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18th Annual NNPDF Family Support and Medical Conference
National Niemann-Pick Disease Foundation
Co-Hosts: Canadian Chapter ~ National Niemann-Pick Disease Foundation
Thursday, August 5 – Sunday, August 8, 2010
Delta Chelsea Hotel ~ Toronto, Ontario CANADA

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 (co-hosted this year by the Canadian Chapter of 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 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 representatives of Genzyme and Actelion.

Q: Will there be childcare available during the conference?

A: Yes, a childcare/youth activity room will be available to families attending the conference. 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 room. Childcare 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, or to sign their children out of the childcare room to join the family for meals between conference sessions. More details regarding the childcare room will be available in the conference registration packet to be mailed out in May.

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

A: The 2010 Family Conference will be held in Toronto, Ontario Canada, at the Delta Chelsea Hotel. The conference is held in various locations around the U.S., and this year, in Canada, as the first international advocacy and family support conference for those affected by Niemann-Pick Disease.

The Canadian Chapter of the NNPDP will co-host this year's conference. The NNPDP works hand-in-hand with the CCNNPDP to promote research and provide support services to families in Canada.

Q: What are the dates of the 2010 Family Conference?

A: The conference will be held Thursday, August 5th through Sunday, August 8th, 2010. 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 conference rates on rooms at the Delta Chelsea Hotel will be available for the three nights prior to the conference, and three nights after the conference, so plan to come early or stay longer to see all Toronto's sights!

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, 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, which research is 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, so pack your dancin' shoes!

Q: Do U.S. citizens need a passport to attend the Family Conference in Canada?

A: Yes, anyone traveling to Toronto from outside Canada, including the U.S., must have a passport. Be sure to allow ample time for your passport to be processed.

Q: Should I convert money to Canadian currency for my trip?

A: Canada's currency differs from U.S. currency, and the exchange rate varies daily. Using credit cards avoids the need to convert cash, as the conversion is handled by the credit card company. If you prefer to carry cash, convert your currency in advance, if possible. (Your home bank should be able to make the conversion or tell you where you can convert currency locally.)

Currency may also be exchanged at Toronto Pearson Airport and at the Delta Chelsea front desk. Many retailers and restaurants in Toronto will accept U.S. currency, but may charge a fee or use an exchange rate not advantageous to the traveler. Do not plan to exchange currency at a bank in Canada, as most banks will only exchange currency for their own regular clients with identification, due to government regulations.

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

A: The NNPfD offers the "Helping Hand" stipend to help ensure that families who need financial assistance are able to attend the conference. The Helping Hand application form is available on the Web site at www.nnpdf.org, and 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: Will my health insurance cover my family while traveling out of the United States?

A: An important part of your travel planning should include a call to your health insurance provider to see what coverage you will have when traveling. Your insurance may cover you as usual, or you may be advised to purchase an additional “rider” or travel policy as a safeguard.

We checked with one U.S. health insurer as an example, and received this advice:

- 1) Since it is unlikely that Canadian health care providers will accept your U.S. health insurance card as assurance of payment, be prepared to pay for medical and prescription drug services at the time they are received, and then file for reimbursement from your health insurance company upon your return home. Obtain the required forms from your insurer before departure, and carry copies of them with you on your trip.
- 2) If you should require medical attention while in Canada, your insurance provider may require notification, depending on your insurer and plan. Be sure to take along important phone numbers for your trip.
- 3) Be sure to obtain itemized bills for any and all services you receive, including prescription drug expenses. The bills must be in English, and show charges in both Canadian and U.S. currency values. Name and address of provider must be included, together with dates of service. Prescriptions must include both U.S. and Canadian brand names, quantity and dosage. Each type of service or prescription must include a specific diagnosis.

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

A: Detailed information and a registration packet for the 2010 NNPfD Family Support and Medical Conference will be mailed to NNPfD and CCNNPfD member families in May. Please make sure the NNPfD has your current mailing and email addresses.

For more information about the NNPfD Family Support and Medical Conference scheduled for Toronto from August 5 – 8, 2010, please contact:

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