



**National Niemann-Pick Disease Foundation, Inc.**  
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May 15, 2009

Dear Families of the NNPDF,

On behalf of the National Niemann-Pick Disease Foundation (NNPDF), we invite you to register now for the 17<sup>th</sup> Annual NNPDF Family Support and Medical Conference scheduled for scenic Seattle, Washington, July 30<sup>th</sup> – August 2<sup>nd</sup>.

All past and present NNPDF members and friends are welcome to join us as we come together to learn the latest in research and treatments, and to renew old friendships and develop new.

This year's conference will be hosted by Karen and Gene Quandt, in honor of their son Ty, age 12 (NPC). The Quandts are excited to welcome you to their "Emerald City," as Seattle is often called. They have worked hard to help coordinate a conference that will be enlightening as well as inspiring to attendees.

Conference sessions will include information about the ongoing care associated with chronic illness; addressing the needs of the child at home, at school, and beyond; and the latest in scientific research toward treatments and a cure. Several of the world's prominent NPD scientists and physicians will be on hand to share their news, expertise and support. A special candle-lighting commemoration service will be held Thursday evening in remembrance of loved ones lost to NPD, allowing families to share memories and support one another.

The Seattle area offers a million and one things to do, places to go, and people to see! We have listed but a few of these attractions in the enclosed conference registration packet. Please see the Seattle brochure (also enclosed), and visit [www.visitseattle.org](http://www.visitseattle.org) for information about dozens more recreational and educational opportunities. Our special hotel rate is valid for three days prior to and three days after the conference, so make the most of your trip and plan to see the sights!

Doubletree Guest Suites has reserved a block of rooms for our conference at an excellent rate (see the Registration Packet for details). Our block will be held until July 1<sup>st</sup>, or until sold out, whichever comes first. Please book your reservations as soon as possible to ensure availability, and be certain to use the Group/Convention Code of NIE.

Enclosed, in addition to the conference information packet, are a conference registration form and a "Helping Hand" Stipend application form. Please return your conference registration form by July 1, and if you plan to apply for a "Helping Hand" Stipend, please return your application by June 15.

The NNPDF is a non-profit 501(c)(3) organization that supports and promotes research to find treatments and a cure for all types of Niemann-Pick Disease, and which provides support services to individuals and families affected by the disease.

Living with Niemann-Pick Disease can create an emotional burden that can be difficult to bear. The NNPDF's Family Services Program works to anticipate and respond to the needs of those dealing with NPD. Our goal is to reduce the burden of Niemann-Pick Disease on affected individuals and families through our family services work and the funding of research. The Annual Family Support and Medical Conference is one key element in meeting this goal, and we hope that you will take advantage of all the conference has to offer.

Registration and opening ceremonies will be held on Thursday evening and conference sessions will begin on Friday morning. Conference sessions will wrap up Saturday evening with a banquet, dance and celebration, allowing families time to gather informally or tour the area on Sunday.

Please read carefully through the enclosed information, and if you have questions or concerns regarding the conference, please feel free to contact me at the NNPDF office. You can reach me by telephone at 920-563-0930; toll-free at 877-287-3672; or by email at [nhill@nnpdf.org](mailto:nhill@nnpdf.org).

Hope to see you in Seattle!

Sincerely,

*Nadine M. Hill*

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***The NNPDF's VISION is a world where Niemann-Pick Disease is no longer a threat to a full and productive life for patients and their families. Medical professionals, thoroughly familiar with the disease, will promptly and accurately diagnose it early in the patient's life, and then prescribe an appropriate therapy. Families affected by Niemann-Pick Disease will not be devastated by the diagnosis or its impact on their lives. Individuals with Niemann-Pick Disease will have the same chance as their siblings and peers to run and play, to hope and achieve, and to live out their dreams.***