

NEWBORN SCREENING OR DNA HARVESTING?

WHAT EVERY MOTHER NEEDS TO KNOW

WHAT IS NEWBORN SCREENING (NBS)?

Within the first days after birth, babies get a state-mandated heel prick, unless a mother exercises her rights to opt out. A nurse takes a few drops of blood and places it on a special card. Then sends it to a state lab for screening. NBS started out in the 1960s as a way to screen for a few treatable, metabolic issues. Parents often think this is something they have to do, but **in most states they have the right to decline**. Few are told this. So a major medical and privacy decision is made automatically by the system instead of by families. If a signature is collected prior to the screen, it's mostly likely to consent to data use, not the test itself.

Today the number of conditions screened varies from 35 to 75, depending on the state. Find out more about your state's requirements and processes so you know: what's included and how to opt out, if you choose. NBS is expanding in a way that raises huge ethical concerns.



WHOLE GENOME SEQUENCING (WGS) TIED TO NBS

The latest push is to add WGS—the mapping and reading of DNA—to NBS, mapping all of a baby's DNA, not just checking for a few treatable conditions.

The National Institutes of Health (NIH), which is the primary U.S. agency responsible for conducting and supporting medical research, is funding a study on NBSxWGS, with a goal to make sequencing “considered trustworthy.” This approach echoes vaccine-era “hesitancy research,” where the aim was not true informed decision making but greater compliance.

Context matters: COVID normalized gene therapy through the rapid rollout of mRNA. Does the public's knowledge of mRNA pave the way for broader acceptance of altering the genome or does it highlight the risks?

EPIGENETICS: GENES ARE NOT DESTINY

WGS doesn't just find clear-cut problems. More often, it uncovers “variants of uncertain significance” or gene mutations that expose probabilities rather than certain outcomes. In most cases, doctors can't say whether those changes will ever cause disease. Only in a handful of conditions, like Tay-Sachs or Huntington's, is expression of the disease pretty much guaranteed.

LABELING A HEALTHY NEWBORN WITH A GENETIC “RISK” ON DAY ONE CAN HAVE HEAVY CONSEQUENCES



It can cause anxiety for parents



It can turn a normal childhood into a medical case



It can push families toward treatments that carry devastating side effects even though it may never have been needed.

Even if a genetic change does lead to illness, there's no way to predict how severe it might be. A child might develop a mild, a moderate or a serious form. Some results even point to risks for diseases that may not appear until adulthood, if they ever appear at all.

This is where epigenetics comes in. Your genes are not a fixed destiny. They can be switched “on” or “off” by many environmental factors—nutrition, mineral levels, stress, environmental exposures, even the balance of bacteria in the gut. Biology is flexible, not hardwired.

PRIVACY: A PERMANENT DIGITAL SHADOW

When a baby's genome is sequenced, the data doesn't disappear, it is stored permanently in ways that can be linked back to the child. These DNA profiles are often shared across states, government agencies, and research groups, frequently without parents ever knowing. Genomic data can never truly be anonymous, because DNA itself is an ultimate identifier. The long-term vision is to shift medicine from treating illness to predicting it, but this shift comes with profound ethical, moral and privacy concerns: once your genetic blueprint is captured, you and your child carry a permanent digital shadow that cannot be erased.

A DIGITAL TWIN FOR YOUR BABY

Jul 23, 2024

Have you heard of infant digital twins?



<https://www.medtechpulse.com/article/insight/a-digital-twin-for-your-baby>

WHAT INFORMED CONSENT MUST MEAN NOW

If WGS is folded into mandatory NBS, the consequences will be more sweeping than any vaccine mandate in history. In the gene-therapy era, informed consent must be rebuilt for gene-editing technologies.

Traditional vaccines introduce a piece of a virus (an antigen) so the immune system responds to it. Newer methods, like mRNA and viral vectors, go a step further: they give your cells instructions to make that protein themselves, so your own body produces the antigen from the inside out. This can have devastating effects on the immune system.

A MOTHER'S DISCERNMENT IS THE ANTIDOTE.

ASKING QUESTIONS BRINGS CLARITY.





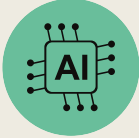
Do you believe your child's body is intelligent?



Is a gene mutation protective or a failure to be fixed?



Does my medical provider's view of health and vision for my child's future align with mine?



Should DNA be manipulated by artificial intelligence?



Where do I stand on gene therapy?

Note: It is well accepted that screening can have significant psychological effects and therefore should only be done if (1) you know what you are looking for, (2) why you are looking for it and (3) how the information will be used.

The question is not whether genetic technologies have any place or any promise. The question is whether parents, advocates, and policymakers will demand informed consent, privacy safeguards, and an end to genetic determinism as policy.