The **Primary Promise** Campaign

Building the Nation's Model Health System for Children

Pediatric Research and the Center for Personalized Medicine

PROJECT OBJECTIVE: Strengthen Primary Children's Hospital in Salt Lake City

What if…you could give young patients access to cures that are not only new and groundbreaking but also customized for each child?

THE SITUATION

Primary Children's Hospital conducts research to identify new ways to diagnose and treat complex diseases. One of the most promising research areas is genomics, in which genetic data from critically ill patients is used to create more effective treatments and even customized cures. Consider that:

- More than 7,000 known genetic diseases exist, many of which can cause lifelong disabilities in children.
- Cures exist for only a handful of genetic diseases — a gap that leads to poor health outcomes and even early death.
- A partnership between the University of Utah and Intermountain Precision Genomics, the Center for Personalized Medicine is the first of its kind in the Intermountain West.

THE CRITICAL NEED

No human body is without flaw. While most genetic mutations remain undetected, some can be devastating, compromising the body's ability to function or develop normally. These effects are first seen in the youngest, most vulnerable lives among us — newborn babies.

Nothing could be more heart-wrenching than a baby who fails to thrive. On any given day, there are multiple babies in Primary Children's neonatal intensive care unit who are suffering from ailments that cannot be diagnosed. Despite passionate attention from expert caregivers and the heartfelt prayers of their families, many languish for weeks or months, and some never recover.

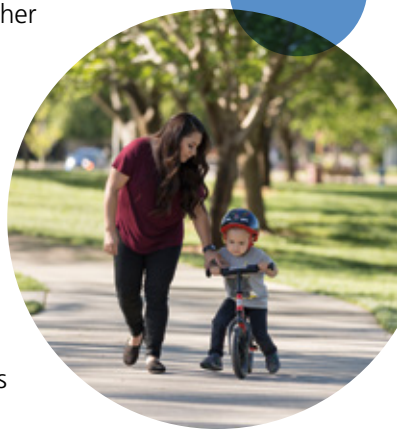
THE PROMISE: Move Research to the Bedside, Ensuring the Tiniest Patients Thrive

Most medical research is academic in nature, focused on the future and not on patients currently under care. In contrast, Primary Children's proposes to become the first to treat serious cases with a "first responder" urgency, focusing extensive resources to research a cure for an individual child in the hospital today.

Thanks to medical science, this rapid response is now possible. Primary Children's is one of a very few places equipped to perform rapid whole genomic sequencing — a process for decoding a baby's entire genome in just 48 hours. This decoding can reveal just what the medical team needs: the presence of a genetic mutation known to cause the child's medical condition. Empowered with this causal link, clinicians can apply precise treatments to compensate for the mutation.

The Center for Personalized Medicine will focus research on three key groups:

- Critically ill children with severe seizures and heart conditions, who need rapid diagnosis and personalized treatment to improve their chance at a healthy life.
- Children with previously debilitating and fatal genetic diseases such as spinal muscular atrophy. Primary Children's is one of only six hospitals nationwide to treat this condition.
- Children with previously incurable and life-threatening diseases, such as cerebral palsy and heart disease, who will be treated through stem cell therapy and other regenerative medicine.



HELP US KEEP THE PROMISE

The Center for Personalized Medicine will revolutionize the care we are able to provide to the hospital's youngest and sickest patients. Because insurers do not reimburse for research-oriented genomic testing, philanthropic support is essential to these lifesaving services.

With donor support to the new Center, *The Primary Promise Campaign* will change the trajectory of thousands of young lives in the years to come.

Intermountain Healthcare