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24th Annual NNPDF Family Support and Medical Conference
National Niemann-Pick Disease Foundation
Thursday, August 11th – Sunday, August 4th, 2016
DoubleTree Boston North Shore Danvers, Massachusetts

FAQs (Frequently Asked Questions)

Q: What is the NNPDF Family Support and Medical Conference?

A: The NNPDF Family Support and Medical Conference is an annual event, hosted by the National Niemann-Pick Disease Foundation. The conference offers families and others affected by Niemann-Pick Disease the opportunity to learn the latest in medical and research information in a warm, comforting atmosphere emphasizing emotional support and practical information.

Q: Who should attend the Family Conference?

A: The NNPDF Family Conference is open to immediate families and extended family members of individuals affected by Niemann-Pick Disease. Caretakers, educators, medical personnel, scientists, researchers, and others directly impacted by and interested in learning more about NPD are also invited to register and attend the conference.

Past conferences have included many grandparents, aunts, uncles, siblings, school teachers, volunteers, NPD families from other countries, and more. The Family Conference offers a welcoming atmosphere, and attendees find that the shared experience of NPD fosters close friendships and a network of caring support.

Also attending the Family Conference will be the board members of the NNPDF, members of the NNPDF Scientific Advisory Board (SAB), the postdoctoral researchers receiving fellowships through the NNPDF, other physicians and scientists, and possibly representatives of Genzyme and Actelion Pharmaceutical companies.

Q: Will there be childcare available during the conference?

A: Yes, a free childcare/young adult activity room will be available to families attending the conference as a service to our attendees. This room will be staffed with experienced volunteers familiar with the needs of individuals affected by NPD, and will also welcome non-affected siblings to join in the fun activities and games being planned.

Parents must sign their children into and out of the childcare/young adult room. Childcare/Young Adult room staff will not administer medications or feedings. Parents will be able to use breaks to visit the childcare room to administer medications and feedings. More details regarding the childcare room will be available in the conference registration packet.

Q: Where is this year's Family Conference being held?

A: The 2016 Family Conference will be held at the DoubleTree Boston North Shore, 50 Ferncroft Road, Danvers, Massachusetts. For reservations call 800-222-8733 (use code NPF), or visit the NNPfD Web site at <http://www.nnpdf.org> for a link to make your reservations online.

Be sure to request the special NNPfD Family Conference rate. The special room rate offers a pre-conference stay of three nights prior to the conference, and three nights after, for those who would like to arrive early or stay longer.

Q: What are the dates of the 2016 Family Conference?

A: The conference will be held Thursday, August 11th through Sunday, August 14th, 2016. Registration will begin late Thursday afternoon, and the conference will conclude with a family banquet celebration and dance Saturday night.

Many families combine a trip to the Family Conference with their summer vacation plans. Special rates on hotel rooms will be available for three nights prior to the conference, and three nights after the conference, so plan to come early or stay longer to see all Chicago's sights. Visit <http://www.bostonusa.com/> for tourism information.

Q: What types of sessions and activities can I expect at the Family Conference?

A: Family Conference programs and activities are designed to provide information and inspiration for families, whether they are newly-diagnosed with NPD or if they have been traveling the NPD journey for years. Further, the conference offers families a time to get away, to have fun, and to build relationships with other families also dealing with the challenges of NPD.

Conference attendees will receive updates on current and ongoing research, progress made since last year's Family Conference, research showing the most promise, and how the latest information can help their own children.

Two panel sessions will be offered during the conference – one for Research topics and one for Medical topics. These sessions offer families the opportunity to ask specific questions of scientists and doctors about the latest in research and disease management.

Breakout sessions give families opportunities to meet with other families and discuss issues and concerns, and to give and receive support. Social gatherings and mealtimes offer families opportunities to relax and have fun, form lasting friendships and build a network of support.

Newly-diagnosed families will be paired with mentors to help them navigate the myriad of information they will be faced with as they learn about Niemann-Pick Disease, and to make the most of the conference itself.

The conference will include a special memorial gathering and ceremony to remember those lost to Niemann-Pick Disease and to honor those family members lost to NPD in the last year. Family members will gather to support one another and to share special photos and memories of their loved ones.

A bereavement support session will be offered for families coping with the loss, or the prospect of the loss of, a family member. The conference will also feature speakers to inspire and give hope to families dealing with a diagnosis of Niemann-Pick Disease.

Last but certainly not least, the weekend will include fun social activities for families, and will conclude with a gala celebration banquet and dance Saturday night, so pack your dancin' shoes!

Q: Are there sources of financial support to help my family attend the Family Conference?

A: The NNPDF offers the “Helping Hand Stipend” to help assist NNPDF families in financial need to offset the financial burden of attending the family conference. The Helping Hand application form is available on the NNPDF Web site (www.nnpdf.org), and a copy will be included with the registration packet.

We also encourage families to seek local support through community organizations such as the March of Dimes and Developmental Disabilities Councils or regional genetic services groups, as well as community groups such as Lions, Rotary and Optimists.

Q: Who should I contact for more information about the conference?

A: Detailed information and a registration packet for the 2016 NNPDF Family Support and Medical Conference will be mailed to NNPDF member families. Please make sure the NNPDF has your current mailing and email addresses.

For more information about the NNPDF Family Support and Medical Conference scheduled for Chicago from August 11 – August 14, 2016, please visit www.nnpdf.org or contact:

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