

**Global Newborn Screening Engagement: Stakeholders Meeting**

**Date:** April 27, 2019

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## Meeting Attendees

Name	Email
<b>Association of Public Health Laboratories</b>	
Jelili Ojodu	<a href="mailto:Jelili.Ojodu@aphl.org">Jelili.Ojodu@aphl.org</a>
Sikha Singh	<a href="mailto:Sikha.Singh@aphl.org">Sikha.Singh@aphl.org</a>
Careema Yusuf	<a href="mailto:Careema.Yusuf@aphl.org">Careema.Yusuf@aphl.org</a>
Guisou Zarbalian	<a href="mailto:Guisou.Zarbalian@aphl.org">Guisou.Zarbalian@aphl.org</a>
<b>Centers for Disease Control and Prevention (CDC)</b>	
Robert Vogt	<a href="mailto:rvogt@cdc.gov">rvogt@cdc.gov</a>
<b>Pediatric Endocrine Society - International Relations Committee</b>	
Yun Yan	<a href="mailto:yyan@cmh.edu">yyan@cmh.edu</a>
Sripriya Raman	<a href="mailto:Sripriya.Raman3@chp.edu">Sripriya.Raman3@chp.edu</a>
Julia von Oettingen	<a href="mailto:julia.vonoettingen@mcgill.ca">julia.vonoettingen@mcgill.ca</a>
Maynika Rastogi	<a href="mailto:Rastogi.Maynika@gmail.com">Rastogi.Maynika@gmail.com</a>
Luisa Fernanda Gonzalez Ballesteros	<a href="mailto:Luisafgonzalezb@gmail.com">Luisafgonzalezb@gmail.com</a>
<b>Vanderbilt University Medical Center</b>	
Michael DeBaun	<a href="mailto:m.debaun@vumc.org">m.debaun@vumc.org</a>
Ed Trevathan	<a href="mailto:Edwin.Trevathan@vumc.org">Edwin.Trevathan@vumc.org</a>

Attendee biographies are found in [Appendix 1](#).

## Background

Newborn Screening (NBS) is a highly effective public health practice that can prevent death and disability in infants and children affected by certain congenital disorders. Although a public health infrastructure for population-wide NBS has been established in many countries, millions of newborns in underserved populations globally remain unscreened. Affected and vulnerable children, their families, and the communities in these unscreened populations do not receive the benefits that early identification through NBS confers. As recognition of this disparity grows, the expansion of NBS to unscreened populations has become a mounting priority among public health proponents and health care professionals in both government and non-governmental organizations.

During the 2019 Pediatric Academic Societies (PAS) meeting, the Pediatric Endocrine Society (PES) convened a meeting of its International Relations Committee (IRC) with global expansion of NBS for congenital hypothyroidism as one of its targeted initiatives. The following day, five

of the PES-IRC members met with several other pediatricians and public health newborn screening experts to review and compare experiences, approaches, obstacles, pathways, and work in progress toward NBS global expansion. The two-hour discussion among these stakeholders is summarized in this report.

### **Discussion Summary**

The discussion focused on newborn screening for two conditions: Congenital Hypothyroidism (CH) and Sickle Cell Disease (SCD). These conditions are included in most established public health newborn screening programs because of their relatively high birth prevalence and the benefits provided by early identification and treatment.

#### **Congenital Hypothyroidism (CH)**

- The Pediatric Endocrine Society's (PES) International Relations Committee (IRC) has been working on improving the status of global newborn screening for congenital hypothyroidism.
- In collaboration with Global Pediatric Endocrinology and Diabetes (GPED), a non-profit organization registered in Canada, the PES-IRC is working on a project in India where culturally sensitive videos are being developed to raise awareness around newborn screening. In 2018, two landmark papers (1,2) were published by the Indian Society for Pediatric and Adolescent Endocrinology (ISPAE) with the goal of supporting initiation of activities around CH screening on the subcontinent. Furthermore, the Indian Journal of Pediatrics published a number of studies led by the Indian Council of Medical Research (ICMR) Task Force on Inherited Metabolic Disorders to inform efforts in India (3-5).
- Several members of [PES IRC](#) are also working with pediatric endocrinologists in developing countries globally to stimulate efforts in initiating or improving local newborn screening programs (Dr. Raman – India, Dr. Rastogi – Trinidad, Dr. von Oettingen – Haiti, Dr. Gonzalez – Columbia, and Dr. Yan – China).
- These recent efforts reflect the long-standing recognition that newborn screening can dramatically reduce the heavy social and economic burdens caused by CH (6).

## Sickle Cell Disease (SCD)

- Dr. DeBaun at the Vanderbilt Institute for Global Health (VIGH) has obtained funding for an initiative to implement newborn screening for SCD in the state of Kano in northern Nigeria, where SCD prevalence is estimated at 3 per 100 births (7). There are operational barriers to transferring funds for use in Nigeria which are currently being addressed. Because of the high birth prevalence, the potential public health impact of NBS for SCD is substantial.
- VIGH has implemented strategies for genetic counseling and integration of religious and state leaders which have proved successful in Kano. Community support for newborn screening is very strong.

## Overcoming Barriers

- Understanding the logistical steps to establish and operate a NBS program.
- Finding sources of provisional funding to implement NBS pilot studies.
- Working with local governments to lead coordination efforts for newborn screening with public and private entities with the goal of improving efficiency and avoiding duplication of efforts.
- Encouraging governmental authorities to provide sustained funds for universal NBS programs.
- Identifying and adapting to cultural sensitivities.
- Arranging access to the essential elements for NBS: Dried blood spot (DBS) collection materials; training for health workers and laboratory technicians in DBS collection and analysis; obtaining and maintaining laboratory facilities and equipment; establishing a stable infrastructure for follow-up and treatment.

## Facilitators

- The United States public health infrastructure at the federal and state government levels provides a strong foundation for education, training, counseling, laboratory

implementation, systems quality improvement, technical assistance, and data collection.

- The potential exists to translate current non-monetary resources (training, technical assistance, educational resources) available in the United States through the Association of Public Health Laboratories (APHL) to other interested countries.
- APHL has in-country offices in several African countries (Mozambique, Zambia, , Ghana, Tanzania), allowing for boots on the ground if resources allow.
- The CDC Foundation provides a pathway to raise donated funds and distribute them to international public health programs through both competitive applications and directed grant distributions.

#### **Potential Actions, Considerations, and Next Steps**

- All vested partners should assemble a collaborative workgroup to establish goals, objectives and action items that will advance newborn screening in underserved populations globally. Birth prevalence, severity, and the availability of interventions should be considered in choosing the initial target conditions for screening.
- Consider point-of-care (POC) testing rather than centralized testing with dried blood spot specimens to introduce population screening in medically underserved populations, especially in areas with limited infrastructure for information dissemination and follow-up activities.
  - Several POC testing devices to detect CH, including newborn screening testing, are currently under development, and some are commercially available (see <https://www.thyroid.org/wp-content/uploads/publications/lab-services/ata-poc-thyroid-management.pdf>)
  - Consider the impact that ambient temperature and humidity may have on Thyroxine and Thyroid Stimulating Hormone (TSH) degradation or elution on dried blood spots over time, as well as on the drying time required for blood spots.

- To ensure ethical, religious, and cultural standards, when establishing NBS-related projects, technologic capability cannot be uncoupled from public health principles. NBS is a system that requires a sophisticated environment of support including professional-level skills, training, equipment, periodic evaluation and assessment, and leadership (8,9).
- Remain mindful of the need to maintain standards for timeliness and quality in medically underserved areas that are comparable to those that exist in established NBS programs.
- Develop a mindful and constructive plan to engage with women actively when introducing newborn screening into underserved areas and populations. Mobilize this stakeholder group as champions of NBS for vulnerable populations, acknowledging that their engagement is paramount to a successful program and community buy-in.
  - Culturally sensitive education and outreach programs should involve women in all settings being explored.
  - Health literacy of each population should be examined in order to introduce the most effective education and communication models.
- Research questions and considerations:
  - What is the best approach to testing? POC testing versus DBS collection and analysis at a central laboratory versus cord blood screening (cord blood for congenital hypothyroidism screen), while considering unique specificities in each region/country.
  - What is the best utility of mobile phones? Pursue modern solutions to modern problems (example: [One World Medical Network](#) in sub-Saharan Africa).
- Pursue pilot projects based on implementation science.
  - What is the hypothesis in the implementation science domain?
    - Essential factors
      - Informatics
      - Training
      - Logistics

- Quality Control
- Pilot size: large sample size required in the pilot population
- Disorders
  - Use process of elimination for deciding which disorders to focus on, ensuring comprehensive and deductive criteria are used to finalize the list.
    - Highest overall prevalence of conditions detected by newborn screening in all populations. Specifically,
      - CH (highest overall prevalence across many populations) and SCD (highest prevalence in malaria endemic regions) may be the most logical choices given their relatively high prevalence with the caveat that there are nuances related to population genetics.
  - What resources currently exist in the target regions that vulnerable (newborn) populations can benefit from? Layer resources and infrastructure as opposed to starting from new.
- Implementation will require governmental support.

## **Publications**

- Specific publications cited in this report are listed in the bibliography below. General literature resources relevant to NBS global expansion include the following:
  - A book entitled “Screening of Newborns for Congenital Hypothyroidism: Guidance for Developing Programs” (6) composed by Drs. Carmencita Padilla and Brad Therrell was published in 2005 by the International Atomic Energy Agency. Although it focuses on CH and does not contain the most current information, it remains a valuable treatment of the general principles that must be addressed for NBS expansion into underserved populations. A PDF download is available at

<https://www.iaea.org/publications/7205/screening-of-newborns-for-congenital-hypothyroidism> An updated edition is anticipated.

- The International Society for Neonatal Screening (ISNS) supervises the publication of *International Journal of Neonatal Screening (IJNS)*, a peer-reviewed open-access journal focused on newborn screening and neonatal medicine. It is published quarterly online and contains a section with well-prepared case reports.
  - ISNS also provides a valuable Literature Service available to members at the following link: <http://membership.isns-neoscreening.org/member/login/>.
  - The Clinical and Laboratory Sciences Institute (CLSI) publishes a series of guidelines and operational standards devoted to newborn screening. The catalog of CLSI newborn screening documents is available at <https://clsi.org/standards/products/newborn-screening/documents/>
- CDC is developing a framework for a special report on the global status and future directions of newborn screening. One possible venue for publication is *Morbidity and Mortality Weekly Report (MMWR)*, the public health digest that serves as the main vehicle for CDC to disseminate public health information and recommendations. In addition to its weekly reports, *MMWR* also publishes occasional special reports on particular public health topics.

### **Potential Partnerships and Funding Sources**

#### Professional/Non-Profit/Governmental Organizations

- [American Society of Hematology](https://www.hematology.org/Advocacy/Sickle-Cell/) (ASH)
  - ASH is undertaking a multifaceted initiative to address the burden of sickle cell disease (SCD), both in the United States and globally (<https://www.hematology.org/Advocacy/Sickle-Cell/>).

- The ASH website includes a short documentary about sickle cell disease, set in sub-Saharan Africa, that addresses the need for newborn screening. It may be accessed at directly at <https://youtu.be/x7fLBI3SDAE>.
- [Pediatric Endocrine Society](#) (PES)
  - The PES International Relations Committee ([https://www.pedsendo.org/members/CommitteesCouncils/assets/Committee\\_Brief\\_Descriptions2.pdf](https://www.pedsendo.org/members/CommitteesCouncils/assets/Committee_Brief_Descriptions2.pdf)) is charged with the development of international collaboration to globally benefit children with endocrine conditions, especially those in resource-constrained environments. Expanding newborn screening for CH into unscreened populations is among its leading priorities.
- [Global Pediatric Endocrinology and Diabetes](#): a non-profit organization with the mission to improve endocrine care for children in low- and middle-income countries.
- [International Society for Neonatal Screening](#) (ISNS)
  - ISNS has nearly 500 members in over 70 countries around the globe. It aims to advance screening for newborn and infant sicknesses and disorders, worldwide.
- [Grand Challenges Canada](#)
  - Grand Challenges Canada funds innovators in low- and middle-income countries and Canada to catalyze innovation that saves and improves the lives of the most vulnerable in Canada and low- and middle-income countries.
  - Newborn screening relates to the focus on [Sustainable Development Goal 3](#), to ensure healthy lives and promote well-being for all at all ages.
- [Vanderbilt Institute for Global Health](#)
  - The VIGH mission is to provide leadership in interdisciplinary education, research, service and advocacy for health and development in resource-limited settings around the world.
- World Health Organization (WHO)
  - WHO addresses newborn screening in a 1998 document entitled “*Proposed International Guidelines on Ethical Issues in Medical Genetics and Genetic Services*” ( <http://www1.umn.edu/humanrts/instreet/guidelineproposal.html>)

## Foundations

- [CDC Foundation](#)
  - The CDC Foundation, an independent nonprofit organization, is the sole entity created by Congress to mobilize philanthropic and private-sector resources in support of the Centers for Disease Control and Prevention's critical health protection work. It has a long-standing history of collaboration with the CDC Newborn Screening and Molecular Biology Branch (<https://www.cdcfoundation.org/newbornscreening>).
- [The Bill & Melinda Gates Foundation](#)
  - The Gates Foundation [Maternal, Newborn, and Child Health Program](#) works to ensure that women and newborns survive and remain healthy before, during, and after childbirth.

## Private Sector

- Pharmaceutical Companies
- Laboratory Suppliers
- Biotechnology Developers

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9. Therrell BL Jr, Schwartz M, Southard C, Williams D, Hannon WH, Mann MY, PEAS Organizing and Working Groups. Newborn Screening System Performance Evaluation Assessment Scheme (PEAS). Semin Perinatol. 2010;34(2):105-20.

## **Appendix 1 | Attendee Biographies**

### **Michael R DeBaun**

#### **Vanderbilt University School of Medicine**

[m.debaun@vumc.org](mailto:m.debaun@vumc.org)

Dr. DeBaun is Professor of Pediatrics and Medicine, Vice Chair of Clinical and Translational Research in the Department of Pediatrics and holds the JC Peterson Endowed Chair at Vanderbilt University School of Medicine. For over two decades, Dr. DeBaun has received continuous funding from the National Institute of Health (NIH) and Robert Wood Johnson, Doris Duke and Burroughs Wellcome foundations. Dr. DeBaun was the primary physician author of the Sickle Cell Treatment Act, signed by President Bush into law on Oct. 22, 2004 Title VII, creating regional networks for enhanced services for with SCD. His research efforts in SCD have focused on the clinical epidemiology of acute and chronic lung disease, sequelae of silent and overt strokes, including leading eight investigator-initiated controlled stroke trials in North America, Europe, and Africa. Additionally, in Ghana, he was the leader of multi-disciplinary team decreasing the death rate of pregnant women with SCD by approximately 90%. Dr. DeBaun is an elected member of the American Society of Clinical Investigation (2006), Association of American Physicians (2008) and National Academy of Medicine (2009). He has received the Ernest Beutler Prize and Lecture in Clinical Science from the American Society of Hematology (2014) and two international mentor awards for his work in Ghana, Nigeria and U.S.: the Maureen Andrews Mentor Award from the Society of Pediatric Research (2017) and the American Society of Hematology Mentor Award (2019).

### **Luisa F. Gonzalez Ballesteros, MD, FAAP**

#### **Lenox Hill Hospital/Northwell Health**

[luisafgonzalez@gmail.com](mailto:luisafgonzalez@gmail.com)

Dr. Gonzalez was born and raised in Colombia. Her interest in medicine has been with her from childhood as she represents the second generation of physicians in her family. She obtained her medical degree from one of the most prestigious universities in Colombia, Pontificia

Universidad Javeriana, and Hospital Universitario San Ignacio. She continued her postgraduate education in the United States by completing residency in pediatrics at Lincoln Medical and Mental Health Center, Weill Cornell Medical College. During these years she developed a strong interest in pediatric endocrinology and decided to pursue an endocrinology fellowship at the Children's Hospital of Pittsburgh of UPMC. She then applied for her second fellowship and was accepted in neonatal-perinatal Medicine at Yale-New Haven Children's Hospital of Yale University. She is also a diplomate of the American Board Of Obesity Medicine After these unique learning experiences of two fellowships and extraordinary exposure to highly recognized medical centers, Dr. Gonzalez is one of the few physicians with a double specialty to join the team of Northwell Health/ Lenox Hill Hospital. Dr Gonzalez is a member of the Pediatric Endocrinology Society (PES) - International Relations Committee (IRC). Dr. Luisa Gonzalez is also a member of: AAP/SONPM, ABOM, ENDO and PES.

**Jelili Ojodu, MPH**

**Association of Public Health Laboratories**

[Jelili.Ojodu@aphl.org](mailto:Jelili.Ojodu@aphl.org)

Mr. Ojodu is the Director for newborn screening and genetics at the Association of Public Health Laboratories (APHL). He has worked in newborn screening and genetics for nearly the past two decades with significant experience in strengthening public and private partnerships. Mr. Ojodu holds a Master of Public Health in Maternal and Child Health and a Bachelor of Science in the Biological Sciences. He is a member of the International Society for Neonatal Screening (ISNS) and was honored in 2019 with the ISNS/Labystems Gerard Loeber Award for Contributions to Newborn Screening Expansion in Developing Countries.

**Sripriya Raman, MD**

**UPMC Children's Hospital of Pittsburgh**

[Sripriya.Raman3@chp.edu](mailto:Sripriya.Raman3@chp.edu)

Dr. Sripriya Raman completed medical school in Chennai, Tamil Nadu, India and subsequently moved to the United States of America to pursue further training in pediatrics and pediatric

endocrinology. She is now a faculty at the UPMC Children's Hospital of Pittsburgh. Dr. Raman has been a member of the Pediatric Endocrine Society (PES) International Relations Committee (IRC) since 2017. With her keen interest in spearheading the efforts of PES-IRC to expand newborn screening for congenital hypothyroidism globally, Dr. Raman led the Newborn Screening sub-committee in 2018-2019 and continues to be actively involved.

**Maynika Rastogi, MBBS, FAAP**

**North Bend Medical Center**

[dr.rastogi@nbmchealth.com](mailto:dr.rastogi@nbmchealth.com)

Dr. Rastogi was born and raised in Trinidad and Tobago in the Caribbean and attended medical school there. She completed her residency at SUNY Downstate, followed by Chief year. She completed a Pediatric Endocrinology fellowship at Oregon Health and Science University where she worked on research with Steve La Franchi, MD, Daniel Marks, MD, PhD and Bruce Boston, MD. Dr. Rastogi returned to Trinidad after fellowship and practiced in a rural hospital for 3 years before returning to the US where she now practice in a Rural Hospital Clinic in Southern Oregon where she does both pediatric endocrinology and General Pediatrics.

**Sikha Singh, MHS, PMP**

**Association of Public Health Laboratories**

[Sikha.Singh@aphl.org](mailto:Sikha.Singh@aphl.org)

Ms. Singh is the Deputy Director of the Newborn Screening and Genetics program at the Association of Public Health Laboratories (APHL), focusing on the management of the Newborn Screening Technical assistance and Evaluation Program (NewSTEPs). She joined APHL in 2009 and has significant experience in high-throughput genomic sequencing. Ms. Singh holds a Master of Health Science degree from the Johns Hopkins University and a Bachelor of Science degree from Temple University. She is a member of the Delta Omega Honorary Society in Public Health, a member of the ISNS, as well as the recipient of a Project Management Professional (PMP) certificate.

**Robert F. Vogt, Jr., PhD**

**Centers for Disease Control and Prevention**

[rvogt@cdc.gov](mailto:rvogt@cdc.gov)

Dr. Vogt is a research chemist in the CDC Newborn Screening and Molecular Biology Branch and serves as Principal Investigator of the Newborn Screening Translation Research Initiative, an ongoing collaborative partnership with the CDC Foundation. He received his graduate training in immunology, toxicology, and experimental pathology under Dr. Arthur M. Dannenberg, Jr. at the Johns Hopkins Bloomberg School of Public Health. His laboratory interests focus on measuring cellular and molecular biomarkers by quantitative fluorescence methods. Since 1999, his public health interests have focused on translating biomedical research findings into newborn screening tests for congenital disorders. Dr. Vogt has numerous professional affiliations including the ISNS and a lifetime membership in the Delta Omega Honorary Society in Public Health.

**Julia Elisabeth Von Oettingen, MD, PhD, MMSc**

**Montreal Children's Hospital**

[Julia.vonoettingen@mcgill.ca](mailto:Julia.vonoettingen@mcgill.ca)

Julia von Oettingen is a pediatric endocrinologist at the Montreal Children's Hospital, Assistant Professor at McGill University, and a Fonds de Recherche du Quebec Sante supported Clinician-Scientist at the McGill University Health Center Research Institute. Originally from Germany, she completed her MD-PhD at Leipzig University, her pediatric residency at the Massachusetts General Hospital in Boston, and her endocrine fellowship training at the Boston Children's Hospital. She obtained her master's in clinical and translational investigation from Harvard University. Dr. von Oettingen's research program focuses on global health in pediatric endocrinology, including epidemiology and phenotypes of diabetes in populations of non-European origin, and care delivery innovation in low-resource settings. She is the founding medical director of Kay Mackenson Clinic, a center for children with diabetes and other chronic diseases in Haiti that collaborates with the Haitian Diabetes Association to provide access to quality diabetes care countrywide. Julia is a site visitor and serves on the steering committee of the Life for a Child program, and is an executive committee member of Global Pediatric

Endocrinology and Diabetes. She is a technical adviser to Partners in Health in Haiti, consultant to UNICEF and the Ministry of Health in Haiti, and pediatric endocrinology consultant to Medecins Sans Frontieres.

**Yun Yan, MD, FAAP**

**Children's Mercy Kansas City**

[yyan@cmh.edu](mailto:yyan@cmh.edu)

Dr. Yan is an associate professor of pediatrics at the University of Missouri, Kansas City, director of the Type 2 Diabetes Prevention Program and a pediatric endocrinologist at the Children's Mercy Kansas City. Dr. Yan received an MD from the Henan School of Medicine in Henan, China and completed dual residencies in pediatrics in Zengzhou Central Hospital in China and at East Carolina University in North Carolina. Dr. Yan also completed a fellowship in Endocrinology at the University of North Carolina in Chapel Hill. Dr. Yan is board certified in pediatrics, pediatric endocrinology and is a fellow of the American Academy of Pediatrics.

**Careema Yusuf, MPH**

**Association of Public Health Laboratories**

[careema.yusuf@aphl.org](mailto:careema.yusuf@aphl.org)

Careema Yusuf is a Manager for the Newborn Screening, Technical assistance and Evaluation Program (NewSTEPS) at the Association of Public Health Laboratories (APHL) where she manages the overall activities related to the website and data repository system for NewSTEPS. Careema provides technical assistance and support related to quality practices, data analysis and reporting. She has worked in a variety of public health settings that have included training in outbreak investigation policies and procedures to health personnel in Ghana, working at the State of Maryland on HIV/AIDS prevention program performance measures and with Johnson, Bassin & Shaw International working on quality improvement activities within substance use treatment programs in the US. Ms. Yusuf holds a Master of Public Health from the George Washington University in Washington, DC.

**Guisou Zarbalian, MS, MPH**

**Association of Public Health Laboratories**

[Guisou.zarbalian@aphl.org](mailto:Guisou.zarbalian@aphl.org)

Guisou Zarbalian is a Newborn Screening and Genetics Manager at the Association of Public Health Laboratories (APHL) where she works closely with state public health laboratories and federal, local, and private partners to improve resources for newborn screening programs. Ms. Zarbalian earned a Master of Science in Pharmacology from Georgetown University and a Master of Public Health in Maternal and Child Health from the George Washington University. She has extensive experience in laboratory science, health communications, and research methodology.