

**NNPDF Informational Conference Call/Webinar with the National Institutes of Health (NIH)
on Niemann-Pick Disease Type C (NPC)
Monday, May 2, 2011
4:00 p.m. Central Time (5:00 Eastern, 2:00 Pacific)**

Instructions for Participants

On Monday, May 2, 2011, the NNPDF will host a conference call/Webinar (online meeting) with key constituents and researchers, for all interested parties in the Niemann-Pick Disease Type C (NPC) community to learn more about the work being done at the NIH. Parents and extended family members, clinicians, researchers, caregivers, educators, and anyone with an interest in NPC is invited to participate.

Agenda topics for the conference call/Webinar are expected to include: NPC Observational Study at the NIH; development of NPC biomarkers; the NAC trial; use of a blood test for NPC diagnosis; and the current effort at TRND/NIH toward developing plans for a cyclodextrin trial at NIH. Presenters will include: Dr. Forbes "Denny" Porter, Dr. Daniel Ory, Dr. Marc Patterson, and Dr. Chris Austin.

This meeting will begin at 4:00 pm Central Time (5:00 pm Eastern, 2:00 pm Pacific). International participants are invited, as well.

The meeting will be held using GlobalMeet's "PGiMeet" interface. Participants will need access to a telephone for the audio portion of the call, as well as a computer to log in to a Web page to see any documents and graphics. Therefore, Internet access as well as access to a telephone will be required for full participation. (Those without access to a computer may participate in the audio portion only – see separate instructions below.)

Test Your System

First-time PGI users -- Run the System Test at any time prior to the meeting to determine if your computer equipment and internet connection are sufficient to support the Webinar.

Click this link to run the test: <http://nnpdfniemannpickdisease.pgimeet.com/utilities/fullbrowsertest.aspx>

Web and Audio Access (preferred method for full participation)

Steps for participants (from any location around the world) who will join the meeting via the Web page (for graphics) and telephone (audio).

Accessing the meeting through this method is free and should not result in long-distance charges to your telephone bill.

About 5 minutes prior to the meeting:

1. Click the link below:

<http://nnpdfniemannpickdisease.pgimeet.com/Web/NNPDFWebConfMeetingRoom2011>

(Enable pop-ups if you are prompted to do so.)

2. Make sure the “Attendee” tab is clicked and highlighted orange.
3. Enter your name and email address in the fields provided.
4. Make sure the “Would you like us to call you for the meeting?” box is checked and enter the telephone number where you want the system to call you. Having the system dial you will save you from paying the cost of the call on your own phone bill. (Those who do not have computer access will have to dial in themselves. See separate instructions titled “Audio Access Only,” below, for dialing in.)
5. Click the orange “Join Meeting” button.
6. Your Web page should change to display the meeting screen.
7. Within a few moments, your phone should ring. Pick up the call and follow the prompts given by the automated attendant. You will be instructed to press “1,” wait for the tone, and then to say your name and press the “#” key. You will hear music if the meeting has not yet begun, or you will hear the voices of the presenters if the meeting line is already open.

Audio Access Only

Please note: This option is offered for those who may not have access to a computer. Accessing the meeting this way may incur long distance call charges to your telephone bill (including international charges), depending on your service plan. Use of the Audio Access Only option will not allow the participant to view any documents or graphics used by the presenters. Attendees using the Audio Access Only option will not be able to submit questions to the presenters, as all audio lines (except the presenters’ lines) will be muted.

Steps for participants who will join the meeting via telephone (audio) only.

About 5 minutes prior to the meeting:

From the U.S. and Canada: Dial 1-719-387-4105

(For countries other than the U.S. or Canada, see the list of dial-in access numbers below.)

The call will be answered by an automated attendant, who will instruct you to enter your “Passcode” (276192), followed by the # sign. You will then be asked to say your name, followed by the # sign. You will then hear music until the meeting begins, or you may hear the voices of the presenters if the meeting line is already open.

NOTE: Using the “Audio Access Only” method to participate in the meeting (dialing into the meeting instead of having the system call you) will result in charges to your telephone bill. These charges may be quite large, as the meeting is expected to last at least an hour, and international rates will apply. Please do not use any toll-free numbers to call in, as the charges to the NNPDF are exorbitant. We recommend that you try to use the Web and Audio Access method detailed above, if at all possible, instead.

Dial-in access numbers for participants in countries other than the U.S. or Canada:

Australia, Melbourne: +61 (0) 3 8687 0519

Australia, Sydney: +61 (0) 2 9009 0646

Austria, Vienna: +43 (0) 1 25301 0158
Bahrain, Manama: +973 1619 9397
Belgium, Brussels: +32 2 789 2131
Bulgaria, Sofia: +359 (0) 2 491 7543
Canada, Montreal: +1 514 315 3156
Czech Republic, Prague: +420 246 019 649
Denmark, Copenhagen: +45 32 71 16 38
Estonia, Tallinn: +372 698 7460
Finland, Helsinki: +358 (0) 9 2310 1673
France, Paris: +33 (0) 1 70 37 14 53
Germany, Frankfurt: +49 (0) 69 66777 5742
Germany, Munich: +49 (0) 89 7104 24677
Greece, Athens: +30 211 181 3802
Hong Kong: +852 3071 2998
Hungary, Budapest: +36 1778 9073
Ireland, Dublin: +353 (0) 1 5530138
Israel, Tel Aviv: +972 3763 0677
Italy, Milan: +39 02 304 648 21
Italy, Rome: +39 06 452 366 17
Japan, Chiba: +81 (0) 43 321 6777
Japan, Fukuoka: +81 (0) 92 290 6777
Japan, Hiroshima: +81 (0) 82 558 6777
Japan, Kanagawa: +81 (0) 45 677 6777
Japan, Nagoya: +81 (0) 52 850 6777
Japan, Osaka: +81 (0) 6 6123 6777
Japan, Sapporo: +81 (0) 11 234 6777
Japan, Sendai: +81 (0) 22 708 6777
Japan, Shizuoka: +81 (0) 54 902 6777
Japan, Tachikawa: +81 (0) 42 841 6777
Japan, Tokyo: +81 (0) 3 4455 1117
Japan, Toyama: +81 (0) 76 408 6777
Japan, Urawa: +81 (0) 48 698 6777
Latvia, Riga: +371 6778 2551
Lithuania, Vilnius: +370 5205 5160
Luxembourg: +352 2088 0607
Mexico, Mexico City: +52 55 1207 7357
Netherlands, Amsterdam: +31 (0) 20 708 5037
New Zealand, Auckland: +64 (0) 9 358 4010
Norway, Oslo: +47 21 00 26 24
Poland, Warsaw: +48 (0) 22 212 06 50
Portugal, Lisbon: +351 2141 59167
Romania, Bucharest: +40 (0) 31 810 7451
Russia, Moscow: +7 495 213 17 59
Singapore: +65 3158 1054
Slovakia, Bratislava: +421 2 3345 6502
Slovenia, Ljubljana: +386 1600 9374
South Africa, Johannesburg : +27 11 019 7033
South Korea, Seoul: +82 (0) 2 3483 1330

Spain, Barcelona: +34 93 545 2562

Spain, Madrid: +34 91 791 7468

Sweden, Stockholm: +46 (0) 8 5051 4933

Switzerland, Geneva: +41 (0) 22 592 7956

Switzerland, Zurich: +41 (0) 43 456 9233

UK, Belfast: +44 (0) 28 9595 0015

UK, Edinburgh: +44 (0) 13 1460 1110

UK, London: +44 (0) 203 059 5712

UK, Reading: +44 (0) 11 8370 1110