

LSD LYSOSOMAL STORAGE DISEASES Advocacy Coalition

We are delighted to announce the formation of the Lysosomal Storage Disease Advocacy Coalition (LSDAC). The LSDAC is a new advocacy coalition of multiple patient advocacy organizations dedicated to advancing public policy priorities that benefit and improve the quality of life for patients living with lysosomal storage disorders (LSDs). The following organizations are founding members of the LSDAC:

- Fabry Support & Information Group
- National Fabry Disease Foundation
- Gaucher Community Alliance
- National MPS Society
- National Neimann Pick Disease Foundation
- Testing for Tots

Lysosomal storage disorders (LSDs) are a group of rare genetic diseases that affect the lysosome, a cellular structure that breaks down waste products. People with LSDs are missing specific important enzymes that are needed to break down these waste products. As a result, the waste products build up in the cells and become toxic.

The LSDAC is a collaboration between nonprofit organizations that represent LSDs. The coalition operates on a collaborative membership model to unite various stakeholders with a shared interest in Lysosomal Storage Disorders. Aviva Rosenberg, Co-President of the Gaucher Community Alliance will serve as inaugural President. Dr. Brian Jones, from Testing for Tots, will serve as Treasurer, and Justin Hopkin of the National Neimann-Pick Foundation will be Vice President.

We welcome additional patient organizations representing LSDs to join the LSDAC as voting members. Additionally, we encourage other stakeholders to participate. The coalition's mission is to work cooperatively with policymakers, pharmaceutical companies, national medical societies, and other stakeholders to advance policies that benefit and improve the quality of life for current and future patients with LSDs.

The LSDAC is currently working on several major initiatives:

- Extending Newborn Screening for Lysosomal Storage Disorders to all 50 States.
- Introduce and Pass Medicare Home Infusion for LSD Patients.
- Advocating for increased funding for research into LSDs.
- Raising awareness of LSDs to Congress and other Stakeholders.

We invite your organization to join the LSDAC and collaborate with us in our mission to advance policy and awareness supporting LSDs. Together, we can make a significant difference in the lives of patients and their families. To join the Lysosomal Storage Disease Advocacy Coalition, please contact Aviva Rosenberg at Aviva@gauchercommunity.org or James Romano at jromano@careandcurepartners.com.