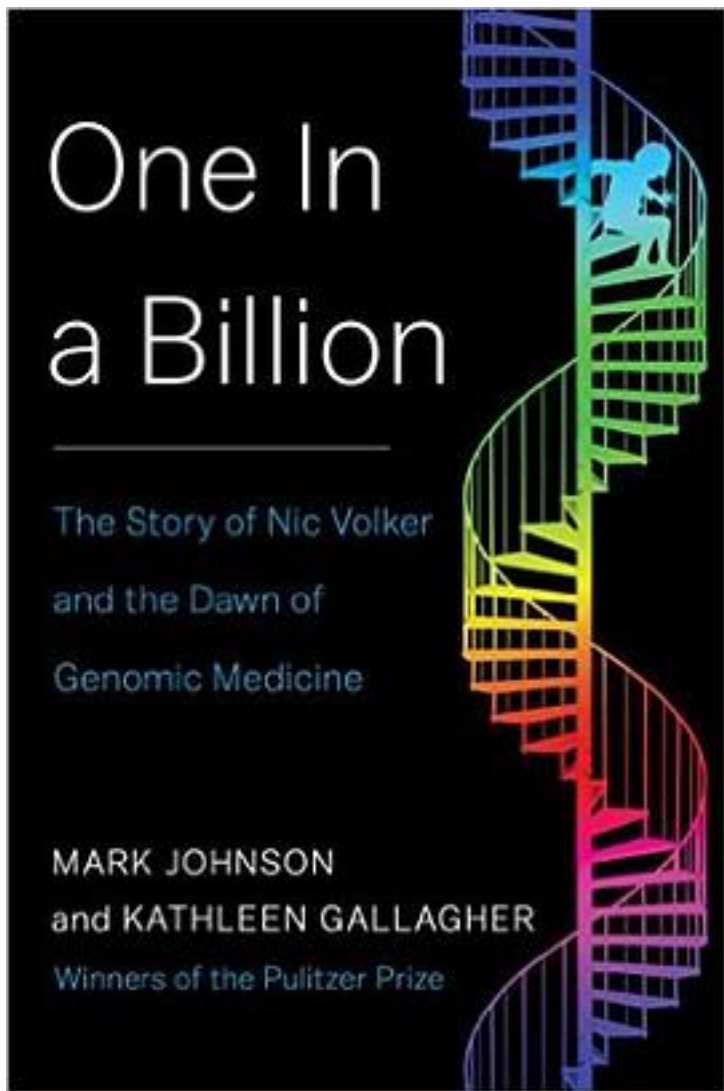


One in a Billion



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著者:Mark Johnson

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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.”

作者介绍:

Mark Johnson is a health and science reporter at the Milwaukee Journal Sentinel, where he has worked since 2000. He was a member of the Journal Sentinel team that won the Pulitzer Prize for explanatory reporting on the Nic Volker story in 2011. He is also a three-time finalist for the Pulitzer Prize and has won numerous other awards for his reporting. He lives with his wife and son in Fox Point, WI.

Kathleen Gallagher is a business reporter at the Milwaukee Journal Sentinel, where she has worked since 1993. She was a member of the Journal Sentinel team that won the Pulitzer Prize for explanatory reporting on the Nic Volker story in 2011. She was also part of a team that won the 2006 Inland Press Association award for explanatory reporting. She lives with her husband and two children in Wauwatosa, WI.

目录:

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标签

精准医疗

基因组

切面

DNA测序

*科普/普及

评论

洋洋洒洒扯了一个病例，牵出人类基因组学发展至今的历史，主要的推动人，技术的更新，从一个概念到人类基因组谱的获得，再进阶用来指导个性化诊断的案例。描写病人家属的心理细节详实，但是技术干货不多。个性化诊断后的治疗依然是骨髓移植，略缺乏创意，但能把病人救活才是正理啊！

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书评

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