



Clinic for Special Children

Genomic Medicine and the Plain Populations of North America

July 17-18, 2013

Barshinger Life Sciences and Philosophy Building

Franklin & Marshall College

415 Harrisburg Avenue, Lancaster, PA 17603

The Clinic for Special Children* is sponsoring a conference to review diagnosis and management of genetic diseases in Plain populations in North America. Objectives of the meeting:

- ❖ Provide an overview of genetic disorders prevalent in various Plain populations,
- ❖ Review newborn screening approaches and compare follow-up programs,
- ❖ Discuss population-specific methods available for genetic testing,
- ❖ Share information on current research projects for specific disorders,
- ❖ Advance collaborative efforts among clinics serving Amish, Mennonite and Hutterite communities.

DESCRIPTION

This is designed as a 2-day review course based upon the idea that *genomics can transform the everyday practice of medicine*. The course will review the catalogue of disorders and gene mutations found in the Plain Populations of North America, identify the disorders that are found by expanded newborn screening, outline the management of biochemical disorders, discuss new approaches to population-specific diagnosis based upon broad phenotypes like cerebral palsy, developmental delay, cardiomyopathy, or seizures, as well as provide lists of laboratories offering targeted mutation detection, high density arrays to detect copy number errors, and exome sequencing for clinicians. We will also summarize on-going research to discover and treat newly recognized disorders.

The Clinic for Special Children, the Das Deutsch Center for Special Needs Children in Geauga County Ohio, the Community Health Center in Topeka Indiana, and The New Leaf Clinic in Holmes County Ohio are community-supported non-profit healthcare centers. Doctors and staff at these Clinics can use knowledge about genetic risks within the Plain populations to do high-risk carrier testing and improve the care of newborns with genetic disease. Rapid, affordable tests limit the cost of diagnosis in pre-symptomatic older children and adults and increase access to care. The education of families, midwives and other health-care workers and a timely approach to care improve health, prevent severe illnesses, limit costly hospital stays, and often prevent disabilities for those with treatable disorders. Such Clinics also provide rapid diagnosis of lethal disorders, limiting unnecessary hospital-based diagnostic voyages and prolonged periods of futile care. Although subspecialty medical care and research are often highlighted in lectures and newsletters from the Clinic for Special Children, clinics like the DDC and the Community Health Center were designed as 'medical homes' for patients with complex health care needs and offer a range of services including parent education, family support groups, nutritional advice, immunizations, occupational and physical therapies, dental care, access to medications and equipment for those with special needs. Increasingly, these clinics are collaborating with regional medical centers to offer on-site, affordable subspecialty services for metabolic diseases, hemophilia, cardiology, hearing and vision testing.

CME CREDITS

CME Credit (12units) is available through Lancaster General Health for registered participants of the conference.

****This conference is supported by the Clinic for Special Children and in part by a grant to Franklin & Marshall College from the Howard Hughes Medical Institute through the Undergraduate Science Education Program.***

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Clinic for Special Children

AGENDA

July 17

8:30 - 9:00	Registration and Coffee
9:00 - 9:15	Welcome and Introduction - Holmes Morton, Clinic for Special Children
9:15 - 9:45	Donald Kraybill, Young Center, Elizabethtown College: Demographics of the Anabaptist Populations of North America
9:45 - 10:15	The Community Health Clinic, Indiana: Identifying Needs, Implementing Services
10:15 - 10:30	Break
10:30 - 11:00	Heng Wang, Das Deutsch Center, Middlefield, OH: A Review of Disease Distribution, Services, and Strategic Priorities
11:00 - 11:30	Olivia Wenger, The New Leaf Clinic, OH: Disease Distribution, Diagnostic Services and Approach to Care
11:30 - 12:00	Victoria Siu, Newborn and Carrier Screening in Southwestern Ontario and FORGE Canada
12:00 - 12:30	Alan Shuldiner, Amish Research Center, University of Maryland: Genetic Diseases in the Amish Adult Population
12:30 - 1:15	Lunch
1:15 - 1:45	Ed Naylor: History of Expanded Newborn Screening in the U.S. and Canada that particularly serve Plain Populations
1:45 - 2:15	Erik G. Puffenberger, Clinic for Special Children: Core Laboratory - Purpose, Organization, Institutional Knowledge
2:15 - 3:00	Kevin A. Strauss, Clinic for Special Children: Measuring Impact of Medical Home Services for Anabaptist Communities
3:00 - 3:15	Break
3:15 - 3:45	Kevin A. Strauss: Work-up for Developmental Delay
3:45 - 4:15	D. Holmes Morton: Approach to Care for Metabolic Disease
4:15 - 4:45	Robert O'Reilly, Nemours A.I. duPont: Patient-centered Research: The Audiology Experience
4:45 - 5:00	Panel Discussion, Q&A

July 18

8:30 - 9:00	Coffee
9:00 - 9:15	Welcome and Overview
9:15 - 9:45	Adam Heaps, Clinic for Special Children: The Challenges and Opportunities of Collaboration: A Survey of Current Projects
9:45 - 10:15	Robert Jinks, Franklin & Marshall College: Bridging the Gap Between Research and Education
10:15 - 10:30	Break
10:30 - 11:00	Berwood Yost, Franklin & Marshall College: Defining Need, Identifying Disease: Designing Healthcare Surveys
11:00 - 11:30	Franklin & Marshall Students: The Handbooks Project - Translating for Parents, Educating Students
11:30 - 12:00	Initiative in Wisconsin: Update
12:00 - 1:00	Lunch
1:00 - 2:30	Dr. Strauss, Dr. Morton: Diagnosis to Medical Care: Case Studies in Genetic Disease
2:30 - 3:00	Aravinda Charkavarti, Johns Hopkins University: Next Generation Screening using Exome Sequencing
3:00 - 4:00	Working Group session to discuss strategies for enhanced communication and collaboration among clinics

Note: Handout information from conference presentations will be available on the Clinic for Special Children web site after the conference.



Clinic for Special Children

Registration Information is attached to this announcement and is also available on the Clinic's web site www.clinicforspecialchildren.org

HOTEL INFORMATION

For conference participants traveling from a distance, hotel rooms are available at the following:

[Lancaster Arts Hotel](#), 300 Harrisburg Pike, Lancaster, PA 17603, Phone 717-299-3000

[Cork Factory Hotel](#), 480 New Holland Pike, Lancaster, PA 17602, Phone 717-735-2075

Note: Please refer to the conference when making a reservation to receive special room rates. Special rates will be available until July 2.

REFERENCES

Morton DH. Through my window—remarks at the 125th year celebration of Children's Hospital of Boston. Pediatrics. 1994 Dec 94(6 Pt 1):785-91.

Morton DH, Morton CS, Strauss KA, Robinson DL, Puffenberger EG, Hendrickson C, Kelley RI. Pediatric medicine and the genetic disorders of the Amish and Mennonite people of Pennsylvania. Am J Med Genet C Semin Med Genet. 2003 Aug 15;121C(1):5-17.

Strauss KA, Puffenberger EG. Genetics, medicine, and the Plain people. Annu Rev Genomics Hum Genet. 2009;10:513-36.

Strauss KA, Puffenberger EG, Morton DH. One Community's Effort to Control Genetic Disease. Am J Public Health. 2012 Jul;102(7):1300-6.

WEB RESOURCES

The Clinic for Special Children: www.clinicforspecialchildren.org

Das Deutsch Center for Special Needs Children in Geauga County, OH: www.ddcclinic.org

The Community Health Center in Topeka, IN: www.indianachc.org/wp/education

Windows of Hope Project: www.wohproject.org

Amish, Mennonite, and Hutterite Genetic Disorder Database: www.biochemgenetics.ca/plainpeople/



Clinic for Special Children

Parking and Franklin & Marshall College Map

CONFERENCE SITE

The Conference will be held in the Bonchek Lecture Hall in the Barshinger Life Sciences & Philosophy Building, #8 on the F & M Campus map attached.

PARKING INFORMATION

Parking for conference participants is available along Race Avenue and also in the parking lots across Harrisburg Pike to the west of building #17 (F & M Map) and adjacent to the athletic fields.



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|--|--|--|--|--|---|
| 1 Lisa Bonchek Adams Auditorium in Kaufman Hall | 10 Bonchek College House
→ Bookstore, see Distler House | 21 Facilities Services, 415 Harrisburg Avenue | 34 Huegel Alumni House Annex,
→ College Guest House
445 College Avenue | 45 The President's House,
508 North School Lane | 60 Sponaugle-Williamson Field |
| 2 Admission, Wohlsen House,
637 College Avenue | 11 Brooks College House | 22 Faculty, Emeriti Faculty &
Foreign Language Tutor
Offices, 711 College Avenue | 35 International House,
446-448 West James Street | 46 New College House | 61 Stager Hall |
| 3 Alumni Sports & Fitness
Center, 929 Harrisburg Avenue | 12 Brooks Tennis Center | 23 Financial Aid,
617 College Avenue | 36 James Street Apartments,
534 West James Street | 47 New Street Studio | 62 Stahr Auditorium |
| 4 Appel Infirmary
→ Asian Cultural Center,
see Multicultural Affairs | 13 Buchanan House | 24 Franklin-Meyran Hall | 37 Joseph International Center,
701 College Avenue | 48 North Museum | 63 Steinman College Center |
| 5 Arts House,
602 West James Street | 14 Business Office,
644-646 Race Avenue | 25 French House,
548 West James Street | → Kaufman Hall, see Lisa Bonchek
Adams Auditorium in Kaufman Hall | 49 Office of Student Academic
Affairs, 623 College Avenue | 64 Sustainability House,
550-52 West James Street |
| 6 Baker Campus,
1300 block of Harrisburg Pike | 15 Centennial Conference Office,
HEDS Consortium, Frederick
Street entrance of Lancaster
Theological Seminary | 26 Gerhart House | 38 Keiper Liberal Arts | 50 Office of Student and
Post-Graduate Development | 65 Tailgating Area |
| 7 Ann & Richard Barshinger
Center for Musical Arts in
Hensel Hall | → College Guest House,
see Huegel Alumni House Annex | 27 Goethean Hall | 39 Klehr Center for Jewish Life,
645 College Avenue | 51 Old Main | 66 Thomas Residence Hall |
| 8 Ann & Richard Barshinger
Life Sciences & Philosophy
Building | 16 College Row | 28 Green Room Theatre | 40 Kunkel Aquatic Center,
929 Harrisburg Avenue | 52 Other Room Theatre | 67 Tylus Field: Ken Gramas Pavilion
→ Warehouse, see Facilities Services |
| Flavors Cafe | 17 College Square
→ Counseling Center,
see Appel Infirmary | 29 Hackman Physical Sciences
Laboratories | 41 Marketplace Dining Hall | 53 Philadelphia Alumni Writers
House, 633 College Avenue | 68 Ware College House |
| 9 Black Cultural Center,
615 College Avenue | 18 Diagnostian Hall | 30 Patricia E. Harris Center for
Business, Government &
Public Policy | 42 Martin Library of the Sciences | 54 Phillips Museum of Art | 69 Weis College House |
| | 19 Dietz Hall | 31 Hartman Green | 43 Maysor Physical Education
Center | 55 POGIL, 713 College Avenue | 70 Carolyn W. & Robert S.
Wohlsen Center for the
Sustainable Environment
→ Writers House, see Philadelphia
Alumni Writers House |
| | 20 Distler House/Campus
Bookstore
Zest Bistro (ZeBi) | 32 Dr. Leon Herman Arts Center | → Meyran Hall, see Franklin-Meyran Hall | 56 Public Safety | |
| | | 33 Huegel Alumni House | 44 Multicultural Affairs,
625 College Avenue | 57 Roschel Performing
Arts Center | |
| | | | | 58 Schnader Residence Hall | |
| | | | | 59 Shadok-Fackenthal Library | |



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REGISTRATION

Please print and complete registration form and send with check for fee to Clinic for Special Children, P.O. Box 128, Strasburg, PA 17579 **or** visit the Clinic's web site at www.clinicforspecialchildren.org.

Name:

Address:

Phone Number:

Email Address:

Affiliation:

Conference Fees: (Speakers and Panelists will not be charged Conference Fees.)

Full Conference – 2 days: \$150

One Day: \$75

Students & Parents: Exempt

Please advise if you have special dietary considerations, i.e. vegetarian, vegan, etc.:

Do you wish to receive CME credit for conference attendance? Yes_____ No_____