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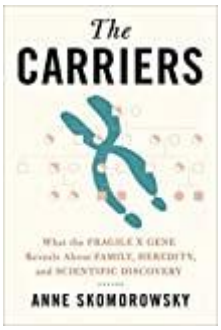
Anne Skomorowsky. *The Carriers: What the Fragile X Gene Reveals About Family, Heredity, and Scientific Discovery.* New York: Columbia University Press, 2022. 280 pp. $28.00, cloth, ISBN 978-0-231-19766-3.



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Anne Skomorowsky's *The Carriers: What the Fragile X Gene Reveals about Family, Heredity, and Scientific Discovery* illuminates the often-overlooked stories of women who carry the fragile X premutation gene. Each chapter follows the lives of these individuals, their families, and their communities, as well as the experts leading efforts to bring greater medical attention to the premutation. Skomorowsky details several conditions associated with the fragile X premutation, including fragile X-associated tremor/ataxia syndrome (FXTAS) and fragile X-associated primary ovarian insufficiency (FXPOI), illustrating the tangible effects on carriers. In addition to sharing personal accounts, Skomorowsky seamlessly integrates genomic science with a history in which women pioneers have long remained invisible. This book urges us to take the fragile X premutation carrier status—and perhaps genetic carrier statuses in general—more seriously given the significant medical and social consequences these can bring. Importantly, it brings to the forefront the lived experiences of those with the premutation and highlights the immense value of recognizing women's accounts in genomic medicine.

Especially noteworthy is Skomorowsky's clear, frank, and compelling writing, ensuring that this book is appealing and accessible to all audiences. In addition, she brings the vantage point of a psychiatrist who has firsthand experience working with those with intellectual disabilities. As such, she presents complex and comprehensive scientific information about fragile X and the premutation in a simple and engaging manner. Throughout, Skomorowsky's attention to epigenetics, wherein embodied genes are inherently socio-environmentally influenced, critically averts the downfalls of genetic determinism. That is, she repeatedly shows the futility of questioning whether a person's intellectual or physical disabilities and health challenges are results of nature (e.g., genetics) or nurture (e.g., parenting), instead emphasizing how the two are necessarily intertwined. With perspectives representing patients and their families, scientific researchers, medical sociologists, and genetic counselors, the book is well re-

searched, captivating, and an important contribution to better understanding our relationship with genes.

This book has a powerful focus on women and mothers who carry the fragile X premutation gene, illuminating untold medical experiences. Skomorowsky centering this group is especially meaningful in the world of fragile X and autism, where mothers have so often been blamed for their children's outcomes. For example, readers may be familiar with the derogatory trope of the "refrigerator mother" unable to show her children affection, making this book's narratives more salient. Further, Skomorowsky shows how fragile X spectrum conditions came to be understood and diagnosed as a result of communities of women willing to empathize and take one another seriously—essential emotional labor that has led to critical medical breakthroughs. Several chapters are dedicated to carriers' challenges with FXPOI, toxic gain of RNA function, and resulting physical and mental health challenges, including brain and ovary damage. Distinct accounts show women being misunderstood or dismissed by medical providers who resort to overmedicating against symptoms without identifying root causes. On the socio-emotional side, we see the overwhelming demands on mothers who are premutation carriers and face complex intellectual and behavioral symptoms, while also parenting their children with fragile X or the premutation. Imperative, however, are women's accounts of self-recognition and identity-building as they learn about their premutation, make sense of their personal history, and free themselves from burdensome self-criticism in their adult lives.

As with most genetic revelations, the fragile X premutation gene has far-reaching effects on multiple aspects of a carrier's life and family history. Carriers discuss being raised by parents who were also unknowingly carriers, revealing often difficult and traumatic childhoods. They detail struggles in their own relationships, education, and professional lives, with women facing stigma as they coped with carrier-related symptoms. Illustrating how one's genes and social lives are enmeshed, Skomorowsky shows that genetic findings are rarely solely about a single person, but rather have "spillover" implications for those surrounding them. Along these lines, she raises a pertinent discussion about reproductive decision-making, where carrier mothers weigh prenatal and preimplantation genetic testing, termination, and in some cases sterilization to avoid future generations facing fragile X. They each bring distinct and complex perspectives, showing how the "right" approach is subjective per family. Emphasizing the need for considerate and informed genetic counseling in these situations, Skomorowsky touches on an increasingly relevant debate as reproductive genetic testing (e.g., noninvasive prenatal testing) becomes commonplace throughout the United States. In underscoring the ripple effects of one's carrier status, this book makes clear how medical communities can better support carriers and those in their orbits.

In terms of historical engagement, readers will appreciate the attention to women's leadership and scientific expertise in genetics and findings around fragile X. For example, Skomorowsky tells the remarkable story of Julia Bell, who not only created the *Treasury of Human Inheritance* (1909-58) documenting familial genetic conditions but was the first to describe X-linked genetic conditions in humans. Such accounts of trailblazing women, against the odds of patriarchal barriers, are critical to situating contemporary biomedical advancements. Similarly, Skomorowsky dedicates a chapter to the "founder effect," illuminating how colonial violence brought with it genetic mutations, like the fragile X premutation, to communities worldwide. However, while Skomorowsky provides gendered and racialized histories, there is a need for more intentional engagement with eugenics and ableism as foundations of genomic medicine. Although she discusses Frances Galton and Karl Pearson, Skomorowsky stops short of re-

cognizing how these early geneticists were fundamentally motivated to prioritize reproducing white and able-bodied populations. Overall, the book's discussions around early conceptions of "feeblemindedness" and those considered "imbeciles" would read more comprehensively if contextualized within the robust scholarship around critical disabilities and the ways ableism has problematically shaped genetics.

Although Skomorowsky does not explicitly underscore genetics' ableist foundations, her rich and thoughtful accounts of families with disabilities related to the fragile X premutation are essential to advancing such conversations. At the heart of this book are human connections, depicting how those carrying the premutation handle lives that are complicated and beautiful. When it comes to their challenges, each family's narrative has a thread of uncooperative medical, social, or educational institutions that unfairly blame parents or children as a result of misunderstanding fragile X and the premutation. Given that Skomorowsky spotlights medically severe carrier cases, one can see these health issues being exacerbated when intertwined with social disorder and neglect. From Johnny who died in a hospital after being deemed unsuitable for care facilities, to Corey for whom "being amphetamine-addicted and shot dead was never a choice," this book reveals myriad ways our structures, institutions, and culture can be more inclusive, tolerant, and better equipped for those with genetic conditions and disabilities (p. 35).

The Carriers challenges readers to broaden their conception of health and medical diagnoses as influenced by genes. It calls for a more nuanced understanding of how genetic conditions may present themselves, specifically with regard to carriers. If social and medical communities are able to harness these insights, the results could be earlier interventions, effective treatments, and greater equity. With each story featured, there is a sense of relief and liberation when a person learns about their carrier status, highlighting the power a diagnosis can bring in naming and explaining all that a person has endured. Most importantly, Skomorowsky makes this critical contribution in a way that is gripping and as easily readable for someone new to the topic as it is for a genomics expert. Undoubtedly, this book will have a profound impact on how readers understand the lived experiences of those with genetic conditions, carrier statuses, and the need to amplify these conversations.

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