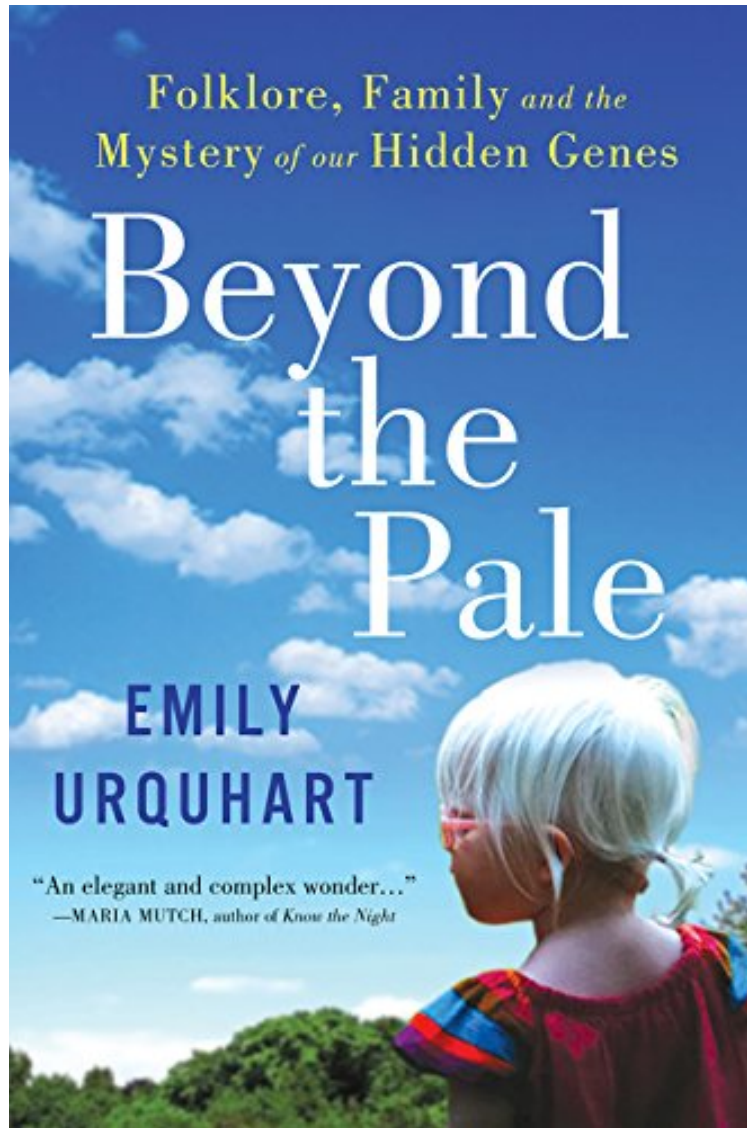


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Beyond the Pale: Folklore, Family and the Mystery of Our Hidden Genes

Emily Urquhart

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#1724442 in Books Urquhart Emily 2015-04-21 2015-04-21 Original language: English PDF # 1 9.20 x 1.00 x 6.30l, .0 #File Name: 0062389165288 pages Beyond the Pale Folklore Family and the Mystery of Our Hidden Genes | File size: 22.Mb

Emily Urquhart : Beyond the Pale: Folklore, Family and the Mystery of Our Hidden Genes before purchasing it in order to gage whether or not it would be worth my time, and all praised Beyond the Pale: Folklore, Family and the Mystery of Our Hidden Genes:

0 of 0 people found the following review helpful. She has what??By Blue Moon This is a very interesting life journey

being chronicled with honesty, warmth and some humor. I never understood the particulars of living with albinism. I didn't know the word albinism. I learned a lot from this book about the condition and about people existing in different situations around the globe with it. I am happy that I found the story of this family and the fascinating ponderings and research by its author. I highly recommend it. 0 of 0 people found the following review helpful. *Beyond the Pale: Folklore, Family, and the Mystery of Our Hidden Genes* By Anne E. Ferguson The birth of a beautiful child with the whitest of white hair starts her parents on a search for knowledge about albinism and family lore. Andrew and Emily travel Canada, the Eastern U.S. and as far away as Africa, finding unexpected facts, refuting long-believed tales, seeing tragic abuse of pale children and delighting in one small, ethereally lovely girl. 0 of 0 people found the following review helpful. GoodBy xyz For a specific interest group, terrific information.

The story begins on St. Stephen's Day, 2010, in St. John's, Newfoundland, when the author gives birth to a baby girl named Sadie Jane who has a shock of snow-white hair. News of the child's icy locks travels across the hospital, and physicians and nurses from all wards visit the unusually beautiful newborn as she lies sleeping in her plastic bassinet. The maternity-floor janitor, however, feels something is amiss. Her eyes wide, incredulous and panicky, Emily asks, "Is she an albino?" The idea is immediately dismissed, but after three months of medical testing, Sadie is diagnosed with albinism, a rare genetic condition where pigment fails to form in the skin, hair and eyes. She is visually impaired and faces a lifetime indoors. She will always have the otherworldly appearance that drew the awestruck hospital staff to her side. A journalist and folklore scholar accustomed to processing the world through other people's stories, Emily is drawn to understanding her child's difference by researching the cultural beliefs associated with albinism worldwide. What she finds on her journey vacillates between beauty and darkness. She discovers that Noah's birth story is believed to be the first record of a baby born with albinism, and that the Kuna people in Panama revere members of their society with albinism, seeing them as defenders of the moon in the night sky. She attends a gathering of people with albinism in St. Louis and interviews geneticists, social scientists, novelists and folklorists in Canada, England and the US. But when she uncovers information about gruesome attacks on people with albinism in Tanzania, rooted in black magic, she feels compelled to travel to East Africa, her sun-shy toddler in tow, in an effort to understand these human-rights violations. While navigating new territory as a first-time parent of a child with a disability, Emily embarks on a three-year journey across North America and Africa to discover how we explain human differences, not through scientific facts or statistics but through a system of cultural beliefs. Part parenting memoir, part cultural critique and part travelogue, *Beyond the Pale*, as the title suggests, takes the reader into dark and unknown territory in the search for enlightenment.

'Beyond the Pale is a brave, thoughtful, clear, and always graceful journey through the terrifying randomness of genetics and the unexpected ways genetic anomalies can mark not just children, but all the lives around them. Best of all, it ends with a surprise—one that will interest anyone thinking of having a family.' Ian Brown, author of *The Boy in the Moon: A father's search for his disabled son*; 'Beyond the Pale is a powerful story about maternal love, the long reach of family and the ways -- good and evil - we react to disability.' Katherine Ashenburg, author of *The Dirt on Clean: An Unsanitized History*; 'A graceful, perceptive rendering of a misunderstood condition.' - Kirkus s About the Author Emily Urquhart, a writer and folklorist, grew up in a small town in southwestern Ontario and has lived in Nice, Dublin, Edinburgh, Toronto, Vancouver, and Kyiv, among other places. She has a doctorate in folklore from Memorial University of Newfoundland and undergraduate degrees in journalism and art history. Her work has appeared in numerous publications, including *Readers Digest*, *Flare*, and *The Walrus*, and she won a National Magazine Award in 2014. Emily Urquhart lives in Victoria, British Columbia, with her family.