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## National Niemann-Pick Disease Foundation Honors Global Niemann-Pick Awareness Day Highlighting Need for Broader Support and Research

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FORT ATKINSON, Wis., Oct. 19, 2021 – The National Niemann-Pick Disease Foundation (NNPDF), the leading advocacy organization for people living with Niemann-Pick disease in the United States, today commemorates the third annual Niemann-Pick Disease Awareness Day, a global effort to build awareness of the significant impact this rare genetic disease has on patients, caregivers and families. NNPDF joins with the global community to honor patients and families and to highlight the critical need for increased awareness and research that can lead to new treatments and services for people affected by the disease.

“Niemann-Pick Disease Awareness Day is an important opportunity to recognize the amazing work of our patient community in fighting to raise awareness and for research that can lead to new treatment options for patients around the world,” said Joslyn Crowe, executive director of NNPDF. “In the past year, we have faced many challenging setbacks, but our community stayed together to continue fighting and advocating for all those affected by Niemann-Pick disease. We have also seen promising advances in research and are hopeful about what the next year might bring to the community.”

In recent months, NNPDF has initiated and engaged in many efforts to support people affected by Niemann-Pick disease including a recent virtual annual meeting where more than 300 community members joined together to learn about advances in clinical research, new support services and different patient family journeys. NNPDF has also led two recent community listening sessions with the U.S. Food and Drug Administration (FDA) to discuss topics important to the Niemann-Pick community including the urgent need for approved treatments. Throughout October, NNPDF has worked to raise awareness of the disease and highlight the needs of the community through various initiatives including webinars with industry partners, a social media campaign, and working with patients and caregivers to help them share their stories of living with Niemann-Pick disease.

Niemann-Pick is a fatal, rare genetic disease that can affect both children and adults. It is neurodegenerative 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 Disease Awareness Day is a time for our community to recognize and celebrate the advances we have made while also working together to continue fighting for access to better care and support for research to develop a treatment for this devastating disease,” said Laurie Turner, family services manager at NNPDF.

**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. NNPDF is the US member organization of the International Niemann-Pick Disease Alliance (INPDA).

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