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 healthcare 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.*


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
4:45 – 5:00  Panel Discussion, Q&A

July 18

8:30 - 9:00  Coffee
9:00 - 9:15  Welcome and Overview
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.
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


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/
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.
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

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_________