

National Niemann-Pick Disease Foundation



October 2008 Niemann-Pick Disease Awareness Month Sample Request for a Proclamation

It's easy! Contact your community 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 get this moved along.....take advantage of their contacts.

To find your community contacts follow the web site links below or look in the Government section of the phonebook.

<https://forms.house.gov/wyr/welcome.shtml> ~ U.S. House of Representatives Contact Link
<http://www.senate.gov> ~ U.S. Senate Contact Link
<http://www.statelocalgov.net> ~ State and Local Government Links

Once you are successful and receive a proclamation.....be certain to make a BIG DEAL of it ~ notify the press (see a sample press release enclosed), frame the proclamation and have a presentation at your event, preferably a government representative from the office can attend and be a part of the presentation.

Sample Letter to a Government Official:

September 15, 2008

The Honorable Jennifer Granholm
Governor of the State of Michigan
Capitol Avenue at Michigan Avenue
Lansing, MI 48901

Dear Governor Granholm:

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 pages.

We are the parents of two daughters with Niemann-Pick Disease Type C (NPC). Our son passed away in 2005 of 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,

Tim and Liz Heinze
7196 West Cronk Road
Elsie, MI USA 48831
989-834-9761
heinze97@hotmail.com

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 over 350 families as members, has funded millions of dollars in research projects, and provides family support through its newsletter, website, and annual family conference. Additional information can be found at www.nnpdf.org.

Contact Person:

Tim and Liz Heinze
7196 West Cronk Road
Elsie, MI USA 48831
989-834-9761
heinze97@hotmail.com

National Niemann-Pick Disease Foundation
P.O. Box 49
Fort Atkinson, WI 53538
920-563-0930
nnpdf@nnpdf.org

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.

Two of Tim and Liz Heinze’s daughters have been diagnosed with Niemann-Pick Disease Type C (NPC). The Heinzes’son passed away in 2005 from NPC. One Heinze daughter is unaffected by Niemann-Pick Disease. The Heinze family is from Elsie, MI.

******* *Insert a photo of your family and/or loved ones with NPD here.* *******

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 this 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 2008 is Niemann-Pick Disease Awareness Month.

Please refer to the NNPfD web site (www.nnpdf.org) for an example of this document and others in MS Word. All web site links and documents in this packet are available on the web site for your use.