SickKids helping to expand access to genomic using the C-GUIDE measurement tool in the iHope program

SickKids is providing the C-GUIDE™ tool evaluation of iHope's genomic testing for the diagnosis, care, and well-being of children worldwide at no cost.

iHope: Diagnosing Sick Kids

DAMASCUS, MD, UNITED STATES, January 29, 2026 /EINPresswire.com/ -- Children living with rare genetic diseases often spend years searching for answers. Without access to advanced testing, families may face repeated misdiagnoses, ineffective treatments, and ongoing emotional strain. Recognizing this, The Hospital for Sick Children (SickKids) is working to ensure that the benefits of genomic medicine can reach more families worldwide.

In 2024, genomic diagnostic laboratories at SickKids and the Children's Hospital of Eastern Ontario (CHEO) joined the iHope program of Genetic Alliance, a global non-profit initiative to provide genomic testing and follow-up services for children with limited access. Through a growing network of 25 clinical partners across 12 countries, the program has already provided genome sequencing to thousands of individuals.
To support this effort, the SickKids Industry Partnerships & Commercialization (IP&C) team finalized a non-exclusive license allowing Genetic Alliance to use the C-GUIDE™ (Clinician-reported Genetic testing Utility InDEx) at no charge.

> We are excited to support Genetic Alliance's mission to improve access to genomic testing. C-GUIDE™ will help measure the real-world impact of clinical genome sequencing in diverse communities."
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> *Dr. Robin Hayeems, Principal Investigator for C-GUIDE™*

The C-GUIDE™ is a validated outcome measure that reflects the clinical utility of genetic testing from the provider's perspective. By assessing how

iHope's testing influences diagnosis, medical management, risk awareness, and overall patient and family well-being, the program aims to build evidence that can guide future decision-making and encourage broader adoption of genomic technologies.

"We are excited to support Genetic Alliance's mission to improve access to genomic testing," says Dr. Robin Hayeems, Senior Scientist in the Child Health Evaluative Sciences program at SickKids and Principal Investigator for C-GUIDE™. "C-GUIDE™ will help measure the real-world impact of clinical genome sequencing in diverse communities."

"The impact of genomic testing has historically been very difficult to quantify," said Erin Venti, Director of Clinical Programs at Genetic Alliance. "The C-GUIDE™ is an invaluable tool in our efforts to understand the effects of genomic testing on patients, no matter their income or geography."
By sharing the C-GUIDE™, SickKids is putting the principles of Precision Child Health (PCH) into action. This ongoing partnership continues to help expand access to genomic medicine for children everywhere and supports our enduring vision of Healthier Children. A Better World.

About C-GUIDE™
Developed by Dr. Robin Hayeems and her team at SickKids, the Clinician-reported Genetic testing Utility InDEx (C-GUIDE™) is a validated tool used to understand how genetic testing helps inform:
- Diagnosis and prognosis
- Medical management
- Awareness and actionability of health and reproductive risks
- Patient and family well-being

C-GUIDE™ has been licensed in ten different countries and translated into multiple languages, helping health systems and policymakers evaluate the real-world value of genetic testing and make informed decisions.
Learn more about C-GUIDE™ › https://lab.research.sickkids.ca/hayeems/c-guide/

About Genetic Alliance

Genetic Alliance is a nonprofit health advocacy organization founded in 1986 to improve health through genetics and genomics. With a global network of thousands of disease-specific organizations, research institutions, clinicians, and industry partners, Genetic Alliance works to ensure that individuals and families—especially those affected by genetic and rare conditions—have access to accurate information, appropriate care, and meaningful participation in research.

Genetic Alliance is recognized for advancing patient-centered, equitable approaches to genetics, including leadership in policy, ethics, data governance, and community-driven research. The organization has played a central role in major efforts such as the passage of the Genetic Information Nondiscrimination Act (GINA), the development of patient-controlled data models,

and the integration of lived experience into research and clinical decision-making. Genetic Alliance also operates its own Institutional Review Board and supports cross-condition registries and biobanks serving participants worldwide.

iHope is a flagship program of Genetic Alliance that provides no-cost clinical genome and exome sequencing for children and others with suspected genetic conditions who lack access to testing due to geography or resources. Through a global network of partner laboratories and clinical sites, iHope focuses on diagnosing the undiagnosed, supporting families after results are returned, and empowering participants with control over their own genomic data. The program builds on more than a decade of experience delivering clinical sequencing in under-resourced settings and is designed to be scalable, ethical, and patient-first.

Together, Genetic Alliance and iHope work to reduce inequities in genetic health, accelerate diagnosis, and ensure that the benefits of genomic medicine reach communities that have historically been left out.

For more information, visit www.geneticalliance.org
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