

# Geneticist's Memoir of Pregnancy, Birth of Babies with Rare Disease

*Intimate journey navigates today's most pressing women's issues.*

NEW YORK, NY, UNITED STATES, February 10, 2025 /EINPresswire.com/ -- When the Baby is Not OK: Hopes and Genes, a new memoir of pregnancy, childbirth and parenthood from geneticist

[Jennifer J. Brown](#), shines a light on what to expect after universal newborn screening. Out of nearly 4 million who get screened each year, about 12 thousand babies are diagnosed with a so-called "rare disease" in the US alone. Brown's daughters were two of them. It was in their DNA.

“

This work balances a compelling mix of personal experience, emotional exploration, and scientific knowledge... A deeply emotional and expansive story of growth, connection, and resilience.”

*Kirkus Reviews*

Nine days after childbirth in New York, Brown's baby's diagnosis with a rare genetic condition known as phenylketonuria (PKU) came as a complete surprise. A graduate student in genetics at Cold Spring Harbor Laboratory at the time, the news that the baby was "not OK" radically changed the course of Brown's life. Her

journey as a single mother takes a deep dive into challenges of health equity, eugenics, DNA testing, rare disease and patient rights.

The memoir is relevant for all pregnant people, for expectant parents, medical trainees and healthcare providers. The author's experience will be of special interest to members of the rare disease and PKU communities as well as patient advocates and genetics counselors.

The true stories in the 24 chapters of Brown's memoir are forged in lived experience, a journey through pressing social issues of the times. From teenage pregnancy to sexism in science, from abortion to pregnancy and childbirth, and from DNA testing to healthcare bias regarding rare disease and disability. The writing is born of empathy and informed by evidence, with an extensive bibliography of over 200 primary sources. The author effectively presents a courageous call to action for more compassionate healthcare in the US today.

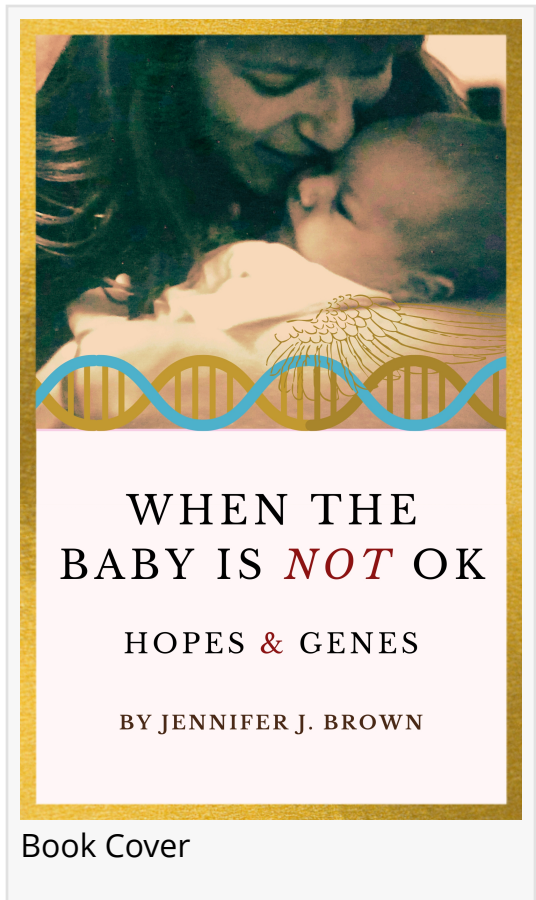
“I believe this book will become a healing presence for anyone who reads it,” says Kevin Alexander, Vice President of the Louisiana Metabolic Disorders Coalition in the US.

"Powerful and unflinching memoir interwoven with a wide-ranging social history, offering a compelling examination of motherhood, medical care, and genetic heritage through the lens of PKU," says Pauline O'Connor, patient advocate in the UK.

"Profoundly moving narrative of resilience, sacrifice and accomplishment....highlights resilience and unwavering dedication to her daughters' well-being," says Kendra J. Bjoraker, PhD, LP, pediatric neuropsychologist.

"Although the book initially follows the thread of Brown's memories, it's effectively expanded by her research... multifaceted sections grow until they're informative essays, revealing, in great depth, the broader implications of these topics and how they touch the lives of many others," says [Kirkus Reviews](#)

Buy the book at Apple, Barnes & Noble, Fable, Kindle, Kobo, Draft2Digital, and in paperback starting February 11, 2025. Also available in [hardcover at Amazon](#).



Author Jennifer J. Brown has a PhD in genetics from SUNY Stony Brook for earlier studies at Cold Spring Harbor Laboratory in New York with Nobel Prize laureate Barbara McClintock. This is Brown's 11th published book as an independent author. Brown serves as a mentor for people diagnosed with PKU and their families at the non-profit National PKU Alliance in the US. 10% of all author book royalties are donated to non-profit The Arc, for people with intellectual and physical disabilities.

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