org](mailto:info@mpsociety.org).



# Pathways Program

**For those with a new diagnosis of MPS or ML**

The Pathways program provides families with education and comprehensive support throughout the first year of diagnosis. Through innovative ways, we connect members with services, both locally and collectively. We equip and strengthen families to manage care and establish resources needed for the MPS and ML journey.



**For more information, [visit us online!](#)**



# National MPS Society

## 2021 Virtual Events Calendar

**March 27:** Virtual Raleigh Run for Rare

**May 2:** Virtual Napa Run for Rare

**May 15:** MPS Awareness Day Virtual Gala

**June 12:** Million Dollar Bike Ride

**June 19-20, 26-27:** Virtual National MPS Society Family Conference

**October 29-November 6:** The Big Bake for MPS and ML

**November 30:** Giving Tuesday

**For more information on fundraising opportunities, [visit us online!](#)**



# Save the Date:

## MPS Awareness Day Gala - May 15, 2021

Join the National MPS Society for a night of entertainment as we honor our families and celebrate MPS Awareness Day.

The evening will feature a silent auction, individual ticket sales, and sponsorship opportunities.

All funds raised from this event will directly support the mission of the National MPS Society.



**For details and sponsorship opportunities contact:**

**[Katelyn@mpsociety.org](mailto:Katelyn@mpsociety.org)**

# 35<sup>th</sup> Annual Family Conference

## Save the Date!

- Taking place virtually over two weekends – **June 19-20 & June 26-27**
- Features clinicians, scientists, researchers, FDA representatives, advocacy, family support, and more.
- Visit [mpssociety.org](https://mpssociety.org) for more info and upcoming registration information.





# Connect With Us!

[mpsociety.org/WORLDSymposium](https://mpsociety.org/WORLDSymposium)

[facebook.com/NationalMPSociety](https://facebook.com/NationalMPSociety)

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