



May 2017

Dear Friends and Families of the NNPDF,

The National Niemann-Pick Disease Foundation (NNPDF) is pleased to invite you to the 25th Annual NNPDF Family Conference in Rosemont, Illinois from August 10 to August 13, 2017, at Hilton Rosemont/Chicago O'Hare. Please mark your calendar and make plans now to join us for this informative family conference.

Over the past 7 months, we have accomplished a great deal and believe this transition time has been a necessary and valuable investment that will pay off in the long term for this reinvention plan. We believe this is a critical moment in our history for us to come together and embrace a new and hopeful vision for all families affected by Niemann-Pick diseases. We will be presenting our ideas for the future vision at the family conference in Rosemont, Illinois from August 10-13, 2017. It is our hope that you can all join us for this exciting time of gathering and rebuilding.

At the conference, we will explore our shared values and develop the principles that we commit to as members. The conference program theme will focus on our future goals as a community, including family services, advocacy, the role of pharmaceutical companies, as well as updates. It will also include a greater focus on break out sessions that will be designed to support families in the daily challenges that come from living with NPD. More information on program details will be coming to you in the coming days before the conference.

More importantly, the NNPDF Annual Family Conference allows you to personally meet and foster connections with other families affected by Niemann-Pick Disease. Nothing compares to the opportunity to meet face-to-face with those who are dealing daily with challenges similar to your own. Our family membership often indicate that the highlight of the conference is meeting and reconnecting with other NPD families, then building upon these bonds as a result of this shared experience.

The NNPDF Central Office has developed a web page that includes 2017 Family Conference information including the 2017 Family Conference packet, registration, and hotel reservation information to assist in your trip planning. Visit the Family Conference web page for access to these links and more at [nnpdf.org/2017fc](http://nnpdf.org/2017fc).

Please be sure to register and remit your conference fees by July 13, 2017. Please note that the block of hotel rooms at the special conference rate will be held only until July 19, 2017 or until the block is filled, whichever occurs first. As always, please don't hesitate to contact the NNPDF Central Office if you have any questions or concerns regarding the Family Conference. We are here to help. Call 920-563-0930 or toll-free 877-287-3672; or email [nnpdf@nnpdf.org](mailto:nnpdf@nnpdf.org).

See you in Rosemont!

Lisa Chavez  
On behalf of the NNPDF Board and Staff



## NNPDF 25th Family Annual Conference

The 25th Annual Family Conference dates are **August 10 -13, 2017**. We will join together this year at the **Hilton Rosemont Chicago O'Hare** at 5550 N River Road in Rosemont, Illinois. The Hilton is located just moments from O'Hare International Airport and a 10 minute walk to the CTA Blue Line station providing convenient access to beautiful downtown Chicago a short 20 miles away.

Conference details are now online on the NNPDF 2017 Family Conference web page at [nnpdf.org/2017fc](http://nnpdf.org/2017fc) including the 2017 family conference packet, registration and hotel reservation information. Additional information will be updated as it becomes available.

### Conference Deadlines

**Conference Registration and Fees:** Thursday, July 13, 2017  
**Hotel Reservations** See page 4 for information: Wednesday, July 19, 2017

**NOTE:** Handicap-accessible rooms, cribs, and mini refrigerators (available at no cost to those with medical needs) will be filled on a first-come, first-served basis. The block of rooms will be held until Wednesday, July 19, or until sold out, whichever comes first.

**Make your room reservations as soon as possible!**

### Conference Registration Information

Online registration is now open. Visit our 2017 Family Conference web page at [nnpdf.org/2017fc](http://nnpdf.org/2017fc) and follow the registration link to register online. Both credit card and pay by check payment options are available for your convenience.

Your complete registration includes our Thursday evening reception, Friday and Saturday lunch, and the Saturday evening Gala Event. Breakfast vouchers for Friday and Saturday will be provided at the front desk upon check in. See the table below for the 2017 registration fees.

Questions? Contact the NNPDF at [nnpdf@nnpdf.org](mailto:nnpdf@nnpdf.org) or 877-287-3672.



REGISTRATION FEES	
Immediate Family Member or Caregiver - ADULT	75.00
NPD Diagnosed Individual	No Charge
Immediate Family - CHILD 6 to 17 Years	\$50.00
Immediate Family - CHILD 0 to 5 Years	No Charge
Extended Family, Friend, Educator, Medical Professional, Other	\$100.00
Pharmaceutical or Corporate Representative	\$450.00
ONLY Saturday Gala Event (No Conference) - ADULT	\$50.00
ONLY Saturday Gala Event (No Conference) - CHILD 6 to 17 Years	\$25.00

## Light of Hope Candle Lighting Ceremony



The “Light of Hope” Candle Lighting Ceremony and Commemoration is presented in memory of all the loved ones we have lost to NPD since our last gathering. This ceremony will be held on Thursday evening after registration, the welcome reception, introductions, and a short welcome program. Complimentary adult supervision will be available during this time in the Activity Zone. Families are invited to bring photos, memory books, etc., of their loved one with NPD to share with other families in attendance.

## Activity Zone

Complimentary care and activities for children and young adults of all ages will be provided during conference sessions (with breaks for lunch) for all families.

The volunteers staffing the Activity Zone 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. The Activity Zone offers a variety of activities, games, crafts, videos, friendship and FUN. If your children or young adult enjoys a particular activity or game, please feel free to bring it along to share with their friends.

Any child taking part in activities in the Activity Zone room MUST be pre-registered and will be signed in and out by their OWN parent or guardian. Volunteer staff are not allowed to administer medications or give feedings. Upon registration confirmation, the NNPDF Central Office will be in contact with you to complete the necessary registration information for those attending the Activity Zone.



## First Time Family Conference Attendee Helping Hand Financial Stipends

Helping Hand Financial Stipends are reserved for NNPDF (U.S. and Canada) registered families who are attending the NNPDF Family Conference for the first time and require financial assistance to be able to attend. Stipend award amounts are determined after all applications are received and total available funding is confirmed. We encourage you to also seek support through your local community organizations, such as, local family support agencies, service groups or religious organizations.

Please contact the NNPDF Central Office at [nnpdf@nnpdf.org](mailto:nnpdf@nnpdf.org) if you are a first time attendee in need of financial assistance to attend the conference and would like to apply for a helping hand stipend.

**If you are applying for a First Time Family Conference Attendee Helping Hand 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.**



## Hilton Rosemont/Chicago O'Hare Reservations

The 25th Annual NNPDF Family Conference will be held Thursday, August 10 through Sunday, August 13, 2017, at the Hilton Rosemont/Chicago O'Hare, 5550 N. River Road, Rosemont, Illinois.

Room reservations **MUST** be made directly with Hilton Rosemont/Chicago O'Hare. Reservations can be made by calling **1-888-452-6943** and use the code **NNP**. To reserve your room online click [Hotel Reservations](#). The NNPDF block will be held until **Wednesday, July 19th**, or until the room block is sold out, whichever comes first.

\*Please be sure to alert the hotel of any special requests that you may have (ie: handicapped accessible rooms, roll-away beds, mini-fridge, crib etc.) Handicap-accessible rooms, cribs, and mini refrigerators (for those with medical needs) will be filled on a first-come, first-served basis.

The special discount rate is available for the conference and apron dates of Tuesday, August 8, 2017 through Monday, August 14, 2017, based on availability.

**\* FOR HANDICAP-ACCESSIBLE ROOM REQUESTS:  
Please contact Hotel Representative Shantella Garrett directly at 1-847-928-6177.**

### Special Family Conference Hotel Rate:

The hotel room is **\$129.00** plus tax & fees per room, per night at the time you book. Total cost to attendees is  $\$129.00 + 14\% / \$18.06$  (tax & fees) = **\$147.06** per night.

The cost of each room includes the following:

- ◆ Complimentary Wi-Fi in all guest rooms.
- ◆ Complimentary use of the fully equipped 24-hour Life Fitness Center including a heated pool.
- ◆ Complimentary cribs and mini-refrigerators (for those with medical needs).  
**Please reserve when making your reservation as limited quantities are available.**
- ◆ Check in is at 3:00 pm. Check out is at 12:00 pm.
- ◆ Free area shuttle 7am to 11pm upon request, based on availability.
- ◆ Discounted self-parking at \$13.00 per day.

**RESERVE  
YOUR ROOMS  
EARLY!**

---

**Deadline is:  
July 19, 2017!**



**Hilton Rosemont/Chicago O'Hare**  
5550 N River Road, Rosemont, Illinois | Direct Line: **1-888-452-6943**

## Shuttle Service Instructions to Hilton Rosemont/Chicago O'Hare

The Hilton Rosemont/Chicago O'Hare provides daily complimentary shuttle service to and from O'Hare International Airport for our guests. The shuttle operates between the hours of 4:05 am until 1:45 am in 20 minute intervals.

**DOMESTIC ARRIVALS:** Upon arrival at Chicago O'Hare, retrieve your luggage from the baggage claim area located on the lower level of the airport.

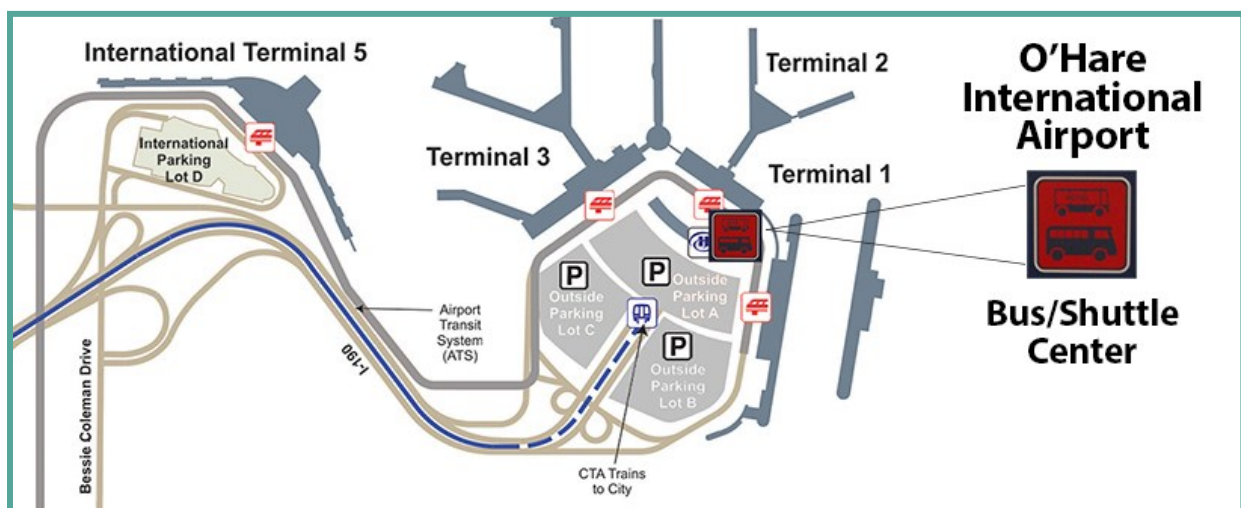
From the baggage claim area, take the stairs or elevator down one level and follow the overhead signs to the Bus/Shuttle Center. You will be directed to an elevator bank. Once inside the elevator, select the Bus/Shuttle Center and Chicago Cubs floor.

Proceed to the Bus/Shuttle Center – **Door #3**

The shuttles are white vans and are identified with the logos of the Hilton Rosemont/Chicago O'Hare, DoubleTree Rosemont, and Embassy Suites Rosemont.

**INTERNATIONAL ARRIVALS:** Upon arrival, call the Hotel directly at 847-678-4488 to arrange shuttle pick up. Pick Up takes place from **Terminal 5 at Door #5-E..**

**RETURN TRIP TO O'HARE:** The shuttle departs from the hotel's main lobby doors every 20 minutes beginning 5 minutes after the hour :05, :25, :45.





## Getting to the Rosemont Area

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

- [travelocity.com](http://travelocity.com)    [expedia.com](http://expedia.com)    [orbitz.com](http://orbitz.com)    [kayak.com](http://kayak.com)  
[priceline.com](http://priceline.com)    [airfares.com](http://airfares.com)    [cheapflights.com](http://cheapflights.com)

We suggest that you pay for airline tickets 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](http://www.amtrak.com) and [www.greyhound.com](http://www.greyhound.com) for more information.

## Chicago O’Hare (ORD)

The historic O’Hare International Airport complex resides on over 7,200 acres and is located within the City of Chicago. As of January 2015, there are 188 gates at O’Hare. The major hub carriers are American Airlines and United Airlines. It is one of the busiest airports in the world in terms of number of annual aircraft operations. Once you disembark the opportunities are endless as to what you can see in the surrounding region. **PLEASE NOTE:** Southwest only flies into the smaller Midway Airport, and would include a \$60 one-way cab ride to the hotel.

Car Rental Agencies at Chicago O’Hare (ORD) Airport	
<b>Advantage</b> 1-847-635-8031 <a href="http://advantage.com">advantage.com</a>	<b>Enterprise</b> 1-847-928-3320 <a href="http://enterprise.com">enterprise.com</a>
<b>Alamo</b> 1-888-826-6893 <a href="http://alamo.com">alamo.com</a>	<b>Hertz</b> 1-773-686-7272 <a href="http://hertz.com">hertz.com</a>
<b>Avis</b> 1-888-849-0277 <a href="http://avis.com">avis.com</a>	<b>National</b> 1-877-222-9058 <a href="http://nationalcar.com">nationalcar.com</a>
<b>Budget</b> 1-800-621-2380 <a href="http://budget.com">budget.com</a>	<b>Payless</b> 1-224-220-0604 <a href="http://paylesscar.com">paylesscar.com</a>
<b>Dollar</b> 1-866-434-2226 <a href="http://dollar.com">dollar.com</a>	<b>Thrifty</b> 1-877-283-0898 <a href="http://thrifty.com">thrifty.com</a>



## What to See and Do in the Greater Chicago Area

So many things to do and so little time!

There are so many things to do in the Chicago area that there is literally not enough time. Not only are there things to do in Chicago, but in the City of Rosemont right near the 2017 NNPDF Family Conference Hotel. Don't forget if an attraction is within 5 miles of the hotel, the hotel shuttle can transport you upon request, based on availability.

Within walking distance of the hotel you can visit:

- |                                    |                      |
|------------------------------------|----------------------|
| Fashion Outlets of Chicago         | Rosemont Theater     |
| Kings Lanes & Lounge Bowling       | Rivers Casino        |
| Rockin in the Park Summer Concerts | Muvico Movie Theatre |

## Take a Day Trip...to the bustling city of Chicago!

Hilton Rosemont/Chicago O'Hare is located in Rosemont, which is only 20 miles from the beautiful city of Chicago! We encourage our families to take this opportunity to explore all the city of Chicago has to offer to make your trip one to remember!

- |                                     |                                     |
|-------------------------------------|-------------------------------------|
| Art Institute of Chicago            | Navy Pier                           |
| Chicago History Museum              | Pirate's Cove Children's Theme Park |
| Field Museum of Natural History     | Shedd Aquarium                      |
| Lake Park                           | West Park                           |
| Legoland Discover Center            | Windella Sightseeing Boats          |
| Magnificent Mile Shopping           | Wolff's Flea Market                 |
| Museum of Science & Industry        | Wonder Works                        |
| Mystic Waters Family Aquatic Center |                                     |

## Rosemont Weather... What to Wear

August temperatures in Rosemont average 83F/28C for daily highs, and 67F/19C for nightly lows.

Pack light clothing to layer, in case a shower pops up or a temperature change occurs. Your friends from the Great Lakes area want to remind you to be certain to pack a sweater, 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.

Saturday evening's dinner/dance Gala Event is an opportunity to gather in celebration and many in attendance enjoy dressing up to make the evening special.

The conference will be a relaxed, family-oriented fun, as well as educational and inspirational!