NATIONAL NIEMANN-PICK DISEASE FOUNDATION, INC.

Supporting patients and families affected by Niemann-Pick Disease

Who We Are

You or a loved one have been diagnosed with Niemann-Pick Disease type ASMD or NPC. You may have many questions, and you may be searching for answers. That's why we are here. The National Niemann-Pick Disease Foundation, Inc. is dedicated to supporting all families in the U.S. through their Niemann-Pick journey. We are an enduring patient support community that embodies strength, hope and empathy for those affected by all Niemann-Pick Disease types. You are not alone.

The National Niemann-Pick Disease Foundation, Inc. (NNPDF) is a non-profit patient advocacy and family support organization dedicated to supporting and empowering patients and families affected by Niemann-Pick Disease through education, collaboration and research. Founded in 1992, NNPDF serves families throughout the nation at all stages of their journeys. The NNPDF is the U.S. member organization of the International Niemann-Pick Disease Alliance (INPDA).









What We Do

Living with Niemann-Pick Disease creates many challenges and the NNPDF seeks to respond to the needs of our ASMD and NPC community. Our goal is to provide information, support, and programs to help reduce the burdens on affected individuals and families.

Family Support Services

NNPDF programs provide support to individuals and family members.

Services can include:

- Crisis support
- Providing research and information about the diseases
- Assistance with insurance companies or other health and human service programs
- Establishing connections with medical experts
- Offering suggestions about day-to-day care and management

Programs We Offer

- NNPDF Family Assistance and Support Program
- NNPDF Family Support & Medical Conference
- NNPDF Community Update Webinar Series
- NNPDF Newsletter
- NNPDF Social Networks

Advocacy

Advocacy is central to our core values and our mission. We take a stand on matters of importance on behalf of all Niemann-Pick patients and families to help amplify their voices. We also facilitate dialogue between individuals and families affected by NPD and the FDA. The NNPDF has resources available to help individuals and families make their voices and personal stories heard at the local, state, and national levels as together we raise awareness of Niemann-Pick diseases. We believe it is important to empower individuals and families in our community and to be a driving force for positive change.

Research & Scientific Exchange

The NNPDF supports research and fellowships to advance the science of Niemann-Pick Disease and fosters scientific discussions amongst experts in the field.

International Collaboration

The NNPDF is the U.S. member of the International Niemann-Pick Disease Alliance (INPDA), a global network of Niemann-Pick Disease support organizations. Together we are working to register every individual who has NPD into one International Niemann-Pick Disease Registry that will encourage efficient and timely diagnosis, improve understanding of disease progression and influence patient care, while supporting global research efforts.

We are here for you

Becoming part of the NNPDF community enables you to join our educational and support networks and programs. We are committed to ensuring you don't miss out on the latest news and updates. Membership is free and open to all families affected by Niemann-Pick Disease including extended family, friends, and community supporters.

Supporting One Another. Supporting Our Community.