



# One in a Billion: The Story of Nic Volker and the Dawn of Genomic Medicine

*Mark Johnson, Kathleen Gallagher*

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The breathtaking story of a young boy with a never-before-seen disease, and the doctors who take a bold step into the future of medicine to save him—based on the authors' Pulitzer Prize-winning reporting.

In this landmark medical narrative, in the tradition of *The Immortal Life of Henrietta Lacks* and *The Spirit Catches You and You Fall Down*, Pulitzer Prize-winning journalists Mark Johnson and Kathleen Gallagher chronicle the story of Nic Volker, the Wisconsin boy at the center of a daring breakthrough in medicine—a complete gene sequencing to discover the cure for an otherwise undiagnosable illness. At just two years old, Nic experienced a searing pain that signaled the awakening of a new and deadly disease, one that would hurl Nic and his family up against the limits of modern medicine.

For years, through false starts and failed cures, Nic holds on to life, buoyed up by his mother's fierce drive to get him the care he needs. But when even the world's experts are stumped by Nic's illness, his doctors come up with a radical, long-shot plan: a step into the unknown.

The next major scientific frontier, following the completion of the Human Genome Project, was to figure out how to use our new knowledge to save lives—to bring genomic or personalized medicine into reality. It's a quest that is undertaken by researchers around the world. But it is only when geneticist Howard Jacob hears about young Nic that the finish line finally comes into sight: It's no longer a race to make history. It's a race to save this boy's life.

*One in a Billion* is an unforgettable tale of the lives that converged to launch a medical revolution. As pioneering geneticist Mary-Claire King pronounced upon learning Nic's story: "It was as if one had heard about Case Zero of AIDS and the cure, all at once."

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