

7th Annual Primary Ciliary Dyskinesia (PCD) Family Education Weekend

June 26-28, 2009
Buffalo, New York

Session Registration

The PCD Foundation is pleased to present the seventh-annual North American PCD Family Education Weekend to be held at the Millennium Airport Hotel Buffalo in Cheektowaga, NY, June 26-28, 2009.

Registration includes: Friday evening welcome reception, Saturday light breakfast, lunch and dinner, Sunday light breakfast as well as all educational sessions. Hotel and transportation costs are the responsibility of attendees. Please register by June 15th, 2009.

Please check one:	Family	Individual
Regular Registration	\$120.00 _____	\$90.00_____
Early Bird—before June 1	\$90.00 _____	\$60.00_____

Attendee Information

To facilitate meal planning and badge production, please provide the following information:

Person filling out this form (name): _____

Relationship to affected individual (self, parent, etc.): _____

Address _____

Phone _____

E-mail _____

Please list additional family members/individuals attending the event:

Name & Age (child or adult)	Relationship (to registrant)

Please indicate how many will be attending each meal:

Friday Reception: ____ ; Saturday Lite Breakfast: ____ children ____ adults;

Saturday Lunch: ____ children ____ adults; Saturday Dinner: ____ children ____ adults;

Sunday Lite Breakfast: ____ children ____ adults

Registrations deadlines are listed above and **MUST** include the signed cross-infection waiver (attached). Registrations will not be confirmed without this waiver. Completed forms and waivers can be mailed to:

PCD Foundation
C/O Lynn Ehrne
61 Lake Meadow Drive
Rochester, NY 14612 USA

Registrations will be confirmed by email or telephone.

Hotel and General Information

A block of rooms has been reserved at The Millennium Airport Hotel Buffalo at the conference rate of \$99.00 (US Funds) + tax per night. The rate will be offered based on availability prior to and after the event dates of June 26th-June 28th. All education sessions will take place at the hotel. The event program will be available at a later date.

Hotel reservations, cancellations and changes are the responsibility of the attendee. To reserve a room, please call the hotel's toll-free number at 800-323-3331, ask for reservations and identify yourself as an attendee of the "PCD Foundation" to ensure that you receive the conference rate. This special rate is only good on reservations made by June 15, 2009. After June 15th, remaining rooms blocked for the PCD Foundation will be released to the general public, and the prevailing rates will apply.

For more information on this hotel, including guest room amenities, guest services, etc. check the hotel website at www.millenniumhotels.com

Millennium Airport Hotel Buffalo

2040 Walden Avenue
Cheektowaga, New York 14225
Phone: 1 800-323-3331
Fax: 1 716-681-8067

The Millennium is just 3 miles from the Buffalo International airport and the Depew Amtrak Station. The hotel does offer free airport shuttle to and from the airport. Upon arrival at the airport, go to ground transportation. Locate the correct hotel courtesy phone to call the hotel for pickup. If you have any questions please contact Lynn Ehrne at linnie1@frontiernet.net or call 585-621-8915.

Preliminary Event Program

Friday, June 26, 6 to 9 pm—Welcome Reception
Saturday, June 27, all day—Educational Sessions from 9 to 5/Group Dinner 6:00
Sunday, July 20—Informal Breakfast Discussion Session
A finalized program will be available soon.

General Information

Conference Attire: Conference attire is casual. Buffalo in June is typically warm. It is best to check weather reports before departure.

Cancellation Policy: Full refunds for registration fees will be allowed with a written request received by the PCD Foundation no later than Friday June 12, 2009. Refunds after this date will be at the discretion of the PCD Foundation.

PRELIMINARY PROGRAM (subject to change)



FRIDAY, JUNE 26

6:00-9:00 PM

WELCOME RECEPTION FOR ALL ATTENDEES

SATURDAY, JUNE 27

8:00 – 8:50

Continental Breakfast

8:50 – 9:00	PCD Foundation Welcome	Michele Manion
9:00 – 9:45	PCD Overview: What is PCD?	Margaret Leigh, MD
9:45 -- 10:45	Ciliary Ultrastructure & Function: Assessing Ciliary Defects in PCD	John Carson, PhD

10:45 – 11:00

Morning Break

11:00 -- 11:45	Ear, Nose & Throat Issues in PCD	TBA
11:45 – 12:30	Current “Best Practices” for PCD Care: The Value of a Center-based Approach	Sharon Dell, MD

12:30 – 1:30

Lunch

1:30 -- 2:15	Adults with PCD: Advanced Lung Disease & Transplant: Current “Best Practices”	TBA
2:15 – 3:00	PCD Genetics & Research Update—New Findings & Exciting Future Directions	Margaret Leigh, MD
3:00 – 3:30	Airway Clearance Options in PCD	Marty Davig, RRT

3:30 – 3:45

Afternoon Break

3:45 – 5:00	Open Question Time- Patient discussion with physician moderators	
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5:00

Group Photo

6:00 – 9:00

Dinner

SUNDAY, JUNE 28

9:00—12:00

Light breakfast and patient informal discussion time

PCD Foundation Cross Infection Guidelines and Waiver

The possibility of cross-infection between PCD individuals observing proper hygienic measures may be very low. Nevertheless, the PCD Foundation prohibits individuals who have cultured positive with MRSA or other pan-resistant bacteria, or who are *actively* infected with *Pseudomonas aeruginosa* or *Burkholderia cepacia* from attending PCD Foundation events. Because non-tuberculous mycobacterial (NTM) infections are not believed to be spread through person-to-person contact, there will be no restrictions for PCD individuals with positive NTM cultures.

Despite extensive precautions, we cannot guarantee a patient event that is free of virulent organisms. The very nature of cross-infection, inaccurate laboratory cultures, and other factors make it impossible to insure a "bug" free gathering. *Therefore we urge you to discuss these issues with your physician and decide together whether you wish to attend this patient event.*

The following cross-contamination prevention suggestions are recommended by the European CF Foundation, and are provided for your information:

- Always cover your mouth and nose when you cough or sneeze (preferably with disposable tissues)
- Regularly wash and dry hands thoroughly or use antibacterial gel, particularly after covering your mouth to cough, and/or using toilet/bathroom facilities
- When using toilet/bathroom facilities, opt for dispenser soap use and disposable paper towels, in preference to multi-use soap bars and hot air hand dryers, where available. Always make sure your hands are as dry as possible (it is preferable to use your own, personal bathroom.)
- Use disposable tissues for sputum, throwing them away immediately after use in an appropriate container
- Refrain from shaking hands with others (an alternative friendly gesture might be a gentle touch of the arm or shoulder)
- Kissing (social or otherwise) is not advisable
- Do not share utensils, cups, canned/bottled drinks, etc with others
- Avoid using any 'dips' which accompany foods at buffets
- In the event of overnight accommodation, sharing rooms is not advisable
- When using the washbasin or shower, allow the cold water to run for 2-3 minutes to dilute any present bacteria
- Carry antibacterial hand gel with you at all times, and use at regular intervals to maximize protection (we will have some on hand)

Please sign to indicate that that you have read and agree to these guidelines and that you understand there is a risk of cross-infection at patient gatherings. By signing you agree to indemnify and hold harmless the PCD Foundation ("PCDF"), its subsidiaries, affiliates, directors, officers, agents and employees against any claim arising from potential cross-infection at a PCD Foundation patient gathering.

Patient (or parent/guardian if patient is under 18)

Date

