

National Niemann-Pick Disease Foundation



October 2016 Niemann-Pick Disease Awareness Month Sample Request for a Proclamation

It's easy! Contact your representatives in the Senate and House of Representatives. Call the Governor's Office or Mayor's Office and ask who handles requests for proclamations and what information they need. Change this sample letter to reflect your own family story, submit your request and follow-up with a call as to the status. If you know someone in local, state or federal government that can help you to move this along, take advantage of their contacts.

Once you are successful and received a proclamation, be sure to make a BIG DEAL of it ~ notify the press, frame the proclamation and have a presentation at your event. Ask if a government representative can attend, and make sure to get photos to submit to the media.

Sample Letter to a Government Official:

September 15, 2011

The Honorable Scott Walker
Governor of the State of Wisconsin
1 State Capitol
Madison, WI 53702

Dear Governor Walker:

We respectfully request that October be declared as Niemann-Pick Disease Awareness Month. Further information about this request and sample wording for a proclamation are provided on the following page.

Our daughter, Stacey, passed away in 2004, at the age of 19, with Niemann-Pick Disease Type C (NPC). We are working to raise awareness of this disease which robs parents of their children, and children of their lives.

Please contact us if you need any additional information. Thank you for your assistance in this matter.

Sincerely,

Barb and Gary Vorpahl
N1590 Fairview Lane
Fort Atkinson, WI 53538
920-563-8677
bvorpahl@charter.net

Requesting Organization: National Niemann-Pick Disease Foundation

The National Niemann-Pick Disease Foundation is a 501(c)(3) non-profit organization. Established in 1992 by six families, the Foundation today has approximately 400 families as members, has funded millions of dollars in research projects, and provides family support through its newsletter, Web site, and annual family conference. Additional information can be found at www.nnpdf.org.

Contact Person:

Barb and Gary Vorpahl
N1590 Fairview Lane
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920-563-8677
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National Niemann-Pick Disease Foundation
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920-563-0930
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Summary:

Niemann-Pick Disease is a devastating metabolic disease which primarily affects children. Niemann-Pick Disease results in deterioration of the brain, central nervous system, liver, lungs, and other organs. The disease is usually fatal by the late teens.

At present, there is no treatment or cure for any form of Niemann-Pick Disease. The disease is difficult to diagnose and can lead to years of uncertainty for parents and family members. The National Niemann-Pick Disease Foundation has been working since 1992 to heighten public awareness of this disease, improve diagnosis, and fund research into a cure. After years of work, there is some hope in sight but more awareness and research is needed to defeat this disease.

******* *Include a photo of your family and/or loved ones with NPD* *******

Sample Proclamation Wording:

Whereas, Niemann-Pick Disease is a devastating metabolic disease that affects children and adults, and

Whereas, Niemann-Pick Disease is a rare genetic illness that is difficult to diagnose, and

Whereas, Niemann-Pick Disease has no known cure or treatment, and

Whereas, families in {insert your state} and throughout the United States are known to be affected by this disease, and

Whereas, promoting awareness of the disease will aid in funding research, improving diagnosis and finding a cure,

Therefore, it is proclaimed that October 2015 is Niemann-Pick Disease Awareness Month.