

# National Niemann-Pick Disease Foundation Recognizes Annual Global Niemann-Pick Awareness Day

Leading advocacy organization for families affected by Niemann-Pick disease supports global effort to raise awareness and support research for ultra-rare genetic disorder.

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**National Niemann-Pick Disease Foundation →**

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FORT ATKINSON, Wis., Oct. 19, 2020 /PRNewswire/ -- The National Niemann-Pick Disease Foundation (NNPDF), the leading advocacy organization for people living with Niemann-Pick disease in the United States, today recognizes international Niemann-Pick Awareness Day, a global initiative to build awareness of the significant impact this rare genetic disease has on patients, caregivers, and families. NNPDF joins with the global community to support research that can lead to new treatments and efforts to bring more services and support to people affected by Niemann-Pick disease around the world.

"Global Niemann-Pick Awareness Day has become a strong international platform to raise awareness of this disease that currently has no approved treatments. As we work to bring more services and resources to our members, the National Niemann-Pick Disease Foundation is very pleased to join with so many dedicated individuals and organizations that are supporting this community today and throughout the year," said Joslyn Crowe, Executive Director of NNPDF. "In the past year, we have seen many

important advances in research that are bringing new levels of hope to patients around the world. We are excited about what the next year will bring to the Niemann-Pick community."

In recent months, NNPDF has initiated and continued many efforts to support people affected by Niemann-Pick disease, including development of a series of "virtual touch" programs and educational resources including a special focus on community needs during the COVID-19 pandemic. In July, NNPDF held its annual meeting as a virtual event where more than 300 participants and presenters provided updates on clinical research, support services and patient family journeys. Throughout October, NNPDF has been taking steps to build new levels of awareness through patients and caregivers who have bravely been sharing their stories and best practices. NNPDF has also sponsored a social media campaign throughout October to share a range of perspectives on the impact of Niemann-Pick from patients, caregivers and others.

Niemann-Pick is a fatal, rare genetic disease that can affect both children and adults. It is neuro-degenerative and caused by a build-up of toxic materials in the body's cells that can cause enlarged liver or spleen, difficulties with motor skills, speech, swallowing and feeding as well as cognitive impairment. For many patients, these symptoms can have a severe impact on the ability to participate in the activities of daily life. There is currently no approved treatment for Niemann-Pick disease.

"Niemann-Pick Awareness Day is also a time to recognize and honor all the families who have joined in the effort to build awareness and support others. We applaud their efforts that are making the journey easier for patients everywhere," said Dr. Justin Hopkin, NNPDF Board Chair.

### **About the National Niemann-Pick Disease Foundation**

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 1993, NNPDF serves families throughout the nation at all stages of their Niemann-Pick journey. The NNPDF is the US member organization of the International Niemann-Pick Disease Alliance (INPDA).

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