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Web Site: <a href="mailto:www.nnpdf.org">www.nnpdf.org</a>; E-mail: <a href="mailto:nnpdf@nnpdf.org">nnpdf@nnpdf.org</a>;

## <a href="#"><Name of event></a> Event to Raise Funds for Niemann-Pick Disease Research

**Your City, State>** (**Date>**) – The <name of event> will be held on <day, date>, at <location>. This <a href="description">description of event, such as golf outing, walk, etc.></a> will raise funds for research into the cause and treatments for Niemann-Pick Disease.

Niemann-Pick Disease, a rare, genetic illness with no known cure, affects <a href="mailto:</a> <a href="mailto:</a

<Paragraph(s) with further description of event – event highlights, celebrities, entry details, prizes, raffles, who to contact for more information, need for volunteers/donations/sponsors, etc.>

The National Niemann-Pick Disease Foundation (NNPDF) was established in 1992, when six families from across the nation met to establish a foundation to raise money for family support services and research. Since then, the Foundation's membership has grown to over 350 families, and over \$4.1 million has been applied toward research. As a result of this research, the gene responsible for Niemann-Pick Disease has been identified, and experimental therapies are being tested.

The NNPDF recently rolled out its new Web site (<u>www.nnpdf.org</u>), providing education and awareness to a broad international audience. To further support families dealing with the day-to-day issues of caring for a family member with a terminal illness, the Foundation offers an annual Family Support and Medical Conference, to be held July 30 – August 2, in Seattle, Washington.

The NNPDF has as its motto, "Persevere!" as in, "be determined, be stubborn, endure, pursue, persist, press on, and get it done!" Families with a member affected by Niemann-Pick Disease need perseverance to face the daily challenges of the illness and to hold fast to the hope that one day soon, no parent will have to lose their child to this devastating disease.

Family-sponsored fundraisers such as <name of event> support the research essential to winning the battle against Niemann-Pick Disease. The <family name, plural form>, like many families across the country affected by NPD, work hard for the day when no more lives will be lost due to NPD.

The NNPDF's new Strategic Plan for Research ensures a research funding strategy that takes into account the needs of the membership; current knowledge in the field of NPD; funding strategies of other NPD organizations; and the advice and expertise of the members of the NNPDF's Scientific Advisory Board. Within this framework the NNPDF funds postdoctoral fellowships that seek to find the cause of, and treatments for, Niemann-Pick Disease.

In addition to its work within the United States, the NNPDF provides support to the Canadian Chapter of the NNPDF, and collaborates with international Niemann-Pick Disease organizations.

For more information about the National Niemann-Pick Disease Foundation, visit <a href="https://www.nnpdf.org">www.nnpdf.org</a> or contact the NNPDF office at 920-563-0930.

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