Newborn Screening Symposium
October 15–19 • Sacramento, CA

Symposium Highlights

Sponsored by the Association of Public Health Laboratories and the International Society for Neonatal Screening

Co-Sponsored by the California Department of Public Health

www.aphl.org/NBS2023
#APHLNBS
About the Symposium

The APHL Newborn Screening Symposium is an annual international gathering of more than 600 public health professionals that includes exhibits featuring the latest in laboratory technology and newborn screening systems practice.

The International Society for Neonatal Screening (ISNS) joins us in a truly international meeting with emphasis on practices and goals shared by our partners throughout the world.

The symposium will address state, national and international newborn screening, genetic testing and policy issues important to public health newborn screening systems. Topics include molecular technologies, current and upcoming conditions, quality improvement, communicating with families and the public, and short- and long-term follow-up.

Participants will enhance their knowledge of national and international newborn screening and genetics as related to emerging laboratory technologies, follow-up, candidate conditions, quality improvement and clinical outcomes.

20+ Scientific Sessions and 75+ Posters
Learn about new technology, trends and issues regarding a variety of topics in newborn screening and genetics.

Networking
Reconnect with old friends and meet new ones! Get inspired by your peers. Renew excitement about your science, your work, your mission and public health.

Continuing Education Credits
Earn P.A.C.E.®, CME, CNE, CHES, CPH and Genetic Counselor credits.

20+ Exhibitors
Discover new products and services, and speak directly with industry partners and company reps.

Parent/Patient Panel
Hear compelling personal accounts of how newborn screening impacts the lives of families. Follow their journeys from screening and diagnosis to treatment and management.

APHL and ISNS Newborn Screening Symposium Awards
Recognize your colleagues for their amazing accomplishments during the APHL/ISNS Newborn Screening Symposium Awards event.

Fun and Engaging Activities
Unwind with your NBS friends at events such as the welcome reception, Ignite session and the Revvity off-site social.

24/7 Virtual Platform Access
Access all session/event recordings for 90 days after the event!
### Exhibitors

*as of July 19*

- Astoria-Pacific
- Asuragen
- Baebies
- Bio-Rad Laboratories
- BSD Robotics
- Cambridge Isotope Labs
- CDC
- EBF, LLC
- EveryLife Foundation for Rare Diseases
- Expecting Health/Baby’s First Test
- HCU Network America
- iConnect Consulting
- Intercientifica
- ImmunoIVD
- ISNS
- Labsystems Diagnostics
- LabVantage Solutions
- Natus
- OpenELIS Foundation
- Quantabio
- Revvity
- Sebia
- STAT Courier Service
- Ultragenyx
- Waters Corporation
- ZenTech

### Location

**SAFE Credit Union Convention Center**

1401 K St, Sacramento, CA 95814

### Hotels

APHL has secured a block of sleeping rooms at two hotels in downtown Sacramento — the *Hyatt Regency Sacramento* and the *Sheraton Grand Sacramento*. Both hotels are across the street from the SAFE Credit Union Convention Center, the location of the symposium.

The conference sleeping room rate is $209 plus tax at both hotels. These room rates are valid on a first come, first served basis until September 22, 2023 (Hyatt Regency) or September 25, 2023 (Sheraton Grand) or until the room blocks are filled. Both hotels offer a limited number of FY 2024 federal per diem rate rooms. The current per diem rate is $145 but the 2024 per diem rate could change on October 1, 2023. Details are on the [symposium website](https://www.aphl.org/NBS2023).

### Major Learning Goals of the Symposium

- Discuss and evaluate quality assurance and quality control measures for newborn screening laboratories
- Evaluate the effectiveness of current newborn screening and genetics follow-up programs
- Describe state and international experiences with candidate conditions and clinical outcomes in newborn screening

### 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

### Registration

Online registration is now open. The in-person early rate of $675 is valid through September 15. The virtual registration fee is $550. Details are on the Symposium website [www.aphl.org/NBS2023](https://www.aphl.org/NBS2023).

**Registration Fees:**

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<th>Badge Type</th>
<th>In-person</th>
<th>Virtual</th>
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<tr>
<td>Full Conference (early)</td>
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[Symposium website](https://www.aphl.org/NBS2023)
Sunday, October 15

4:00 pm – 4:30 pm
Welcome

4:30 pm – 6:00 pm
Parent/Patient Panel (TBD)

6:00 pm – 7:30 pm
Welcome Reception

Monday, October 16

7:00 am – 8:00 am
Innovate! Sessions: Revvity and Waters Corporation (TBD)

8:00 am – 8:30 am | Break

8:30 am – 10:00 am
Concurrent Sessions:
Short-term and Long-term Follow-up, Part 1

• Barriers and Facilitators to Initial Follow-up and Care Engagement for Newborns with Sickle Cell Disease: Results of the ENHANCE I Project
Najibah Galadanci, PhD, MBBS, MPH, University of Alabama at Birmingham

• A Five-Year Review of Newborn Screening for Spinal Muscular Atrophy in Utah
Kim Hart, MS, LCGC, Utah Newborn Screening Program

• Minnesota Longitudinal Follow-up With Families That Have a Child With a Newborn Screening (NBS) Condition: Findings From Local Public Health (LPH) Nursing Assessment
Lexie Barber, MPH, Minnesota Department of Health

• Adrenoleukodystrophy National Registry: A Longitudinal Monitoring Platform for Newborns Diagnosed with Adrenoleukodystrophy
Ashish Gupta, MD, MPH, University of Minnesota

New Methodologies

• Province-wide Genomic Screening for Permanent Hearing Loss Risk: The First 3 Years’ Experience in Ontario
Lauren Gallagher, MS, Newborn Screening Ontario

• A Novel Dried Blood Sample (DBS) Based N-glycan Analysis Paves the Way for Newborn Screening of CDGs
Ernest James Paul Daniel, MD, The Childrens’ Hospital of Philadelphia

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

10:00 am – 10:30 am
Break | Visit the exhibitors and posters

10:30 am – 12:30 pm
Keynote Session (TBD)

• Maurizio Scarpa, MD, PhD, Azienda Sanitaria Universitaria
• Jerry Vockley, MD, PhD, UPMC Children’s Hospital of Pittsburgh
• Robert Nussbaum, MD, Invitae
• Haydar A. Frangoul, MD, MS, Cellular Therapy @TriStar Centennial

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

1:30 pm – 2:00 pm
Dessert in the exhibit hall

2:00 pm – 3:30 pm
Concurrent Sessions:
Short-term and Long-term Follow-up, Part 2

• Progressing from Post-its to Production: North Dakota’s Experience in Building a Long-term Follow-up System for Newborn Screening
Joyal Meyer, RN, MSN, North Dakota Health and Human Services

• Strengthen and Expand the Core Capacity of Long-term Follow-up Model System in New York
Kathy Chou, PhD, New York State Department of Health

• Six Years of X-linked Adrenoleukodystrophy Long-term Follow-up in California
Jamie Matteson, MPH, California Department of Public Health

• The Tip of the Iceberg: Long-term Follow-up for Congenital Hypothyroidism
Patricia Hall, PhD, Mayo Clinic

• Use of Hydroxyurea for Treatment of Sickle Cell Disease in Children Identified by Newborn Screening and in Long-term Follow-up Care in California
Trish McLendon, MPH, California Department of Public Health
Data Analytics and Bioinformatics

• Harmonization of Mass Spectrometry Data For Advanced Analytics and Tool Development
  Nicolas Szabo, PhD, Utah Public Health Laboratory

• Enhancing Data-driven Disease Detection in Newborns: An Update on the CDC ED3N Project
  Amy Gaviglio, MS, CGC, Connetics Consulting/CDC/APHL

• Developing Data Mining Applications to Improve the Accuracy of Newborn Metabolic Disease Screening
  Curt Scharfe, MD, PhD, FACMG, Yale University School of Medicine

• Standards Work Better with Standardization: How Newborn Screening Programs Can Help Informaticists Improve NBS Interoperability
  Brendan Reilly, BS, Texas Department of State Health Services

• Achieving NBS Interoperability in California: Strategies, Progress and Lessons Learned
  Stan Sciortino, MPH, PhD, California Department of Public Health

3:30 pm – 4:00 pm
Break | Visit the exhibits and posters

4:00 pm – 5:30 pm
Concurrent Sessions:
Financial, Legal, Ethical, Policy and Social Implications
(FLEPSI)

• The Role of Race/Ethnicity in Evaluating Newborn Screening Performance
  Hao Tang, PhD, California Department of Public Health

• Implementation of a Broad Consent Education Tool for Retention of Newborn Screening Dried Bloodspots
  Erin Johnson, PhD, University of Utah

• The “Screen” Versus “Don’t Screen” Conundrum: Revisiting the Net Benefit Equation in Newborn Screening
  Don Bailey, PhD, RTI International

• Convening the Community to Identify Opportunities to Enhance Our Newborn Screening System: Action Items Yielding from the Newborn Screening Modernization Roundtable Series
  Dylan Simon, MS, EveryLife Foundation for Rare Diseases

• Increasing Equity of Screening for Critical Congenital Heart Disease (CCHD) Among Infants Born Out-of-Hospital
  Kristen Thompson, MPH, Michigan Department of Health and Human Services

5:30 pm – 6:00 pm | Break

6:00 pm – 7:30 pm
Genetics Privacy Session Part 2 (TBD)

Tuesday October 18 – ISNS Day

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

8:00 am – 8:30 am | Break

8:30 am – 10:30 am
The Development of Newborn Screening in Low and Middle Income Countries (LMICs)
Moderator: Dianne Webster, PhD, Auckland City Hospital

• Developing Newborn Screening in Low and Middle Income Countries: Principles and Practice
  James R. Bonham, PhD, Sheffield Children’s Hospital

• Long Term Care Beyond Newborn Screening Through Continuity Clinics in the Philippines and Other Lessons When Developing Screening in LMICs
  Carmencita Padilla, MD, MAHPS, University of the Philippines, Manila

• Developments in Delhi
  Seema Kapoor, MD, Maulana Azad Medical College and Lok Nayak Hospital

• Developing Newborn Screening in South Africa — A Valuable Model
  Chris Vorster, Centre for Human Metabolomics, North-West University
• Advancing Newborn Screening in Latin America — Initiative for Implementing a National Program in the Dominican Republic
  Van Leung-Pineda, PhD, DABCC, Children’s Healthcare of Atlanta

• Egypt’s NBS Journey from Past to Future
  Lamyaa Mohamed Kamal Fadl Mohamed, MD, Egyptian Centers for Disease Control and Prevention

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

10:30 am – 11:00 am
Break | Visit the exhibits and posters

11:00 am – 12:30 pm
The Development of Newborn Screening in Low and Middle Income Countries (continued)
Moderator: Van Leung-Pineda, PhD, DABCC, Children’s Healthcare of Atlanta

• Newborn Screening for Sickle Cell Disease in Africa
  Andrew Zapfel, MPH, American Society of Hematology

• Sickle Cell Disease in Ghana — The Role of Newborn Screening
  Solomon Ofori-Acquah, PhD, Vascular Medicine Institute, University of Pittsburgh

• The Development of Newborn Screening in Latin America
  Gustavo Borrajo, PhD, Congenital Error Detection Program of the Argentine Biochemical Foundation of La Plata

• Screening for Inborn Errors as Part of Comprehensive Newborn Screening: Cost and Efficacy Improvement Strategies for Better Quality of Life for Children in LMICs
  Sreerahi Madhavankutty Nair, MD, Indian Ministry of Health & Family Welfare

• Visualizing the World of Neonatal Screening: An Interactive Map for the 21st Century
  Peter Schielen, PhD, International Society for Neonatal Screening

12:30 pm – 2:00 pm
Lunch in the exhibit hall | Visit exhibits and posters

2:00 pm – 3:50 pm
The Role of Genomics as a First Line Test in Newborn Screening
Moderator: Peter Schielen, PhD, International Society for Neonatal Screening

• Genomics, A New Tool to Use in Newborn Screening?
  Robert Nussbaum, MD, Invitae

• The Project Screen4care: A Multidisciplinary Approach Combining Genetic Newborn Screening and Artificial Intelligence to Achieve an Early Diagnosis of Rare Diseases
  TBD

3:50 pm – 4:10 pm
Break | Visit the exhibits and posters

4:10 pm – 6:00 pm
The Role of Genomics as a First Line Test in Newborn Screening (continued)
Moderator: James R. Bonham, PhD, Sheffield Children’s Hospital

• Next Generation Sequencing in the Diagnostic Workup of Neonatal Dried Blood Spot Screening in Sweden
  Anna Wedell, MD, PhD, Karolinska Institutet

• An Integrated Multiomics Approach to the Expansion of Newborn Screening for Genetic Disorders
  Enzo Ranieri, PhD, University of Adelaide

• Ethical Issues When Using Genomics
  Amy Gaviglio, MS, CGC, Connetics Consulting

• Panel Discussion

6:00 pm – 6:30 pm | Break

6:30 pm – 7:30 pm
Ignite Session (TBD)

Wednesday, October 18

7:00 am – 8:00 am
Roundtables:

• User-focused, Large-scale Approaches to Informed Consent for Newborn Screening
  Holly Peay, PhD, RTI International

• The Need for a Comprehensive Workflow Analysis of Newborn Screening Communication to Support Quality Improvement and Intervention Design
  Karen Eilbeck, MSc, PhD, University of Utah

• How? When? If? Emerging Challenges with Prognostic Uncertainty in NBS
  Anne Atkins, MPH, Children’s National Research Institute

8:00 am – 8:30 am | Break
8:30 am – 10:00 am
ACHDNC Session (TBD)

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

10:00 am – 10:30 am
Rapid Poster Presentations (TBD)

10:30 am – 11:00 am
Break | Visit the exhibits and posters

11:00 am – 12:30 pm
Concurrent Sessions:
Adoption and Use of Second-tier Testing

• Expanding the Utility of Dried Blood Spot Glycosaminoglycan Second Tier Testing: Observations from Early Mucopolysaccharidosis Type II Screening Patricia Hall, PhD, Mayo Clinic

• A Closer Look at Results from a Second-Tier Test for Congenital Adrenal Hyperplasia in Texas Patricia Hunt, Texas Department of State Health Services

• Validation and Initial Results of Improved Second-tier Testing of Dried Blood Spots for Newborn Screening for the Homocystinurias (Classical Homocystinuria and Remethylation Disorders) Devinder Kaur, PhD, New England Newborn Screening Program

• Second-tier Glycosaminoglycan Analysis in Dried Blood Spots by the Endogenous Non-Reducing End Method Provides the Best Approach for Reducing False Positives in Newborn Screening of MPS-I and MPS-II Michael Gelb, PhD, University of Washington

Emergency Preparedness and Contingency Planning

• Updating the National Newborn Screening Contingency Plan (CONPLAN) Scott M. Shone, PhD, HCLD(ABB), North Carolina Department of Health and Human Services

• Lessons Learned: Maintaining Operations for a Two-Screen Newborn Screening Program Through a Full Laboratory Building Shutdown Gwen Hanley, MS, RN, Texas Department of State Health Services

• The Oklahoma Newborn Screening Laboratory: Sent Through Warp Speed Changes, Going Where No Lab Has Gone Before Jeremy Thompson, Oklahoma State Department of Health

• Newborn Screening In a Time of Crisis: Lessons Learned During the COVID-19 Pandemic Urh Groselj, MD, PhD, MA, UMC — University Children’s Hospital Ljubljana

• The Iowa COOP CQI Project: Developing, Testing and Implementing a COOP Communications Plan Carol Johnson, CMA, Iowa Newborn Screening Program

12:30 pm – 2:00 pm
Lunch (in the exhibit hall) | Visit the exhibits and posters

2:00 pm – 3:30 pm
Concurrent Sessions:
Quality Improvement, Quality Control and Quality Assurance Activities

• Celebrating 45 Years of CDC’s Newborn Screening Quality Assurance Program Joanne Mei, PhD, Centers for Disease Control and Prevention

• A Novel Biomarker Indicative of Total Parenteral Nutrition Administration Multiplexed into Primary Tier Newborn Screening Assays C. Austin Pickens, PhD, Centers for Disease Control and Prevention

• One SIP at a Time: Quality Improvement for Cystic Fibrosis Newborn Screening Marissa Rollins, MPH, Cystic Fibrosis Foundation

• Improving NBS Quality at the Birthing Facility Level Through the Implementation of NBS Audit Procedures and Site Visits Jennifer Weaver, Indiana Department of Health

• Intra-laboratory Variation of the ImmunolVD SPOT-it TREC Screening Kit Highlights the Need to Review Newborn Screening Algorithms to Ensure They Are Consistent with Analytical Performance Rachel Carling, PhD, MSc, Synnovis, Guys & St Thomas’ NHSFT

Conditions Commonly Included in National Screening Panels

• Rapid LC-MS/MS First-Tier Newborn Screening Assay with Intelligent Reflex to Second-tier Screening Samantha Isenberg, MD, Centers for Disease Control and Prevention

• Evaluation of the Performance of the Dutch Newborn Screening for Tyrosinemia Type 1 Marelle Bouva, PhD, RIVM, Centre for Health Protection, The Netherlands

• Updates on Newborn Screening for ALD in New York: 9 Plus Years of Screening, Case Reviews and Correlation of Screening Results with Variants of Uncertainty Versus Known Pathogenicity Joseph Orsini, PhD, New York State Newborn Screening Program

• Harmonization of TREC Screening Results Using Developmental Quality Control Dried Blood Spot Materials Christopher Greene, PhD, Centers for Disease Control and Prevention
Please keep in mind that this schedule is a work in progress and subject to change.