



The NNPDF Your Safe Harbor

Dear Friends and Families of the NNPDF,

The National Niemann-Pick Disease Foundation is pleased to invite you to the 19th Annual NNPDF Family Support and Medical Conference in Norfolk Virginia, July 28 - 31, 2011, at the Sheraton Norfolk Waterside Hotel. Please mark your calendar and make plans now to join us for this informative and fun family conference!

Norfolk offers fantastic cultural and recreational opportunities for the entire family. With so much to see and do, you may want to plan your conference trip to include a couple of extra days to take advantage of all the area has to offer. (Our special hotel rates are also available three days prior to, and three days following, the conference.)

Of course, the centerpiece and highlight of your trip to Norfolk will be the Family Conference itself. We are putting together an exciting agenda to include all the latest in research and clinical news, networking opportunities, and fun family activities.

We expect a very good turnout of the experts in Niemann-Pick Disease at this summer's conference. This is your opportunity to hear the latest in medical and research information directly from the eminent researchers, doctors and scientists who work with NPD.

And we promise, you will remember forever the family connections you make at the Family Conference. Nothing compares to meeting face-to-face with others who are dealing with challenges similar to your own. If there is a blessing to be found with NPD, it is the wonderful families you meet and bond with as a result of this shared experience.

We have selected the Sheraton Norfolk Waterside Hotel for our conference. Norfolk's only waterfront hotel, the Sheraton offers guests both luxury and convenience. With 468 guest-rooms and suites, the Sheraton wraps you in all the comforts of home, with many additional amenities.

Just steps from the Sheraton's door, the Waterside Marketplace features many specialty shops, restaurants, and entertainment venues. You'll want to enjoy the outdoor activities at nearby Town Point Park, or explore one of the many nearby museums and memorials.



2011 NNPFD Family Support & Medical Conference

We have prepared this packet of information regarding the conference especially for you, including the conference schedule and registration deadlines, the Childcare Activity Room (CAR), the First-Time Fundraiser Contest, the Helping Hand Stipend, Norfolk-area attractions and resources, hotel details, travel tips, and more.

Please read through the packet and then complete and return your conference registration form by July 1st. (Helping Hand Stipend applications are due June 15.)

Please note that the block of hotel rooms at the special conference rate will be held only until June 27th or until the block is filled, whichever occurs first. Handicap-accessible rooms will be filled on a first-come, first-served basis.

Don't hesitate to contact the NNPFD Central Office if you have any questions or concerns regarding the Family Conference. Call 920-563-0930; toll-free 877-287-3672; or email nnpdf@nnpdf.org.

You may also wish to visit our special Family Conference Web page at http://www.nnpdf.org/familyservices_03.html for updated conference information, as details are being added to the page frequently.

We look forward to welcoming you to Norfolk in July!

Sincerely,

Your 2011 NNPFD Family Support and Medical Conference Hosts

**Karen R. Quandt, RN, MSN
Chair, NNPFD Board of Directors
Mom of Ty Quandt (NPC)**

**Nadine M. Hill
NNPDF Director of Family Services**

Conference Deadlines

Hotel Reservations (make directly with the Sheraton – see page 5 for details)	The block of rooms will be held until June 27, or until sold out , whichever comes first. We recommend you make your room reservations as soon as possible!
(Handicap-accessible rooms will be filled first-come, first-served.)	
“Helping Hand” Stipend Applications	June 15, 2011
Conference Registrations	July 1, 2011
First-Time Fundraiser Contest Entries	July 1, 2011

Conference Schedule

The agenda for the 2011 Family Conference is being developed focusing on medical and research issues, and will be announced in detail closer to the conference. To assist you in making travel arrangements, the conference schedule has been established as follows:

Thurs., July 28	7:00 p.m.	Registration and Welcome Reception
Fri., July 29 & Sat., July 30	Daytime	Joint Sessions and Breakout Sessions
Sat., July 30	8:00 p.m.—midnight	Conference wrap-up and farewell; Evening of entertainment and celebration

Caregiving/Childcare Services & Activity Room

Childcare and young adult activities will be provided during conference sessions (with breaks for lunch). The volunteer childcare/activities staff will NOT administer medications or give feedings. We hope to be able to provide a refrigerator nearby where you can store medications during the day.

The volunteers staffing this service are committed to ensuring that your children, both NPD –affected and their siblings, along with our young adult NPD family members, are in a safe and fun-filled environment offering a variety of activities, games, crafts, videos and friendship. If your children enjoy a particular activity or game, please feel free to bring it along to share with their friends in the activity room.

Once a child has been registered into the childcare/ activity room, they **MUST** stay in the room until their parent or guardian signs them out. Any child taking part in activities in the childcare/activity room **MUST** be signed in and out by their **OWN** parent or guardian.



Commemoration

The “Light of Hope” Candle Lighting Ceremony and Commemoration, in memory of all the loved ones we have lost to NPD, will be held on Thursday evening after registration and introductions. Families are invited to bring photos, memory books, etc., to share with other families in attendance.



First-Time Fundraiser Contest

Since 2002, the Foundation has held an annual “First-Time Fundraiser” contest as a way to encourage and recognize families who have taken their first steps in raising funds to support the work of the Foundation. The grand prize winner receives a free hotel room for the three nights of the Family Conference.

Contest rules are simple:

- ◆ Entrants must be first-time fundraisers.
- ◆ Fundraising results and receipts must be submitted to the NNPDF Central Office by July 1, 2011.
- ◆ The 2011 contest year runs from July 1, 2010 —June 30, 2011. (Events must have been held during this time period.) First-Time Fundraisers may have hosted more than one event during that timeframe, with proceeds from all events in that timeframe counting toward the entrant’s total.
- ◆ NNPDF board members, employees and their relatives are not eligible to participate.
- ◆ The First-Time Fundraiser who raised the most money for NNPDF wins the grand prize — three free nights at the Sheraton for the Family Conference!

If you are in the running for the First-Time Fundraiser Contest, please do not wait to make your hotel reservations — make your hotel reservations now to avoid disappointment. If you are the contest winner, the NNPDF will cover the room cost for the three nights of the conference (July 28, 29 & 30).

Fundraising is vital for moving research forward. If you have been thinking about fundraising, this is the time to jump in. The NNPDF offers a Fundraising Packet, a Guide to Getting Media Coverage, and support to help you get started.

Contact the NNPDF at nnpdf@nnpdf.org or 920-563-0930 for more information or assistance.



2011 NNPDF Family Support & Medical Conference

Sheraton Norfolk Waterside Hotel

The 19th Annual NNPDF Family Conference will be held in Norfolk, Virginia, from Thursday, July 28th through Sunday, July 31st, 2011, at the Sheraton Norfolk Waterside, 777 Waterside Drive.

Room reservations must be made directly with the Sheraton.

Make reservations by calling 1-888-627-8042; or via a link at our Web site, http://www.nnpdf.org/familyservices_03.html. The NNPDF block will be held until June 27, or until the room block is sold out, whichever comes first. Handicap-accessible rooms will be filled on a first-come, first-served basis.

The special discount rate is available for the conference and apron dates of Sunday, July 24 through Tuesday, August 2 (departure on August 3), based on availability.

Special Family Conference rates include a choice of rooms: City View room for \$89 per night (\$101.57 with 13% taxes and \$1.00 fee); or Harbor View room for \$109 per night (\$124.17 with 13% taxes and \$1.00 fee)

Sheraton Norfolk Waterside

777 Waterside Drive
Norfolk, VA 23510
Reservations: 888-627-8042
Hotel: 757-622-6664
www.sheraton.com



**Conference Rate
Offered Until
June 27 or
Until Sold Out**

**Reserve Your
Rooms Early!**



Hotel Location, Highlights & Hotspots!

Norfolk's only waterfront hotel, the Sheraton Norfolk Waterside Hotel offers both comfort and convenience to guests. Just steps from the front door, Waterside Marketplace features many specialty shops, restaurants, and entertainment venues. Stroll through Town Point Park, a beautiful spot to enjoy panoramic river views or a sunset cruise, or explore one of the many nearby museums and memorials. The area features outdoor concerts, world-class galleries, performing arts and festivals, and more. Then, when your day has ended, let the Sheraton wrap you in relaxation and luxury.

The hotel has 468 guest rooms, with a choice of City View or Harbor View accommodations. Handicap accessible rooms are available, as well as Extended Stay Suites. The Sheraton's City Dock Restaurant offers traditional and contemporary favorites for indoor or outdoor dining. The 24-hour fitness facility helps you make the most of your free time, and the outdoor pool offers family fun.

A wide array of guest services are provided to ensure that guests enjoy their stay to the fullest.



Hotel Amenities and Services

- ◆ 468 guest rooms
- ◆ Handicap-accessible rooms, reserved on a first-come, first-served basis
- ◆ High-speed (wired) Internet access available in all rooms (fee required)
- ◆ Free high speed internet access in Link@Sheraton (lobby business center)
- ◆ Free daily newspaper
- ◆ Coffee and tea maker
- ◆ Check-in time 3:00 p.m.; check-out time 11:00 a.m.
- ◆ Express check-out
- ◆ Completely smoke-free facility
- ◆ Indoor parking
- ◆ In-room movies
- ◆ Gift/Sundry shop
- ◆ Laundry/valet and dry cleaning services
- ◆ Tennis nearby (outdoor)
- ◆ Golf courses nearby
- ◆ Luggage storage and safe deposit boxes
- ◆ Concierge
- ◆ ATM

“Helping Hand” Financial Stipends



“Helping Hand” Financial Stipends are available to assist families in financial need with the cost of attending the conference. We encourage you to also seek support through your community’s organizations such as local family support agencies, service groups or churches.

A stipend application is enclosed with this packet. Applications are due at the Foundation office by June 15th, 2011. Stipend award amounts are determined after all applications are received and total available funding is confirmed. The stipend normally covers part, but not all, of the cost of travel and hotel for one participant and is intended to help ensure that one individual from each NPD family can attend the conference.

If you are applying for a stipend, please make your hotel reservations as soon as possible. Do not wait for notification of the stipend award, as the block may fill up and our special room rate will expire. **Stipend Application Deadline — June 15th, 2011**

Please mail your completed “Helping Hand” Stipend application to NNPDF; P.O. Box 49; Fort Atkinson, WI; 53538-0049; in time to arrive by the deadline, June 15th.

Norfolk Weather/What to Wear



Norfolk is nearly surrounded by the waters of the Chesapeake Bay. The city is situated at the mouth of three rivers — the James, Elizabeth and Nansemond Rivers —about 200 miles southeast of Washington, D.C.

July temperatures in Norfolk average 87F/30C for daily highs, and 71F/22C for daily lows. With such warm summer weather, outdoor activities, events and festivals abound. An average July in Norfolk will see rain about 11 days out of the 31, with four to five inches of precipitation throughout the month.

Pack light clothing to layer, in case a shower comes up or a temperature change occurs. Be sure to pack a cardigan or blazer, as air-conditioned meeting rooms can sometimes feel cool.

Attire for the Family Conference is business casual to casual. Wear what makes you comfortable, whether that is a skirt, khakis, blue jeans, or capris. You may want to pack something a little special for Saturday evening’s dinner and dance, but again, wear whatever makes you feel comfortable. The conference will be relaxed, family-oriented fun, as well as educational and inspirational!



Hospitals, Pharmacies, etc.

In Emergency DIAL 911

Hospitals/Urgent Care /Police

Sentara Leigh Hospital
830 Kempsville Rd.
Norfolk, VA 23502
(757) 261-6000

Sentara Norfolk General Hospital
600 Gresham Drive
Norfolk, VA 23507
(757) 388-3000

Urgent Care
Sentara Urgent Care
1326 East Little Creek Road
Norfolk, VA 23518
(757) 583-6338

City of Norfolk Police Department
Second Patrol Division
2500 N. Military Hwy.
Norfolk, VA
(757) 664-6900

Pharmacies/Dental/Optical

Walgreens Pharmacy (24 hours)
2232 E. Little Creek Road
Norfolk, VA 23518
(757) 480-4116

Walmart Pharmacy
1170 N. Military Hwy.
Norfolk, VA 23502
(757) 461-2125

Kool Smiles (Dentistry)
5900 E. Virginia Beach Blvd.
Norfolk, VA 23502
(757) 466-3622

Walmart Vision Center
1170 N. Military Hwy.
Norfolk, VA 23502
(757) 461-3268





Getting to Norfolk

The Internet makes comparison shopping for airfares simple. Some sites you might check out:

www.travelocity.com www.expedia.com www.orbitz.com www.kayak.com
www.priceline.com www.airfares.com www.cheapflights.com

We suggest that flight reservations be paid for with a credit card. Should an airline go out of business or cancel a flight, you may be able to dispute the charges and receive your money back. You can also purchase travel insurance through a travel agent or services such as AAA. Many airlines offer trip insurance on their Web sites.

Cancellation policies differ between airlines. Some airlines may honor tickets for one year from the date of issue, subject to an additional fee. (If the replacement ticket costs more than the original, the difference must also be paid.) Some airlines may charge a per person fee for any changes, plus any difference in the price of the new fare. Check with your airline for its specific policy.

Depending on your location, you may want to consider other modes of transportation, such as train or bus. Visit www.amtrak.com and www.greyhound.com for more information.

Norfolk International Airport

Norfolk International Airport (ORF) is located one mile east of I-64, just minutes from downtown Norfolk. Air service is available daily via American, Continental, Delta, Southwest, United Express and U.S. Airways.

The airport features food concessions from full-service menu dining to fast-food, gourmet coffee and desserts. Services include clothing and gift shops, newsstands, bank, business service center, foreign currency exchange, ATMs, wireless internet access, TDD phones, etc. Visit www.norfolkairport.com for more information.

Ground Transportation from the Airport: Continuous shuttle service to Norfolk hotels and attractions is offered, and taxi service is also available.

(Conference registrants will receive further details about shuttle service to and from the airport.)

Car Rental Agencies at Norfolk International Airport:

Alamo: 1-800-462-5266 www.alamo.com

Enterprise: 1-800-736-8227 www.enterprise.com

Avis: 1-800-831-2847 www.avis.com

Hertz: 1-800-654-3131 www.hertz.com

Budget: 1-800-527-0700 www.budget.com

National: 1-800-227-7368 www.nationalcar.com

Dollar: 1-800-800-4000 www.dollar.com

Thrifty: 1-800-367-2277 www.thrifty.com

What to See and Do in and around Norfolk

There are a thousand exciting things to do and see in the Norfolk area! While Norfolk embodies the cultural advantages of a much larger city, visitors are enchanted by its charm, historic past and friendly atmosphere. Below is just a small sampling of area attractions. For more information see www.visitnorfolktoday.com and www.virginia.org, search “Virginia tourism,” or search specific attractions by name.

Arts/Music/Theater

Chrysler Museum of Art
 Wells Theatre
 Harrison Opera House
 The NorVa
 Virginia Symphony

Children’s Interests

Busch Gardens Amusement Park, Williamsburg
 Children’s Museum of Virginia, Portsmouth

Historic Sites

Colonial Williamsburg
 Smithfield and Isle of Wight

Nature

Norfolk Botanical Garden with World of Wonders Children’s Garden Interactive Area
 Virginia Zoological Park with Zoo Train
 Virginia Aquarium, Virginia Beach
 Virginia Living Museum, Newport News
 Beaches

Naval/Maritime/Military

Nauticus, featuring the Battleship *Wisconsin*
 Hampton Roads Naval Museum
 U.S. Naval Station
 General MacArthur Memorial
 Armed Forces Memorial
 The Mariners’ Museum, Newport News
 Military Aviation Museum, Virginia Beach

Shopping

MacArthur Center Shopping Mall
 The Waterside Festival Marketplace

Sports

Rentals – bicycle, fishing boat, jet-ski, windsurfing
 Virginia Sports Hall of Fame and Museum, Portsmouth
 Golf
 Beaches, surfing

Touring

Harbor Cruises
 Cannonball Trail
 Segway rentals

