

Newborn Screening Training Opportunities in the United States

Strengthening Newborn Screening in North Africa and the Middle East Conference

Marrakech, Morocco
November 15, 2006

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ASSOCIATION OF PUBLIC HEALTH LABORATORIES



About APHL

The Association of Public Health Laboratories (APHL) works to safeguard the public's health by strengthening public health laboratories in the US and across the world.

ASSOCIATION OF PUBLIC HEALTH LABORATORIES



About APHL

- In collaboration with members, advances laboratory systems and practices, and promotes policies that support healthy communities
- Non-profit, 501(C)(3) organization

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APHL: Committees

- Emergency Preparedness and Response
- Environmental Health
- Finance
- Food Safety
- **Global Health**
- Infectious Diseases
- Informatics
- Knowledge Management
- Laboratory Systems and Standards
- Membership and Recognition
- **Newborn Screening and Genetics**
- Public Policy

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Newborn Screening and Genetics in Public Health Committee

- Strengthens the role of PHL's
- Facilitates implementation
- Fosters evaluation and improvement
- Develops of policy statements
- Coordinates workshops and web cast

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Newborn Screening and Genetic Testing Symposium

- Began in 1981, occurs every 18 months
- Mix of testing, technology, education & policy issues
- October 2005 meeting Portland, OR
- Over 400 participants, 22 countries
- Pre conference workshops

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2007 Newborn Screening and Genetic Testing Symposium

- Hyatt Regency Minneapolis, MN
- May 7-10, 2007
- <http://www.aphl.org>

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Newborn Screening Quality Assurance Program

- Services provided:
 - Filter paper evaluation
 - Reference materials
 - Quality control materials
 - Proficiency testing
 - Training, consultations, network resources

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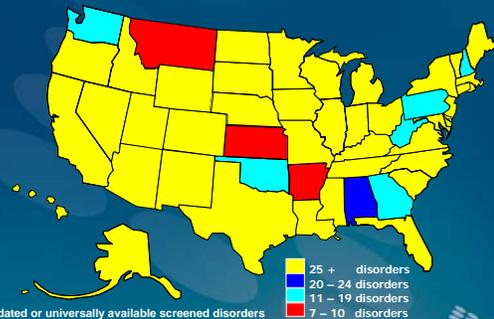
Newborn Screening Quality Assurance Program

- Partners
 - Association of Public Health Laboratories
 - 73 domestic screening laboratories
 - Laboratories in 54 countries
 - 400 plus screening laboratories worldwide

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US Newborn Screening



* Mandated or universally available screened disorders

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Tandem Mass Spectrometry Workshops

- Co-sponsored by APHL, NNSGRC, CDC and HRSA
- Began in May 2002
- 1-week intensive training
- Duke & Baylor Universities
- 59 participants from 31 states

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Newborn Screening Training Opportunities in the US

- Web conferences on newborn screening issues
 - Unsatisfactory specimens
 - Contingency planning
- Workshop on collection of dried blood spots
 - Future workshops on molecular genetics

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APHL Global Health

- PEPFAR and GAP activities
- Core Activities
 - Laboratory capacity building
 - Education and training
 - Twinning agreements
 - Scientific publications
 - Cross-border collaborations



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Future Initiatives

- Collaborating with ISNS
 - 2007 NBSGT Symposium
- Training workshops for international newborn screening programs
- Laboratory assessment and expertise

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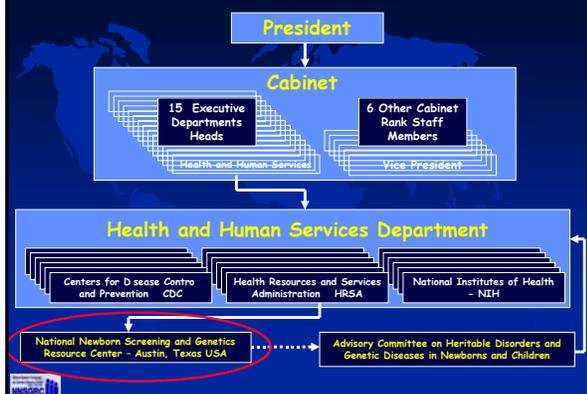
Training Assistance U.S. National Newborn Screening and Genetics Resource Center

Brad Therrell, Ph.D.

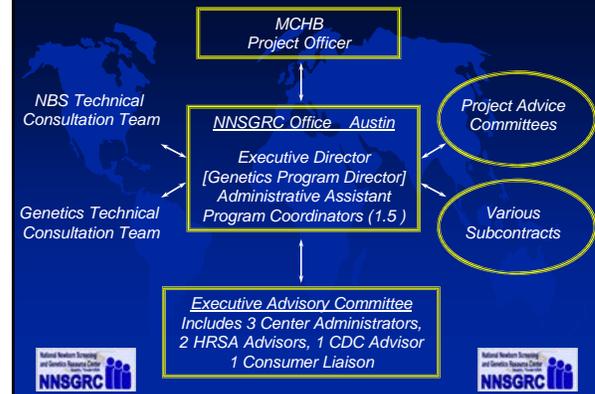
University of Texas Health Science Center at San Antonio
Newborn Screening and Genetics Resource Center
Austin, Texas



U.S. Health Administration and NNSGRCC



NNSGRCC INFRASTRUCTURE



On line genetics and newborn screening program information and assistance:

NNSGR Website:
<http://genes-r-us.uthscsa.edu>

(Genetics and Newborn Screening Resource Center of the U.S.)

- Resource links
- National newborn screening data
- References and reports of regional or national significance
- Searchable Genetics Educational Materials database
- State genetics plans (and/or local linkages)
- And much, much more



NNSGR Website Homepage

National Newborn Screening and Genetics Resource Center - Microsoft Internet Explorer

Address: <http://genes-r-us.uthscsa.edu/>

NNSGR
 National Newborn Screening & Genetics Resource Center

Welcome to the National Newborn Screening and Genetics Resource Center (NNSGR) web site. (Genes-R-Us, Genetic and Newborn Screening Resource Center of the United States).

The National Newborn Screening and Genetics Resource Center (NNSGR) is a cooperative agreement between the Maternal and Child Health Bureau (MCHB), Genetic Sciences Branch and the University of Texas Health Science Center at San Antonio (UTHSCSA), Department of Pediatrics.

We provide information and resources in the area of newborn screening and genetics to benefit health professionals, the public health community, consumers and government officials.

Quick Links

- Current Newborn Screening (NBS) Conditions by State
- Commenced and Res.Peds NBS Laboratories
- MCHB Data/Sys/Integrating Child Health Information Systems, 1/00/00/04
- MCHB Webcast: Integrating Child Health Systems
- USDCS Connections - 04/04/04 to 05/04/04

Updated 07 July 2004

Contact Denise Williams with questions or comments concerning the website

GEM Database Homepage

Genetic Education Materials Database (GEMDatabase) - Microsoft Internet Explorer

Address: <http://www.gemdatabase.org/GEMDatabase.asp>

Provided by the National Newborn Screening and Genetics Resource Center (NNSGR)

INTRODUCTION

The Genetic Education Materials (GEM) Database is a searchable listing of public health genetics policy documents and clinical genetics educational materials. It is a project of the National Newborn Screening and Genetics Resource Center (NNSGR). Funding is provided by the Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB).

At present, this database includes materials developed by the ten regional genetics networks, genetics-related products of other HRSA-funded projects, genetics publications approved by national health professional organizations, and other policy documents helpful to state genetics programs. Listings are updated frequently.

A list of public health genetics-related organizations is available on the NNSGR web site.

The GEM Database is a work in progress. Your comments and suggestions are appreciated.

Disclaimer: All material within this website is presented as a public service, and does not necessarily represent endorsement by the NNSGR or its sponsoring agencies. Users of this website are responsible for checking the accuracy, completeness, currency, and reliability of all submissions.

NNSGR Information System Homepage

<https://www2.uthscsa.edu/nnsis>

National Newborn Screening and Genetics Resource Center - Microsoft Internet Explorer

Address: <http://www2.uthscsa.edu/nnsis/>

National Newborn Screening Information System

Welcome to the National Newborn Screening Information System (NNSIS) database.

The database is hosted by the National Newborn Screening and Genetics Resource Center (NNSGR) and is designed to provide a secure, Internet based, real-time, information collection and reporting system for capturing state and territorial newborn screening information.

The system uses existing reporting requirements specified in the former National Newborn Screening Annual Report.

- Obtain a Report
- Enter Individual or Annual Case Information
- Contact NNSGR

NNSIS Online NBS Data System

NNSGR Training Support for NBS

Cooperation between NNSGR (HRSA) and APHL (CDC) for Laboratory and Follow up Training Courses in Tandem Mass Spectrometry Methodologies.

1-week intensive course on the basics of tandem mass spectrometry methods and interpretations. Courses were initiated at Duke and the Institute for Metabolic Disease (Dallas) to provide an interim solution to training gaps resulting from rapid implementation of expanded screening in many states.



Training Courses in Tandem Mass Spectrometry Methodologies



Duke Medical School
Durham



Institute for Metabolic Disease
Baylor (Dallas)



NNSGRC Consultative Reviews

'Expert' Assistance to state health departments to evaluate and improve the newborn screening program at the state level.

A valuable external review system using experts in laboratory, follow-up, administration, quality assurance and medicine to address specific program needs at the request and invitation of a public health screening program.



NNSGRC Consultative Newborn Screening Reviews



Missouri Review



Louisiana Review



External Training Facilitation Examples:

- ◆ Facilitated week long training in newborn basic newborn screening implementation
- ◆ Assisted in organizing scientific visits of foreign newborn screening personnel (follow up and laboratory) to U.S. sites.
- ◆ Assisted with in country seminars on various aspects of newborn screening.
- ◆ Assisted with IAEA Expert program reviews.



Thailand
Regional Public Health Directors

Newborn Screening Training - Texas -



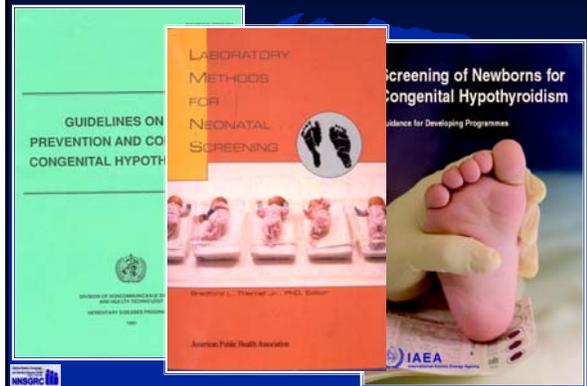
Thailand
Regional Public Health Directors
Newborn Screening Training - Texas -



IAEA Workshops



Training Manuals



Summary

- NNSGRC is a HRSA – sponsored cooperative agreement providing a focal national point for newborn screening information and assistance.
- Sponsored activities include:
 - Newborn screening policy development meetings.
 - National information exchange symposia.
 - Training courses for laboratory and follow up specialists.
 - Consultative newborn screening program reviews as a means of program quality improvement.
 - A publicly accessible database of nationally accumulated program and summary data.
 - A comprehensive website and international NBS listserv.

Thank You!

NNSGRC Website:

<http://genes-r-us.uthscsa.edu>

email: therrell@uthscsa.edu

NBS Listserv membership available upon request.