Can Genomic Sequencing at Birth Transform Medicine?

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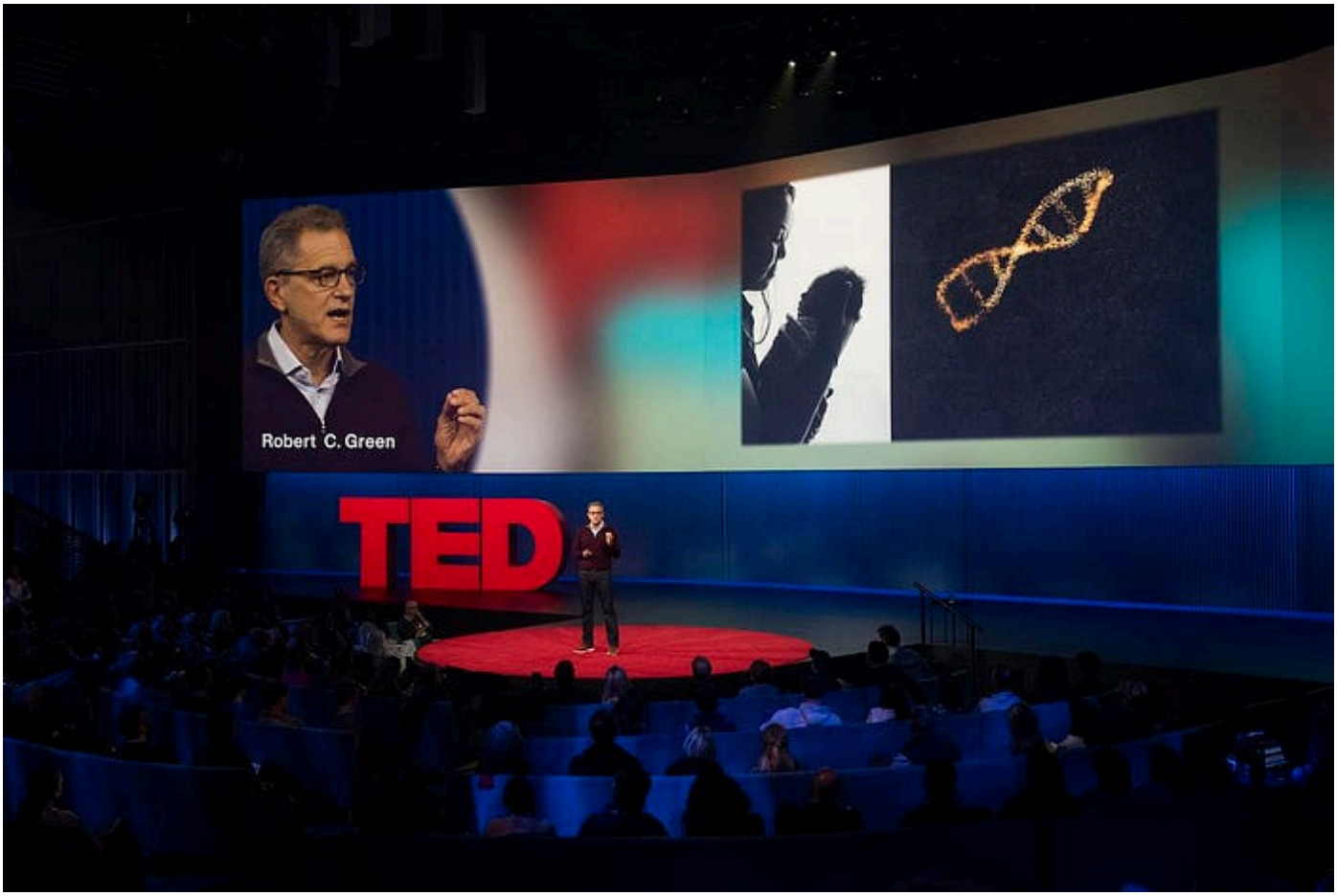
Reflections from my TED Talk

By Dr. Robert C. Green



This year I was invited onto the TED main stage to share the story of newborn sequencing- and the full 12 minute talk is now available to watch.

Ten years ago, our BabySeq Project sequenced the first newborn in human history. Four years ago, we co-founded the first international consortium pulling together 27 research groups around the world in this space, and just a few weeks ago, we won federal funding for the first nationwide project, the BEACONS initiative, to assess the feasibility of newborn sequencing through public health programs in the U.S. When I spoke about this at TED, I wanted to give people a sense of just how fast this field is moving — and why it matters — right now.

Actionable Results are Surprisingly Common

In the original BabySeq Project, we found that genomic risk is far more common than most people realize. Now a second iteration of BabySeq is underway, and as those results begin to come into focus, we have more detail about those risks.

On the TED stage, I invited the audience to imagine a world where a single test at birth could change the trajectory of a life — and then shared what we've discovered so far. If we screen newborns for around 400 genes that are clearly linked to actionable childhood conditions — in other words, conditions with readily available treatments, about 4% of babies carry at least one of those mutations. This is already an attention-getting number, and it's only going to grow; that list of 400 genes is bound to expand, perhaps drastically, with the continual discovery of more risk mutations and treatments.

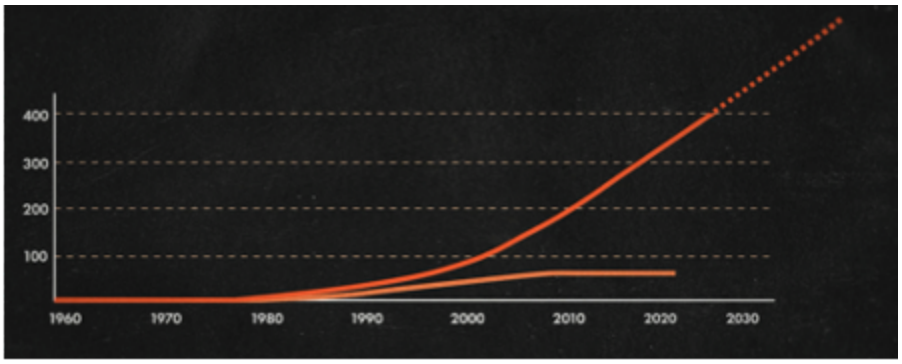
We explored that expansion in BabySeq, looking at a much longer list of 5,000 genes linked to risk mutations that may not be actionable yet, or that may not manifest until adulthood, and found that an astonishing 12% of babies carried at least one of these mutations.

This 12% figure can't be understated. It projects to over 400,000 babies born with these mutations each year in the United States alone, and over 15 million globally.

For families, these aren't abstract percentages. They are stories of lives changed: A baby whose genetic result prompted a scan that found — and allowed monitoring of — a narrowing aorta. A child with biotinidase deficiency who has been spared brain damage by taking a daily supplement. A newborn whose *BRCA2* finding revealed his own mother's cancer risk, leading her to preventive surgery that may have saved her life.

Each of these cases illustrates why sequencing is not simply about information — it's about the opportunity to act before it's too late.

While not every child (or adult) will end up actually experiencing these diseases, this information gives them advance notice, something to watch for, information to share with their doctors to make sure these uncommon conditions — with symptoms that otherwise could easily be overlooked or misdiagnosed — are on their radar. For many of these conditions, treatment isn't available today, but it *will* be available in the future. This is how sequencing saves lives.



In the U.S., standard newborn screening (bottom orange line) still trails far behind the projected number of treatable genetic conditions (top red line). (Source)

A Bigger, Better Newborn Screening

The type of traditional newborn screening currently offered around the world has saved countless lives, but it hasn't been able to keep up with the pace of genomic advances. In the U.S., each state screens for between 30–60 conditions, far fewer than the nearly 400 treatable conditions we included in BabySeq — and since 2008, only nine new genetic conditions have been added to the standard newborn screening list.

The gap between what is possible and what is practiced keeps growing. If we want to close it, we need to bring genomics into newborn screening in a responsible and scalable way.

At TED, I explained why this isn't just a local challenge — it's a global one. This is why I envisioned and co-founded the International Consortium on Newborn Sequencing (ICoNS). ICoNS started as a small network and has now grown to 27 partners around the world, each exploring how to implement genomic sequencing for newborns within their own healthcare systems. We share results, compare strategies, and confront challenges together. Our May 2025 paper in *Genetics in Medicine* compared gene lists across all 27 global programs, and created a ranked, adaptable gene list to guide more consistent and informed global practice. To me, ICoNS feels like the birth of a new field of medicine, one that requires global partnership to realize its potential.

And now, this vision is taking a bold new step forward. I am honored to serve as one of the multiple principal investigators on BEACONS, a newly launched, NIH-funded multi-state collaboration that plans to enroll up to 30,000 newborns across the country to evaluate the feasibility of integrating genomic sequencing into the U.S. public health newborn screening system. This initiative, the first of its kind at a national scale, reflects how quickly the promise I spoke about on the TED stage is moving toward real-world implementation.

In my TED Talk, I shared why this work matters now more than ever, and why it will take courage — on the part of scientists, parents, healthcare systems, and policymakers — to move from treating illness to anticipating and preventing it. If we can embrace this shift, we won't just save lives; we'll redefine medicine itself.

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