Preliminary Program

Sponsored by the
Association of Public Health Laboratories

Co-Sponsored by the
International Society for Neonatal Screening
and the Washington State Department of Health

www.aphl.org/NBS2022
#APHLNBS
About This Conference

This year’s APHL Newborn Screening Symposium will be our first in-person gathering in three years! In addition, a large portion of the meeting will be livestreamed, and meeting content will be available in real-time. The program includes poster and oral presentations drawn from submitted abstracts, invited oral presentations, exhibits, the Meet the Manufacturers event and more! Input and participation by parents and advocacy organizations are encouraged.

The Symposium addresses state, national and international newborn screening, genetic testing and policy issues important to public health newborn screening systems. Presentations feature reports from around the globe emphasizing challenges faced and the data generated. Topics include molecular technologies, current and upcoming conditions, quality improvement, communicating with families and the public, and short- and long-term follow-up.

The purpose of this symposium is to enhance participant knowledge of national and international newborn screening and genetics, as related to emerging laboratory technologies, follow-up, candidate conditions, quality improvement and clinical outcomes. Join us in Tacoma, WA!

Major learning goals of this symposium are to:

Discuss and evaluate quality assurance and quality control measures for newborn screening laboratories

Describe state and international experiences with candidate conditions and clinical outcomes in newborn screening

Evaluate the effectiveness of current newborn screening and genetics follow-up programs

Who will benefit from attending this conference?

Newborn screening and genetics laboratory professionals, newborn screening and genetics program personnel and counselors, students, health care practitioners or other maternal and child health service providers, public health nurses, specialists, public health laboratory directors, and other public health professionals involved with newborn screening and genetic testing issues and follow-up.
General Information

Registration

Advanced registration through APHL is required; registration is now open on the conference webpage www.aphl.org/nbs2022. Discounted virtual group registrations are available; details are on the website. If you have any questions, please contact Terry Reamer at terry.reamer@aphl.org or 240.485.2776.

- Full registration, in-person: $675
- Full registration, virtual: $550
- One day: $350
- Student: $200

Continuing Education Credits Available

APHL is an approved provider of continuing education programs in the clinical laboratory sciences through the American Society of Clinical Laboratory Science (ASCLS) P.A.C.E.® program. Attendees have the opportunity to earn up to 21.0 contact hours by attending the entire conference. Nursing and genetic counseling continuing education units (CEUs), certified public health (CPH), certified health education specialist (CHES), and continuing medical education (CMEs) will be available.

Hotel Information

Blocks of sleeping rooms in Tacoma have been arranged at the Marriott Tacoma Downtown Hotel and Hotel Murano. Details may be found at www.aphl.org/nbs2022.

Consent to Use Photographic Images

Registration and attendance at or participation in APHL conferences and other activities constitutes an agreement by the registrant to APHL’s use and distribution (both now and in the future) of the registrant’s or attendee’s image or voice, without compensation, in photographs, video and audio recordings of such events and activities.
Not-to-Miss Events!
All listed times are Pacific Standard Time (PST).

**Parent/Patient Panel**
Sunday, October 16 | 4:30–6:00 pm
Hear compelling personal accounts of how newborn screening impacts the lives of families. Follow their journeys from screening and diagnosis to treatment and management, and discover the small but powerful community of parents of children with disorders detected by newborn screening.

**Welcome Reception**
Sunday, October 16 | 6:00–7:30 pm
Let loose, reunite with old friends or meet up with new colleagues, and visit with our industry partners over drinks and hors d’oeuvres.

**Innovate! Sessions**
*concurrent*
Tuesday, October 18 | 7:00–8:00 am
Connect with your industry partners and learn of new technologies and services.

**Meet the Manufacturers**
Tuesday, October 18 | 6:00–7:15 pm
Light-hearted presentations from our industry partners.

**Awards Ceremony Lunch**
Wednesday, October 19 | 12:00–1:30 pm
Applaud your colleagues and celebrate their achievements over lunch.
Exhibits and Poster Hall

All listed times are Pacific Standard Time.

Exhibits and posters will be open and available for viewing throughout the conference. Be sure to visit the exhibitors to see the latest products and services and the posters to learn the latest science and practices. On the virtual platform, you can watch videos, see e-posters and chat with exhibitor staff and poster presenters.

Exhibiting Companies

Astoria-Pacific
Baebies
Bio-Rad Laboratories
BSD Robotics
DiaSorin Molecular/Luminex
Centers for Disease Control and Prevention
EBF, LLC
Everylife Foundation for Rare Diseases
Expecting Health/Baby's First Test
GelbChem, LLC
Labsystems Diagnostics Oy
National Coordinating Center for the Regional Genetics Networks
Novartis Gene Therapies
OpenELIS Foundation
PerkinElmer
Quantabio
Sebia
STAT Courier Service, Inc.
Waters Integrated Software Solutions

Hours

Sunday, October 16
6:00 pm – 7:30 pm

Monday, October 17
Tuesday, October 18
Wednesday, October 19
10:00 am – 4:00 pm
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All listed times are Pacific Standard Time (PST). Sessions in teal will be livestreamed to the virtual platform.
Agenda of Events
All listed times are Pacific Standard Time (PST).
As of August 2, 2022. Subject to change.

Sunday, October 16

4:00 pm – 4:30 pm  Welcome

4:30 pm – 6:00 pm  Parent/Patient Panel
Moderators:
• Angelica Watkins, Washington State Public Health
• Lani Culley, MPH, Washington State Department of Health Laboratory
Speakers: (to be determined)

6:00 pm – 7:30 pm  Welcome Reception
Visit the exhibits and posters

Monday, October 17

7:00 am – 8:00 am  Concurrent Roundtables
Exploration of Privacy-Enhancing Technologies to Ensure Patient Trust, Privacy, and Data Transparency in CDC ED3N
Amy Gaviglio, MS, CGC, Connetics Consulting/CDC/APHL

What Does Long-Term Follow-up Mean to You? A Discussion With State NBS Programs
Jennifer Taylor, PhD, American College of Medical Genetics and Genomics

A Community of Practice: Exploring Current Newborn Screening Result Communication Practices
Brianne Miller, MPH, Children’s National Hospital

8:00 am – 8:30 am  Break
8:30 am – 10:00 am

**Financial, Legal, Ethical, Policy and Social Implications (FLEPSI)**

Moderators:
- Aaron Goldeberg, PhD, MPH, Case Western Reserve University
- Kim Hart, MS, LCGC Utah Department of Health and Human Services

**The State of Newborn Screening Systems in the United States in 2021–2022**

Sikha Singh, MHS, PMP, Association of Public Health Laboratories

**Newborn Screening Modernization: Issues and Strategies**

Don Bailey, PhD, RTI International

**Development of a Biobank to Support Research for Current and Future Newborn Screening Disease Targets in Canada**

Monica Lamoureux, MSc, PMP, CCRP, Children’s Hospital of Eastern Ontario

**Newborn Screening Research and Consent — A Review of the Current Landscape in the United States**

Shibani Kanungo, MD, MPH, FAAP, FACMG, University of Western Michigan

**Counting Conditions on Newborn Screening Panels: Not as Easy as 1, 2, 3**

Guisou Zarbalian, MS, MPH, Association of Public Health Laboratories

10:00 am – 10:30 am  **Poster Speed Dating**

10:00 am – 4:00 pm  **Exhibit and Poster Hall Open**

10:30 am – 11:00 am  **Break in the Exhibit Hall**

Visit the exhibits and posters

11:00 am – 12:30 pm  **Keynote Session**

Moderators:
- John Thompson, PhD, MPH, MPA, Washington State Public Health Laboratory
- Michele Caggana, ScD, FACMG, Wadsworth Center, New York Department of Health

Speakers:
- Philip J. (P.J.) Brooks, PhD, National Institutes of Health
- Julie Kanter, MD, The University of Alabama at Birmingham Adult Sickle Cell Clinic
- Sandra Sirrs, MD, University of British Columbia

12:30 pm – 2:00 pm  **Lunch (on your own)**
2:00 pm – 3:30 pm

Health Equity

Moderators:
• Michelle Mills, MSFS, Kansas Department of Health and Environment
• Carla Cuthbert, PhD, FCCMG, FACMG, Centers for Disease Control and Prevention

Using NewSTEPs Data to Assess Disparities in Newborn Screening
Amy Gaviglio, MS, CGC, Connetics Consulting/CDC/APHL

Building Relationships to Reduce the Gaps: How Analysis of LFU Data Led to Newfound Partnerships, a More Comprehensive Educational Program, and Increased Equity Within Program Activities
Drew Duncan, Kansas Department of Health

Towards Equity and Timeliness in Cystic Fibrosis Newborn Screening
Albert Faro, MD, Cystic Fibrosis Foundation

TBD
Invited speaker from CDC or Washington state

3:30 pm – 4:00 pm

Break in the Exhibit Hall
Visit the exhibits and posters

4:00 pm – 5:30 pm

Short-term and Long-term Follow-up

Moderators:
• Christen Crews, MSN, RN, Virginia Division of Consolidated Laboratory Services
• Kelly Kramer, MPH, Washington State Public Health Laboratory

Putting Families First: Innovative Approaches of Long-Term Follow-up Cares and Check Initiative (LTFU-Cares & Check)
Kee Chan, PhD, American College of Medical Genetics and Genetics

Pilot Project to Reconnect Michigan’s Lost to Follow-up Phenylketonuria Population with Information and Services
Kristy Karasinski, MPH, Michigan Public Health Laboratory

The Forest or the Trees: 12 years’ Experience of CF, CRMS and Diagnostic Transitions Following Newborn Screening for CF in California
Stanley Sciortino, MPH, PhD, California Department of Public Health

Initial Success of the NewSTEPs Follow-up Learning Exchange (FLEX) Program
Erin Darby, MPH, MCHES, Association of Public Health Laboratories
Tuesday October 18

7:00 am – 8:00 am  Innovate Sessions
PerkinElmer
Waters Integrated Software Solutions
Novartis Gene Therapies

8:00 am – 8:30 am  Break

8:30 am – 10:00 am  International Perspectives
Moderators:
• Joanne Mei, PhD, Centers for Disease Control and Prevention
• M. Christine Dorley, PhD, MT(ASCP), Tennessee Department of Health, Laboratory Services

Expanded Neonatal Bloodspot Screening Programmes: A Framework to Prioritize New Conditions With Stakeholders
Marleen Jansen, PhD, National Institute for Public Health and the Environment

Performance Evaluation of Latin America Laboratories in the CDC Newborn Screening Quality Assurance Programs, 2016–2022
Ernesto Gonzalez Reyes, PhD, Centers for Disease Control and Prevention

Evaluation of the First Year of Screening for MPS I in The Netherlands
Rose Maase, PhD, National Institute for Public Health and the Environment

Evaluating the Use of Whole Genome Sequencing in Newborn Screening: The Genomics England Newborn Genomes Programme
David Bick, MD, Genomics England

10:00 am – 10:30 am  Poster Speed Dating

10:00 am – 4:00 pm  Exhibit and Poster Hall Open

10:30 am – 11:00 am  Break in the Exhibit Hall
Visit the exhibits and posters
11:00 am – 12:30 pm

Current Recommended Uniform Screening Panel (RUSP) Conditions to State NBS Panels

Moderators:
• Graham Sinclair, PhD, British Columbia Children’s Hospital
• Denise Kay, PhD, Wadsworth Center, New York State Department of Health

Congenital Hypothyroidism Detection in Texas: A Ginormous Study of T4 and TSH as Primary Analyte
Brendan Reilly, BS, Texas Department of State Health Services

Multiplexing Homocysteine into FIA-MS/MS Primary-Tier Screening with Amino Acids, Acylcarnitines, Succinylacetone, Adenosine, Deoxyadenosine and Other Biomarkers by Selective Homocysteine Derivatization
Austin Pickens, PhD, Centers for Disease Control and Prevention

Michigan’s Experience Transitioning from Digital Microfluidics to MS/MS for Lysosomal Storage Disorder Screening
Shawn Moloney, MPH, Michigan Newborn Screening Laboratory

LDT Implementation for the Screening of X-ALD, Pompe Disease and MPS-I with One Dried Blood Spot using LC-MS/MS
Nicolas Szabo, PhD, Utah Public Health Laboratory

Neonatal Screening for Peroxisomal Disorders: New and Novel Lipid Biomarkers
Enzo Ranieri, SA Pathology at the Women’s & Children’s Hospital

12:30 pm – 2:00 pm
Lunch in the Exhibit Hall
Visit the exhibits and posters

2:00 pm – 3:30 pm

Quality Improvement, Quality Control and Quality Assurance

Moderators:
• Lorrie Folmar, RN, BSN, Alaska Division of Public Health
• Lisa Shook, MA, MCHES, Cincinnati Children’s Hospital Medical Center

Using Systems Design Thinking to Improve Internal Notifications Between Laboratory and Follow-up Components of the Kansas Newborn Screening Program, Part 1: Understanding the Current System, User Needs and Improvement Measures
Kinsey Anderson, Kansas Department of Health and Environment

A Quality Management Project with Inherited Metabolic Disorders Specialty Care Centers to Reduce Referrals Lost to Follow-up
Kathy Chou, PhD, New York State Department of Health
Development of Post-analytical Methodologies for the Uniform Interpretation of Newborn Screening Data  
Nicolas Szabo, PhD, Utah Public Health Laboratory

Beyond the Fax Machine: Improving Operations and Communication between Follow-up, NBS Laboratory and NICU  
Christen Crews, MSN, RN, Virginia Department of Health

Newborn Screening Follow-up Harmonization Project  
Lani Culley, MPH, Washington Public Health Laboratories

3:30 pm – 4:00 pm  Break in the Exhibit Hall  
Visit the exhibits and posters

4:00 pm – 5:30 pm  Training, Education and Communication

Moderators:
- Sarah Viall, MSN, PPCNP-BC, Oregon Health & Science University
- Carol Johnson, University of Iowa Hospitals and Clinics

Understanding Clinician Needs and Preferences with Respect to Returned NBS Results  
Nicole Ruiz-Schultz, PhD, Utah Public Health Laboratory

Discrepancies between Parent-reported and Known NBS Results: Examining Parent Experiences with Qualitative Interviews  
Anne Atkins, MPH, Children’s National Hospital

Engaging Family Leaders in the NBS System  
Marianna Raia, MS, CGC, Expecting Health

Developing an Integrated, Mixed-Methods Parent Engagement Research Program: The ScreenPlus ELSI Studies  
Aaron Goldenberg, PhD, MPH, Case Western Reserve University

6:00 pm – 7:15 pm  Meet the Manufacturers
Wednesday, October 19

7:00 am – 8:00 am  Concurrent Roundtables

Hemoglobinopathy Newborn Screening: Is It Time to Increase Molecular Testing?
Amanda Ingram, RN, Tennessee Dept. of Health

Embracing Expanded COVID-era Capabilities in Metabolic Newborn Screening (NBS) Follow-up in Oregon
Sarah Viall, MSN, PPCNP-BC, Oregon Health Sciences University
Leah Wessenberg, FNP, MN, Oregon Health Sciences University

Good, Better, Best: Setting a Standard for the Newborn Screening Workforce of Today, Tomorrow and the Future
Susan Tanksley, PhD, Texas Department of State Health Services

8:00 am – 8:30 am  Break

8:30 am – 10:00 am  Data Analytics and Bioinformatics

Moderators:
• Charles Lechner, MS, Tennessee Department of Health: Laboratory Services
• Christian Alcorta, MS, Virginia Division of Consolidated Laboratory Services

Creating a National Newborn Screening Bioinformatics and Variant Interpretation Tool: LIMS Lite and ED3N
Amy Gaviglio, MS, CGC, Connetics Consulting/CDC/APHL

Benefits and Burdens of Gene Variant Analysis in the Newborn Screening Setting
Denise Kay, PhD, Wadsworth Center, New York State Department of Health

Creation of a Variant Analysis Pipeline for Texas Newborn Screening DNA Sequencing
Samantha Marcellus, MPH, Texas Department of State Health Services

Newborn Screening Variant Reclassification and Reporting — Virginia’s Experience
Gretchen Cote, MS, Virginia Division of Consolidated Laboratory Services

10:00 am – 10:30 am  Break in the Exhibit Hall

10:30 am – 12:00 pm  Molecular Technology

Moderators:
• Richard Olney, MD, MPH, California Department of Public Health
• Sainan Wei, MD, PhD, Kentucky Division of Laboratory Services
Severe Combined Immunodeficiency (SCID) Screening for Premature Infants Quality Improvement Project
Ruthanne Sheller, MPH, Association of Public Health Laboratories

Molecular Investigation of Idiopathic T-cell Lymphopenia Cases in New York State
Denise Kay, PhD, Wadsworth Center, New York State Department of Health

Expanded Screening for Cystic Fibrosis - No Sweat
Michael Cellucci, MD, Delaware Newborn Screening Program

The p.Y319C GALC Variant and Newborn Screening for Krabbe Disease
Dietrich Matern, MD, PhD, Mayo Clinic

12:00 pm – 1:30 pm  Awards Ceremony Lunch

1:30 pm – 3:00 pm  Health Information Technology (HIT)

Moderators:
• Brendan Reilly, BS, Texas Department of State Health Services
• Stanley Sciortino, MPH, PhD, California Department of Public Health

Promoting Newborn Screening Interoperability — How to Effectively Communicate Benefits to Improve Hospital Engagement
Emily Hopkins, MS, Virginia Division of Consolidated Laboratory Services

Advancing Electronic Data Sharing for Newborn Screening Programs
Craig Newman, PhD, Altarum

Utilizing a Data Exchange to Achieve Interoperability in Newborn Screening
Heather Brand, Minnesota Department of Health Newborn Screening

Improving COOP in South Carolina: Lessons Learned from Memorial Day Weekend 2021
Elizabeth Bair, MS, South Carolina Dept of Health & Environmental Control

3:00 pm – 4:00 pm  Break and Raffle in the Exhibit Hall  
Visit the exhibits and posters

4:00 pm – 5:30 pm  Conditions Under Consideration for Addition to, or Removal from, State NBS Panels

Moderators:
• Mei Baker, MD, FACMG, Wisconsin State Laboratory of Hygiene
• Pranesh Chakraborty, PhD, Newborn Screening Ontario
Clinical Sensitivity of Dried Blood Spots and Saliva for Detection of Congenital Cytomegalovirus Disease
Tatiana Lanzieri, MD, MPH, Centers for Disease Control and Prevention

Evaluation of Testing for Congenital Cytomegalovirus in Dried Blood Spot Using Real-Time PCR in Minnesota
Carrie Wolf, MBS, Minnesota Department of Health

Early Check Newborn Screening Pilot Study for Duchenne and Related Muscular Dystrophies in North Carolina
Holly Peay, PhD, MS, RTI International

Factors Influencing Creatine Kinase-MM Levels in Newborns and the Relevance for Newborn Screening for Duchenne Muscular Dystrophy
Norma Tavakoli, PhD, Wadsworth Center, New York State Department of Health

6:00 pm – 10:00 pm  Off-site Social sponsored by PerkinElmer

Thursday, October 20

7:00 am – 8:00 am  ISNS Membership Meeting

8:00 am – 8:30 am  Break

8:30 am – 10:00 am  Adoption and Use of Second-tier Testing

Moderators:
• Ewa King, PhD, Association of Public Health Laboratories
• Joseph Orsini, PhD, New York State Department of Health

The Changing Landscape of Mass Spectrometry-based Biochemical Second-tier Newborn Screening
Kostas Petritis, PhD, Center for Disease Control and Prevention

Newborn Screening for Mucopolysaccharidoses: Evolution and Improvement of a Two-tier Screening Approach
Patricia Hall, PhD, Mayo Clinic

Dual 2nd-tier Screening of Lysosomal Disorders Glycogen Storage Disease Type II (Pompe) and Mucopolysaccharidosis I (MPS I) with Biochemical and Sequencing — A Comparison of Data, Benefits and Outcomes
Michelle Mills, MS, Kansas Department of Health and Environment
Newborn Screening for the Homocystinurias (Classical Homocystinuria and Remethylation Disorders) — Expanding and Improving Biomarkers and Algorithms
Devinder Kaur, PhD, New England Newborn Screening Program

Vitamin B12 Deficiency: Implications for Newborn Screening
Graham Sinclair, PhD, British Columbia Children’s Hospital

10:00 am – 10:30 am  Break

10:30 am – 12:00 pm
Pilot Studies
Moderators:
• Aranjeet Singh, MA, MCHES, Washington State Public Health Laboratory
• Susan Berry, MD, University of Minnesota

Reimaging Newborn Screening Pilots: Models, Mining and More
Amy Brower, PhD, American College of Medical Genetics and Genomics

It Takes a System: Implementation of Screening for Pompe Disease, MPS I and Krabbe Disease in Georgia — Pilot Studies, Post-analytical Tools, Second-tier Testing and a Lot of Communication
Patricia Hall, PhD, Mayo Clinic

ScreenPlus: A Pilot Study to Screen for 14 Disorders: Overview, Challenges and Preliminary Results
Joseph Orsini, PhD, New York State Department of Health

Staged Newborn Screening for Common Childhood Diseases — The Combined Antibody Study for Celiac And Diabetes Evaluation (CASCADE Study)
William Hagopian, MD, PhD, University of Washington

12:00 pm  Symposium Adjourns

12:30 pm – 4:00 pm
Optional Tour to the Washington State Public Health Laboratory, Newborn Screening Laboratory

Please keep in mind that this schedule is a work in progress and is subject to change.