

Open in app ↗



Search

Write



★ Get unlimited access to the best of Medium for less than \$1/week. [Become a member](#)



Global Leaders Convene in London: Advancing Newborn Sequencing on an International Scale



Genomes2People

4 min read · Just now



The second International Conference on Newborn Sequencing (ICoNS) brings together leading researchers in newborn sequencing.

by Rose Heald & Nic Encina



Photo credit: ICoNS

“Over the course of the next few decades, the availability of cheap, efficient DNA sequencing technology will lead to a medical landscape in which each baby’s genome is sequenced, and that information is used to shape a lifetime of personalized strategies for disease prevention, detection, and treatment.”

— Francis S. Collins, 2014

The sequencing of the first human genome was completed with the The Human Genome Project in 2003. Now, twenty years later, conversations about the widespread genome sequencing of newborn babies are happening all over the world. Newborn genome sequencing has the potential to completely transform newborn screening and health care as we know it. So: Are we ready?

In 2015, Phase I of The BabySeq Project was a first-of-its-kind randomized clinical trial designed to assess the use of genomic sequencing in routine

newborn care. Since then, research on newborn sequencing has accelerated as more programs are taking on the question of how to make newborn sequencing a public health reality. In order to maximize efficiency and progress in this space, we'll need to prioritize collaboration and sharing among leaders and investigators. It was from this idea that the International Consortium on Newborn Sequencing (ICoNS) was born.

Earlier this month, leading researchers and experts in genomics and newborn sequencing representing the U.S., the U.K., Europe, Australia, and the Middle East came together in London at the Royal Institution for the second annual International Conference on Newborn Sequencing co-hosted with Genomics England to present updates regarding their own research and share future plans.

The annual conference is put on by the International Consortium on Newborn Sequencing, which was founded in 2022 by the leaders of eight newborn sequencing research projects (BabySeq, Genomics England, GUARDIAN Study, BeginNGS, Early Check, Screen4Care, ScreenPlus, and BabyBeyond) as a global alliance of stakeholders in this space. The Consortium has been intentional in seeking perspectives from and collaboration amongst scientists, government officials, industry leaders, healthcare providers, ethicists, and patient advocates who share a common vision of implementing newborn sequencing in public health.

Nicolas Encina, co-founder and Executive Director of ICoNS, explains that “robust and effective clinical implementation of newborn sequencing can only be achieved through common understanding and coordination across the critical stakeholders that are required to build the infrastructure necessary to support it at population levels.”



Robert Green shares updates on the BabySeq Project at ICoNS'23. Photo credit: ICoNS

Since its debut in 2022, the Consortium has doubled in size and now includes 17 newborn sequencing projects from seven countries around the globe. This year, the conference included presentations from 12 international newborn sequencing research projects (Generation Study, EarlyCheck, Screen4Care, BabySeq, ScreenPlus, BabyScreen+, GUARDIAN, Qatar Pediatric Precision Medicine Program, BeginNGS, PERIGENOMED, NewbornsInSA, and FirstSteps) complemented by panel discussions and additional sessions focused on critical issues in the newborn sequencing space, such as upstream tools and services and downstream support systems necessary for implementation, economic considerations, care delivery, health policy, patient perspectives, ethics, and data sharing.

In addition to being a platform for experts to discuss relevant issues in newborn sequencing, the conference also presented an opportunity for the Consortium to identify key priorities based on input from conferees. In a poll facilitated by Dr. Aaron Goldenberg, conferees identified having a space for idea exchange and harmonizing outcome measures as two of the most valuable ways that ICoNS can support consortium members.

An explicit objective of ICoNS is to harmonize evidence and address precompetitive industry challenges that benefit all participants. In that spirit, an ICoNS working group has been establishing a mechanism for

making project documents and materials available to new projects, aligning on terminology and metrics, and ultimately consolidating results data such that researchers may learn in aggregate, thereby propelling the field forward as a whole at a more rapid pace. At the 2023 meeting, Dr. David Bick, Dr. Nidhi Shah, and Rose Heald unveiled an ICoNS Member Network to facilitate easy communication and future data sharing within the consortium, which organizations and individuals may [request to join here](#) for free.

The Consortium is co-chaired by Drs. Robert Green (BabySeq) and David Bick (Genomics England). “We felt that creating a centralized place for collaboration and knowledge sharing is essential for driving research and innovation in this space,” said Robert Green, Director of Genomes2People. “ICoNS provides an excellent opportunity for global leaders in newborn sequencing to come together with the shared vision of preventing treatable disease before it even begins.”

Next year, [ICoNS will be held in New York City on October 9–10, 2024](#) (www.icons24.org). We hope to see you there!

[Rose Heald](#) is a Research Assistant with the Genomes2People Research Program at Brigham and Women’s Hospital and Harvard Medical School.

[Nic Encina](#) is Executive Director of the International Consortium on Newborn Sequencing (ICoNS) and Director of Strategy of the Precision Population Health Initiative at Ariadne Labs and Harvard T.H. Chan School of Public Health.

[Genetics](#)[Genetic Testing](#)[Medicine](#)[Neonatal Care](#)[Medical Conferences](#)



Written by Genomes2People


Edit profile

65 Followers

The G2P Research Program (www.genomes2people.org) is focused on the judicious integration of genomic research into personalized medicine & clinical practice.

More from Genomes2People



 Genomes2People


The True Cost of Whole Genome Sequencing

By Dr. Robert C. Green

4 min read · Sep 12, 2018

 137 

 Genomes2People

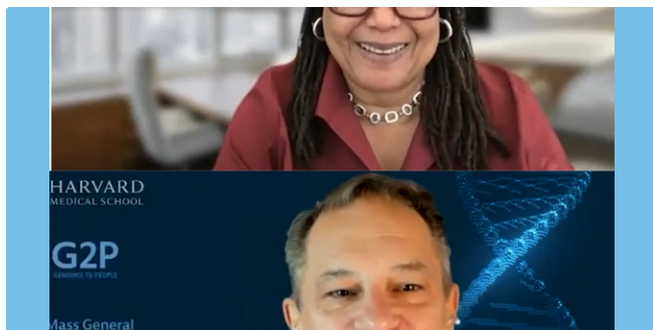
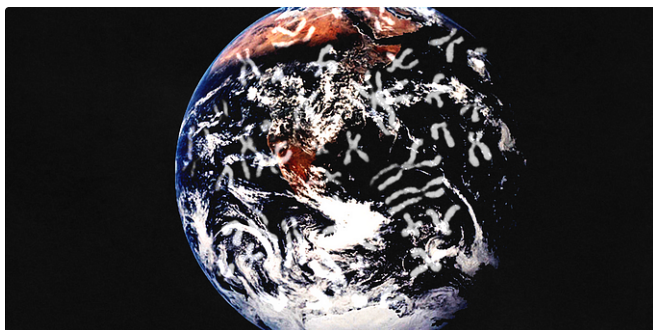
How overturning Roe v. Wade restricts the power of genomics


Sequencing the human genome was a transformative step for human health and...

5 min read · Aug 19, 2022

 57 



 Genomes2People

Race, Ancestry, and Representation: The Role of...


Race is a social construct, but representation matters in genetic studies—and on that fron...

6 min read · Sep 21, 2020



112



 Genomes2People

Making Genomics as Diverse as Humanity

The lack of diversity in genomic research may be a call to fundamentally change the...

4 min read · Nov 15, 2022



54



See all from Genomes2People