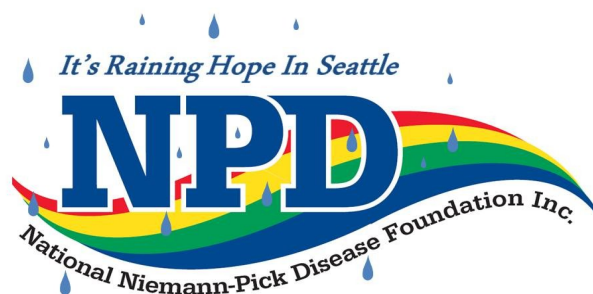


Destination Seattle 2009



**The bluest skies you've ever seen are in Seattle
And the hills the greenest green, in Seattle
Like a beautiful child, growing up, free and wild
Full of hopes and full of fears, full of laughter, full of tears
Full of dreams to last the years, in Seattle.**

Hugo Montenegro

Dear Friends and Family,

We are pleased and excited to invite you to the “Emerald City” of the northwest, also known as Seattle, Washington, for the 2009 National Niemann-Pick Disease Foundation Family Support and Medical Conference. The conference will be held July 30th - August 2nd at the Doubletree Guest Suites (www.seattledoubletree.com) in Seattle.

The hotel, located 3.6 miles from the Seattle-Tacoma International Airport, offers free shuttle service to and from the airport, and free parking at the hotel. The hotel will also offer complimentary rides to our new Sound Transit Light Rail Line (opening mid-July) for a quick zip to downtown Seattle! The Westfield Southcenter Shopping Mall is across the street from the Doubletree with 240 shops, 16-screen movie theater and 40 restaurants, all within walking distance. All rooms at the Doubletree are two-room suites, with wheelchair-accessible rooms available.

The Family Conference will offer valuable medical and research information in a warm, comforting atmosphere emphasizing emotional support and practical information. Along with the support of the Family Conference, you and your family will find the Seattle area has so many fun, exciting, educational and cultural opportunities!

Downtown, grab a cup at the original Starbucks and sip while you shop Pike Place Market, America's premier farmers' market, attracting 10 million visitors a year. Stroll the waterfront along Puget Sound, see the Seattle Aquarium, and watch the ferries and Alaskan cruise ships come and go. Take an elevator to the top of the Space Needle, (built for the 1962 World's Fair), dine in the revolving



restaurant and see the view of Seattle from the top of the Needle (on a clear day – priceless!).

Visit the Experience Music Museum and explore the creativity and innovation of popular music. Marvel at the breathtaking, precision flights of the U.S. Navy’s Blue Angels and the jaw-dropping power of the fastest boats in the world, all appearing at the Seafair festival July 31 – Aug 2. Schedule time for visits to the Boeing Museum of Flight and the Woodland Park Zoo. Above all, take in the wonders of Mt. Rainier National Park, Olympic National Park, and Mt. St. Helen’s National Volcanic Monument.

Our conference theme, “It’s Raining Hope in Seattle,” shouldn’t have you worrying about the weather! You have probably heard it rains a lot in Seattle. Yes, that is true, but July 31st is known locally as the driest day of the year, so you may not even see any raindrops while you are here!

Last year, prior to our conference in Atlanta, Melissa and Jimmy King gave us a “heads-up” about how Southerners make the English language their own. This year I will give you some insight into our local “Northwest-speak:”

- ◆ “Scattered showers with a chance of rain” -- drizzling rain with rain later in the day
- ◆ “Scattered clearing” -- rain with a chance of clear sky sometime during the day
- ◆ “Sunbreaks” -- chance of seeing the sun sometime during the day
- ◆ “Fog blanket” -- no chance of seeing the sun or sky during the day
- ◆ “The mountain is out” -- you are able to see Mt. Rainier for a time during the day
- ◆ “Tall, grande, venti” -- Starbucks lingo for small, medium and large
- ◆ “Coho, Chinook, Sockeye, Pink, Silver, King, Red, and Humpy” – Salmon 101
- ◆ “Fish tacos”-- try them - you will like them!

We are happy to be hosting the Family Conference in our hometown of Seattle. Our goal is to offer you the support you need and friendships to help you through the year. Please, come join us this summer in Seattle, where “It’s Raining Hope!”

We look forward to welcoming you in person to our “Emerald City,”

Karen and Gene Quandt

2009 NNPDF Family Conference Hosts

In honor of our son Ty (NPC ~ age 12)



Conference Deadlines

Hotel Reservations (make directly with Doubletree Guest Suites– see page 4 for details)	The block of rooms will be held until July 1st or until sold out , whichever comes first. We recommend you make your room reservations as soon as possible!
“Helping Hand” Stipend Applications	June 15, 2009
Conference Registrations	July 1, 2009
First-Time Fundraiser Contest Entries	July 1, 2009

Conference Schedule

The agenda for the 2009 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 start and end times of the conference have been established as follows:

Thursday, July 30	7:00 p.m.	Registration and Welcome Reception
Saturday, August 1	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, 2009.
- ◆ The 2009 contest year runs from July 1, 2008 —June 30, 2009. (Events must have been held during this time period.) First-Time-Fundraisers may have hosted more than one event during that time- frame, with proceeds from all events in that time frame 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 Doubletree Guest Suites 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 30—Aug 1).

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 Central Office at nnpdf@nnpdf.org or 920-563-0930 for more information and assistance.



Hotel Reservations

The 17th Annual NNPDF Family Conference will be held in Seattle, Washington, from Thursday, July 30 through Sunday, August 2nd, 2009, at Doubletree Guest Suites, 16500 Southcenter Parkway, Seattle, WA, 98188.

Room reservations must be made directly with Doubletree Guest Suites.

Rooms may be reserved online via a link at our Web site, http://www.nnpdf.org/familyservices_03.html, or by calling 800-222-TREE (8733), or 206-575-8220. Be sure to indicate that you are with the NNPDF conference, Group/Convention Code NIE. The NNPDF block will be held until July 1, or until the room block is sold out, whichever comes first.

The special discount rate of \$100 per night (plus taxes and fees) is available July 30 –August 1 (the three nights of the conference). Conference attendees may also take advantage of this special rate for three nights prior to and three nights after the conference (based on availability). **This special rate is limited to our block of rooms, so be certain to make your reservations early!**



Doubletree Guest Suites

16500 Southcenter Parkway
Seattle, WA 98188
800-222-TREE (8733)
206-575-8220 (direct)
www.seattle.doubletree.com
Group/Convention Code: NIE

~ At a Glance ~

Make your reservations directly with Doubletree — 800-222-TREE (8733) or via the link at http://www.nnpdf.org/familyservices_03.html

Special Room Rate — \$100 per night plus taxes and fees — Use Group/Convention Code: NIE

Special Rate also available three nights prior to, and three nights after, the conference dates.

Block Rate Offered Until July 1st or Until Sold Out ~ Limited Availability ~ Reserve Early!



Hotel Location, Highlights & Hotspots!

Doubletree Guest Suites is located in the heart of the state's best shopping district, across the street from Southcenter Mall, boasting 150 fine department stores and specialty shops.

The Space Needle, the waterfront's many attractions, and the many other shops and museums of downtown Seattle are just a few minutes away.

Only three miles east of Sea-Tac International Airport, the Doubletree offers complimentary shuttle service to and from the airport 24 hours a day, and a complimentary local shuttle within a five mile radius. For those who drive in or opt to rent a vehicle, the hotel has complimentary outdoor self-parking.

The hotel includes 221 two-room suites, rising eight stories around a dramatic atrium lobby. The Doubletree offers an indoor pool, sauna and spa, racquetball courts and exercise equipment. Also, the hotel has an on-site restaurant featuring seafood and pasta specialties, with over 40 additional restaurants within a ten-minute walk.

Hotel Features and Amenities

Two-room Suites

- ◆ Large living room with sofa bed
- ◆ Separate bedroom with king-size bed or two double beds
- ◆ Bathroom
- ◆ Wet bar and refrigerator
- ◆ Coffee maker with complimentary coffee and tea
- ◆ Two phones with voicemail and data ports
- ◆ Two televisions with pay-per-view movies and free HBO
- ◆ Large desk with ergonomic chair and desk-level electrical and data port outlets
- ◆ Electric door locks
- ◆ Iron and ironing board
- ◆ Hairdryer
- ◆ Individual climate control
- ◆ AM/FM clock radio
- ◆ USA TODAY each weekday morning
- ◆ Non-smoking and accessible rooms available

On-Site Facilities & Services

- ◆ 221 two-room suites
- ◆ Indoor pool, sauna and spa
- ◆ Racquetball courts and exercise equipment
- ◆ Northwest Landing Restaurant featuring seafood and pasta specialties
- ◆ In-room dining
- ◆ Complimentary shuttle service within a 3-mile radius, including to and from Sea-Tac Airport
- ◆ Atrium lobby
- ◆ High-speed Internet access
- ◆ Complimentary 24-hour business center
- ◆ Complimentary outdoor self-parking
- ◆ Outdoor pool available at the Red Lion Hotel across the street
- ◆ Instant check-in/check-out
- ◆ Check-in time 3:00 p.m.; check-out time 12:00 p.m.



“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 seek local support through your community’s organizations such as local family support agencies, service organizations or churches.

A stipend application is enclosed with this packet. Applications are due at the Foundation office by June 15th, 2009. 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, 2009

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.

Seattle Weather

It doesn’t really rain all the time in Seattle! Although it does rain a good bit of the time in the winter, summer is much more likely to bring sunny days. Average rainfall each of the winter months is 5-6 inches, but in summer, rainfall is only about an inch per month.

Summer temperatures in Seattle average a pleasant 75 degrees during the daytime, although an occasional heat wave can bring it up into the 80’s or even low 90’s. Evening lows in August average in the high 50’s to low 60’s. The best way to pack is to bring clothing to layer, because you never know when a sudden rainstorm or drop in temperature could occur.

Seattle-Tacoma International Airport

17801 Pacific Highway S
Seattle, WA 98158
1-800-544-1965



Seattle-Tacoma International Airport (also known as Sea-Tac Airport), is located in SeaTac, Washington, at the intersections of State Routes 518, 99, and 509. As the 18th-busiest airport in the United States, Sea-Tac served nearly 32.2 million passengers in 2008, on 31 airlines. Sea-Tac has one terminal with four concourses.



Preferred Airline Carriers

We have selected **Midwest Express** and **Alaska Airlines** as our preferred carriers.

Midwest Express

Midwest Express offers a 10% discount for conference attendees who purchase tickets at least 60 days in advance, and a 6% discount on tickets purchased within 60 days.*

Promo Code CMZ7188

Three convenient options for booking your flights on Midwest:



- ◆ Online: Visit midwestairlines.com and enter promo code **CMZ7188**
- ◆ Telephone: Call Midwest at 800-452-2022 and provide agent with promo code **CMZ7188**
- ◆ Travel Agent: Purchase tickets through a travel agent and request promo code **CMZ7188**

* Discount is valid from any city served by Midwest Airlines to the event city

* Reciprocal frequent flyer program with Northwest; however, discount does not apply to code share itineraries

Alaska Airlines

Alaska Airlines offers a 5% discount off normal fares and 10% off full coach or first class fares.

Space must be booked in the same class of service as the fare being discounted. All fare rules and blackout dates apply. Fare discounts are valid on Alaska and Alaska/Horizon combined itineraries only. Reservations must be made online at the Alaska Airlines Web site only.



Promo Code CMB0981

To book your flights on Alaska Airlines visit www.alaskaair.com and use **Promo Code CMB0981**.

We strongly suggest that all 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. Both Midwest Express and Alaska Airlines offer trip insurance at their Web sites.

If one needs to cancel their trip, Midwest tickets are good 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. Alaska Airlines tickets are good for one year from the original outbound date of travel, and can be changed for a \$100 per person change fee, plus any difference in the price of the new fare.



Ground Transportation

Doubletree Guest Suites, the site of our Family Conference, offers complimentary shuttle service to and from Sea-Tac Airport, and to destinations within a three-mile radius of Doubletree.

Upon arrival at Sea-Tac Airport, after collecting your baggage, call the hotel at 206-575-8220 and request the shuttle. There is a bank of telephones at the 3rd floor "Shuttle Pick Up" area. The Pick Up area has three islands, with the Doubletree Shuttle picking up at islands #1 and #3 only.

Please Note: There is another Doubletree Hotel (in closer proximity to the airport). Be sure you board the correct shuttle, bound for Doubletree Guest Suites, 16500 Southcenter Parkway.

Ground Transportation Information Booths are located at the north and south ends of the airport's Baggage Claim area at Doors 6 and 26.

Sea-Tac International Airport is served by King County Metro Transit bus system and Sound Transit regional express buses. Taxis, rental cars and door-to-door shuttle services are available. No train service is available from Sea-Tac Airport.

Car/Taxi: Sea-Tac Airport is located 13 miles south of Seattle and 20 miles north of Tacoma. Travel time is around 20-30 minutes to Seattle. Taxis are available on the third floor of the parking garage. Courtesy phones are available curbside. Fare is approximately \$30 to Seattle.

Bus/Van: The Airport Express bus service has departures every 30 minutes to many area hotels, leaving from outside Baggage Claim area at Doors 6 and 26. Fare: \$8.50 one way; \$14 round trip. The Sound Transit bus has frequent service to downtown Seattle, leaving from Door 6 on the Baggage Claim level. Fare \$1.25—\$2.00 one way. Several other shuttle services operate almost around the clock. Shuttle Express offers shared ride, door-to-door service.

Rental Cars: Nine rental car companies have information counters in the Baggage Claim area, and five have car pick-up and drop-off at the airport on the first floor of the garage across from the Main Terminal. In addition, off-airport rental car companies provide courtesy van service to the airport.

On-site rental counter and cars:

Alamo 1-800-462-5266

Avis 1-800-331-1212

Budget 1-800-527-7000

Hertz 1-800-654-3131

National 1-800-227-7368

On-site rental counter, off-site cars:

Dollar Car Rental 206-433-5825

Enterprise 206-246-1953

Thrifty 877-283-0898



Hospitals/Medical Facilities, etc.

Valley Medical Center—Emergency Department and Pharmacy (3.17 mi)
400 S. 43rd Street
Renton, WA 98055
425-251-5185
www.valleymed.org

Highline Medical Center (5.34 mi)
16251 Sylvester Rd SW
Burien, WA 98166
206-244-9970
www.highlinemedicalcenter.org

Harborview Medical Center (12.06 mi)
325 Ninth Avenue
Seattle, WA 98104
206-744-3000
<http://uwmedicine.washington.edu/Facilities/Harborview/>

Seattle Children's Hospital, Research & Foundation (17.39 mi)
4800 Sand Point Way NE
Seattle, WA 98105
206-987-2000
www.seattlechildrens.org

Northwest Hospital & Medical Center (19.90 mi)
(main campus)
1550 N. 115th Street
Seattle, WA 98133-9733
206-364-0500
www.nwhospital.org

Target (Pharmacy and Groceries) (0.3 mi)
301 Strander Blvd
Tukwila, WA 98188
206-575-0682
www.target.com

Safeway (Pharmacy) (1.7 mi)
4011 S. 164th
Seattle, WA 98188
206-244-2567
www.safeway.com

West Valley Dental (1.39 mi)
15668 W. Valley Hwy.
Tukwila, WA 98188
425-430-9099
www.westvalleydental.com

Sears Optical (0.49 mi)
644 Southcenter
Seattle, WA 98188
206-241-3486
www.searsoptical.com





Local Attractions

Fun Things to See and Do in Seattle

Sometimes the difference between ordinary and amazing is where it happens.

Seattle is anything but ordinary! It's a place where bike messengers share elevators with world-renowned researchers. Where fishermen have lunch alongside top surgeons. It's a city where the extraordinary is commonplace and commonplace is anything but.

From a jet engine to an espresso machine to grunge rock, Seattle's world-changing events have all had a distinct sound. Your visit to Seattle may bring you the sound of an orca blowing as it surfaces, the roar of the crowd at Safeco Field or the near-silence of the Olympic rainforest. Come to Seattle and hear for yourself!

Below are just a smattering of Seattle-area attractions. For much more info, including suggested itineraries, visit <http://www.visitseattle.org/>. Truly, Seattle offers something for every interest!

University of Washington Botanic Gardens—Washington Park Arboretum — a spectacular urban green space on the shores of Lake Washington, just east of downtown Seattle, containing internationally recognized woody plant collections on 230 acres. North America's largest collection of Sorbus and Maple, the second largest collection of Hollies and significant collections of oaks, conifers and camellias.

Future of Flight Aviation Center and Boeing Tours — 25 miles north of Seattle, 90-minute tours seven days a week. Advance notice required for wheelchair/physically-challenged accommodation; children must be at least 4 feet tall and visitors may not carry babies on the tour; no child-care facilities on-site. Check for additional safety regulations. No exceptions to safety regulations.

Seattle Locks Cruise and Sightseeing Tour — 2 1/2 hour locks tour; cruise connects the salt water of Puget Sound and the fresh water of Lake Union. Narration of Seattle's history, view of historic waterfront and spectacular skyline and majestic Cascade and Olympic mountain ranges.

Wild Waves & Enchanted Village — 70-acre combination theme park and water park featuring 32 amusement rides, nine water slides, wave pool, speed slides, raging river, and the five-story Zooma Falls adventure.

Pike Place Market — Seattle's number one tourist draw; public farmers' market is the hub of waterfront activity since Seattle's early days. The market draws up to 40,000 visitors on summer Saturdays. Street performers, craftsmen, artists, florists, fruit vendors, specialty food shops, fish. Shop, dine, stroll.

Qwest Field — Home of the Seattle Seahawks; 67,000 seat capacity; sit in a luxury suite, suit-up in the visitor's locker room, and set foot on the Next-Generation Field Turf. Ninety-minute tours are fully wheelchair accessible.

Snoqualmie Falls — one of Washington state's most popular scenic attractions with more than 1.5 million visitors every year; two-acre park, hiking trail, observation deck, gift shop, and the famous 270-foot waterfall.

Space Needle — built for the 1962 World's Fair; 605 feet tall, 138 feet wide, weighing 9,550 tons, built to withstand winds up to 200 mph and earthquakes up to 9.5 magnitude. Observation deck, gift shop, rotating restaurant.

Victoria Clippers — Victoria, British Columbia, Canada, is as close as 2.5 hours, year-round, via the Clippers. During summer, Clipper also offers daily orca whale-watching trips with a stop on San Juan Island.

For more information, visit <http://www.visitseattle.org/>