



National Niemann-Pick Disease Foundation, Inc.
17th Annual Family Support and Medical Conference
Seattle, Washington
Thursday, July 30—Sunday, August 2, 2009
Conference Agenda
Thursday, July 30th, 2009

Time	Activity and Location	Attendees/Speaker
7:30—8:00 am	Grand Rounds <i>~Seattle Children's Hospital~</i>	Dr. Marc C. Patterson
9:00 am—12:00 pm	NNPDF Board Meeting <i>~ Sunrise Room ~</i>	NNPDF Board Members
12:00 —1:30 pm	Luncheon <i>~Sunrise Room~</i>	NNPDF Board, Scientific Advisory Board, Invited Guests
1:30—2:00 pm	NNPDF Board Meeting with Scientific Advisory Board (SAB) <i>(Closed Session) ~Sunrise Room~</i>	NNPDF Board Members SAB Members
2:00—4:00 pm	Scientific Advisory Board Meeting <i>(Closed Session)</i> <i>~Sunrise Room~</i>	SAB Members
2:00—5:00 pm	NNPDF Board Committee Meetings <i>~Conference Room Suites 1202 & 1203~</i>	NNPDF Board and Committee Members
4:30—6:00 pm	NNPDF Research Committee Meeting with Dr. Dan Ory, SAB Chair <i>(Closed Session)</i> <i>~Sunrise Room~</i>	NNPDF Research Committee Members and Dr. Ory
6:30—10:30 pm	NNPDF "Store" Open (Persevere Wear and Other Products) <i>~Elevator Foyer~</i>	Conference Volunteers

17th Annual NNPDF Family Support and Medical Conference
Thursday, July 30th, 2009, continued

Time	Activity and Location	Attendees/Speaker
7:00—8:00 pm	Conference Registration ~Dallas/Phoenix Foyer~	All Conference Attendees
7:30—8:00 pm	First-Time Conference Attendees & New Family Orientation ~Summit Room I & II~	First-Time Conference Attendees, NNPDF Board Members & other Mentors
8:00—10:00 pm “Greets & Treats” Cash Bar	Welcome Reception ~Monterey Room~ Greetings and Welcome to Seattle! Welcome from Our Foundation Chair Introductions Board Members & Special Guests Scientific Advisory Board (SAB) NNPDF Coordinator for Education, Referral and Advocacy NNPDF Family Membership Conference Volunteers	All Conference Attendees Karen and Gene Quandt, 2009 Conference Hosts Barb Vorpahl, NNPDF Chair Barb Vorpahl Susan Green Cate Walsh Vockley Nadine Hill Karen Quandt
9:00—9:05 pm	Break	
9:00—9:30 pm	Childcare Activity Room Open ~Summit Room I & II~ (Open during the “Light of Hope” Ceremony)	Childcare Volunteer Staff
9:05—9:20 pm	Light of Hope — Candlelighting Ceremony A special time to remember those lost to NPD during the past year <i>Supervision for children who may not wish to attend the candlelighting is available in the Child-care Activity Room</i>	Karen and Gene Quandt <i>Special thanks to Lisa Chavez, Mom to Breann (NPC), for the handmade memorial candles.</i>
9:30—10:00 pm	Childcare Activity Room Open House ~Summit Room I & II~ <i>Come and see all the wonderful activities Karen, Brenda and Adelina have planned for the kids and young adults!</i>	Childcare Volunteer Staff
9:20—10:00 pm	Family Gathering and Fellowship	All Conference Attendees

17th Annual NNPDF Family Support and Medical Conference
Friday, July 31st, 2009

Time	Activity and Location	Attendees/Speaker
7:30—9:00 am	Various NNPDF Board Committee Meetings ~Conference Room Suites 1202 & 1203~	Committee Members — Please check with your committee chair for specifics
8:00—8:45 am	Volunteer Childcare Staff Training/Orientation ~Childcare Activity Room/Summit Room~	Brenda Teller ~ CAR Coordinator Volunteer Childcare Staff
8:00—9:00 am	Late Registration ~Dallas/Phoenix Foyer~ Fresh coffee and hot tea refreshments	Nadine Hill Conference Volunteers
8:00 am—5:30 pm	NNPDF “Store” Open (Persevere Wear and Other Products) ~Dallas/Phoenix Foyer~	Conference Volunteers
8:45 am—12:00 pm	Childcare Activity Room Open ~Summit Room I & II~	Volunteer Childcare Staff
9:00—10:40 am	<p><u>Concurrent Sessions</u></p> <p>Niemann-Pick Disease Research Updates Current and ongoing research Progress since the 2008 conference What research shows the most promise? How can this help my child and when?</p> <p>NPD Type A & B Research Updates ~Paradise Room~ Dr. Edward Schuchman — “New Research Developments in ASMD Niemann-Pick Disease” Cyndi Frank— “The Gaucher Experience”</p> <p>NPD Type C Research Updates ~Dallas/Phoenix Rooms~ Dr. Dan Ory— “New Research Developments in Niemann-Pick Disease Type C” Dr. Steve Walkley— “Cyclodextrin and NPC” Dr. Denny Porter— “Biomarker validation study in Niemann-Pick Disease Type C”</p>	<p>All Conference Attendees</p> <p>NPD Type A & B (ASMD) Families Dr. Edward Schuchman Cyndi Frank, Gaucher Foundation</p> <p>NPD Type C Families Dr. Dan Ory, Dr. Steve Walkley, Dr. Denny Porter</p>
10:40—11:00 am	Break — Beverage refreshments ~Dallas/Phoenix Foyer~ Fresh coffee and hot tea refreshments	

17th Annual NNPDF Family Support and Medical Conference
Friday, July 31st, 2009, continued

Time	Activity and Location	Attendees/Speaker
11:00—12:00 pm	<p><u>Joint Session</u> Research Panel Discussion <i>~Dallas/Phoenix Rooms~</i> Members of the Scientific Advisory Board and special guests will respond to the specific scientific and research questions submitted by conference attendees</p>	<p>NPD Types A and B (ASMD) and Type C Families</p> <p>Panel members will include: Dr. Dan Ory, Dr. Steve Walkley, Dr. Marie Vanier and Dr. Edward Schuchman</p>
12:00—2:00 pm	<p>Lunch Members of our Scientific Advisory Board (SAB), Specials Guests and the NNPDF Members of the Board will be available to network and answer questions you may have during lunch <i>~Monterey Room~</i></p>	All Conference Attendees
12:30—2:00 pm	<p>Grand Rounds <i>~Seattle Children's Hospital~</i></p>	Dr. Marie Vanier
1:45—5:00 pm	<p>Childcare Activity Room Open <i>~Summit Room I & II~</i></p>	Volunteer Childcare Staff
Until 5:30 pm	<p>NNPDF "Store" Open (Persevere Wear and Other Products) <i>~Dallas/Phoenix Foyer~</i></p>	Conference Volunteers
2:00—3:30 pm	<p><u>Joint Session</u> Dealing with a Diagnosis of Niemann-Pick Disease <i>~Dallas/Phoenix Room~</i> Author, chaplain and breast cancer survivor Debra Jarvis will present an insightful, inspirational and good-humored message about facing the realities of a Niemann-Pick Disease diagnosis</p>	<p>All Conference Attendees</p> <p>Debra Jarvis</p>
3:30—3:45 pm	<p>Break <i>~Dallas/Phoenix Foyer~</i> Refreshing iced tea and lemonade</p>	All Conference Attendees
3:45—5:00 pm	<p><u>Joint Session</u> Empowerment Taking charge after a diagnosis of NPD <i>~Dallas/Phoenix Room~</i></p>	<p>All Conference Attendees</p> <p>Guest Speakers</p>

17th Annual NNPDF Family Support and Medical Conference
Friday, July 31st, 2009, continued

Time	Activity and Location	Attendees/Speaker
5:00 pm	Dinner on Your Own Join up with other families for a dinner out on the town ~ Refer to the Seattle Dining Guide in your conference packet	All Conference Attendees
7:00—8:30pm	Ice Cream Social <i>Join us for yummy ice-cream treats, family networking and games for all.</i> ~On the lawn ~ Doubletree Guest Suites~	All Conference Attendees

17th Annual NNPDF Family Support and Medical Conference
Saturday, August 1st, 2009

Time	Activity and Location	Attendees/Speaker
7:00—9:00 am	NNPDF Board & Committee Meetings 7:00—8:00am Finance Committee Meeting 8:00—9:00am NNPDF Full Board Meeting ~ <i>Sunrise Room</i> ~	Committee Members—Please check with your committee chair for specifics NNPDF Board Meeting ~ Special Guest Speaker Cyndi Frank—Gaucher Foundation
8:30—9:00 am	Late Registration ~ <i>Dallas/Phoenix Foyer</i> ~ <i>Fresh coffee and hot tea refreshments</i>	Nadine Hill Conference Volunteers
8:30 am—3:30 pm	NNPDF “Store” Open (Persevere Wear and Other Products) ~ <i>Dallas/Phoenix Foyer</i> ~	Conference Volunteers
8:45 am—12:00 pm	Childcare Activity Room Open ~ <i>Summit Room I & II</i> ~	Volunteer Childcare Staff

17th Annual NNPDF Family Support and Medical Conference
Saturday, August 1st, 2009, continued

Time	Activity and Location	Attendees/Speaker
9:00—10:40 am	<p><u>Concurrent Sessions</u> NPD Medical and Clinical Updates</p> <p>NPD Type A & B (ASMD) Medical and Clinical Updates <i>~Paradise Room~</i> Dr. Margaret McGovern—Living day-to-day with ASMD/NPD and updates on the Genzyme-sponsored clinical trials Dr. Edward Schuchman—ASMD vs. NPD — Why the name change?</p> <p>NPD Type C Medical and Clinical Updates <i>~Dallas/Phoenix Rooms~</i> Dr. Marc Patterson—Zavesca trial — What is next?; Update on the NPC International Patient Registry sponsored by Actelion Dr. Denny Porter—NIH NPC Natural History Study; NIH Neurological Diseases and NPC (Dr. Sidransky NIH study)</p>	<p>All Conference Attendees</p> <p>NPD Type A & B (ASMD) Families Dr. Margaret McGovern Dr. Edward Schuchman</p> <p>NPD Type C Families Dr. Marc Patterson Dr. Denny Porter</p>
9:00—10:40 am	<p>Bereavement Session Kathy Kovich, Licensed Counselor <i>~Sunrise Room~</i> An opportunity for those families who have lost a loved one to NPD to join other parents and family members for an open and supportive discussion of the long term issues facing families during the bereavement process.</p>	<p>Families who have lost a loved one Kathy Kovich</p>
10:40—11:00 am	<p>Break — Beverage Refreshments <i>~Dallas/Phoenix Foyer~</i> Fresh coffee and hot tea refreshments</p>	<p>All Conference Attendees</p>
11:00 am—12:00 pm	<p><u>Joint Session</u> Medical and Clinical Panel Discussion <i>~Dallas/Phoenix Rooms~</i> Medical and clinical specialists will respond to the specific medical and clinical questions submitted by conference attendees Panel members will include: Dr. Margaret McGovern, Dr. Marc Patterson, Dr. Denny Porter, Nicole Yanjanin, Cate Walsh Vockley, Sandra Cowie, and Sara Kerrick</p>	<p>NPD Types A and B (ASMD) and Type C Families</p>

17th Annual NNPDF Family Support and Medical Conference
Saturday, August 1st, 2009, continued

Time	Activity and Location	Attendees/Speaker
12:00—2:00 pm	Lunch ~Monterey Room~	All Conference Attendees
1:00—2:30 pm	Childcare Activity Room Open ~Summit Room I & II~	Volunteer Childcare Staff
1:00—2:00 pm	Board of Directors Meeting NNPDF Board Executive Committee with SOAR Parents (Closed Session) ~Sunrise Room~	NNPDF Board of Directors
1:15—2:00 pm	<u>Concurrent Sessions</u> Dealing with Dementia Kathy Kovich, Licensed Counselor ~Paradise Room~ Physical Therapy Questions Sara Kerrick, Physical Therapist ~Rainier Room~ Moms' Session Judy DeSouza ~Dallas/Phoenix Room~ Dads' Session Jim Ward ~Dallas/Phoenix Room~	All Conference Attendees Kathy Kovich Sara Kerrick Judy DeSouza Jim Ward
2:00—3:00 pm 3:00—5:00pm	NNPDF Board Meeting (Closed Session) ~Sunrise Room~ Various NNPDF Committee Meetings ~Sunrise Room, Rainier Room & Conference	NNPDF Board Members
2:00—6:00 pm	Free Time for Families to Explore Seattle Look for tourism information in your conference packet	

17th Annual NNPDF Family Support and Medical Conference
Saturday, August 1st, 2009, continued

Time	Activity and Location	Attendees/Speaker
6:00—6:30 pm	Reception — Cash Bar ~Monterey/Phoenix Rooms~	All Conference Attendees
6:30pm-12:00am	Family Celebration Banquet ~Monterey/Phoenix Rooms~	All Conference Attendees
6:30—7:30 pm	Banquet Dinner	
8:00 pm—Midnight	Conference Wrap-Up and Farewell Introductions: Special Guests and Thank You's Farewell until 2010 Family Conference Announcement of 2010 Conference Location DJ ~ Matt O'Neill Family Dance Extravaganza Celebrating Our Children A family celebration for all! Singing, dancing and an opportunity to celebrate new-found friendships and to reconnect with friends of old.	



Many, many thanks to our 2009 Family Conference Hosts,
Gene and Karen Quandt!
We appreciate all the hard work you have put into this wonderful opportunity for families affected by Niemann-Pick Disease to come together to learn and share and support each other.
Thank you from the bottom of our hearts!