

# The iHope Program and iHope Network

Helping underserved families with children facing rare and undiagnosed diseases find answers.

## Introduction

The iHope Program is a philanthropic initiative, launched by Illumina, established to increase awareness and build momentum to use clinical whole-genome sequencing (cWGS) to help find answers for underserved families with children facing rare and undiagnosed genetic diseases (RUGD).

Through whole-genome sequencing, the process of determining the order of all the DNA in a person's body, Illumina and the iHope partners strive to end years-long diagnostic odysseys of unnecessary and inconclusive testing for these children and their families.

### What is the origin of the iHope Program?

The iHope Program was created out of an awareness of the challenges facing patients with rare and undiagnosed genetic diseases and their families, many of whom face financial hardship and are not otherwise able to access next-generation sequencing-based testing. Approximately 50% of those affected by rare diseases are children and 30% do not live to be five years old.

### What is the iHope Network?

The iHope Network is a network of laboratories committed to end years-long diagnostic odysseys for these children and their families and to drive the next generation of genomic testing into practice.

### What is the difference between the iHope Network and an iHope clinical partner?

The iHope Network is a collection of member institutions who have committed to providing cWGS testing to underserved families through their regulated laboratories. Each member organization works directly with their respective iHope partner organizations to identify and serve patients and their families.

For example, Illumina, one of the member organizations of the iHope Network, is currently partnering with six clinical recipient organizations, including Foundation for the Children of the Californias, Rare Genomics Institute, UCSF Benioff Children's Hospital San Francisco, Vision for Children, Washington University, and Lebonheur Children's Hospital. Together, they have committed to identify participants and sequence the genomes of nearly 100 patients and their parents in the inaugural year.

### What is the ultimate hope for the iHope Network and its supporters?

Through action, the iHope Network hopes to increase awareness and build momentum for cWGS and demonstrate that genomes are a needed resource for all RUGD patients.

### Who are the members of the iHope Network?

Today, Network members include Illumina, GeneDx, Genome.One, and Hudson Alpha.

### How can patients/clinicians/laboratories be part of this effort?

Clinical experts affiliated with iHope partner institutions will make referrals to the iHope Network institutions. These experts, including pediatric intensivists, medical geneticists, genetic counselors, and others, will refer children who have financial need and undiagnosed conditions suspected to be of genetic origin.

### Is there a cost associated with services provided by the iHope Network?

Eligible program participants selected by the iHope program partners will receive whole-genome sequencing at no cost.

### What are the clinical site requirements for the Illumina iHope Program?

Clinical experts affiliated with iHope partner institutions will make referrals to the Illumina Clinical Services Laboratory, which is certified under the Clinical Laboratories Improvements Amendments (CLIA) and accredited by the College of American Pathologists (CAP). These experts, including pediatric intensivists, medical geneticists, genetic counselors, and others, will refer children who have financial need and undiagnosed conditions suspected to be of genetic origin.

### Who can I get in touch with to learn more?

Please contact Julia Ortega McEachern, PA, MHS, Research and Program Collaborations at Illumina at [jmceachern@illumina.com](mailto:jmceachern@illumina.com).