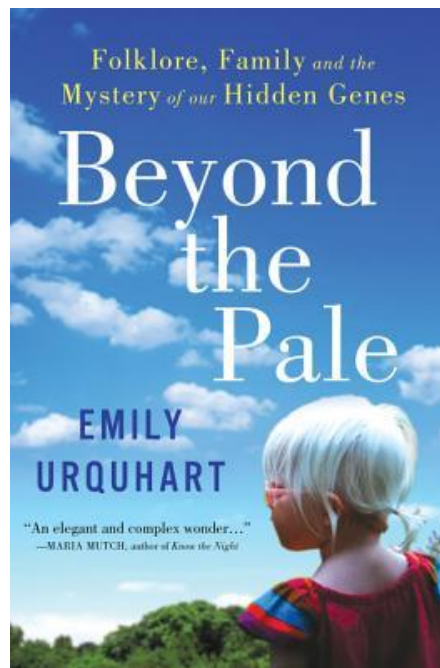




## Beyond the Pale: Folklore, Family and the Mystery of Our Hidden Genes

*Emily Urquhart*

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

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## **Beyond the Pale: Folklore, Family and the Mystery of Our Hidden Genes** Emily Urquhart

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, the janitor 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 avoiding the sun. 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 witchcraft, she feels compelled to travel to East Africa, her sun-shy toddler in tow, in an effort to understand these human-rights violations. Upon her return to Canada she discovers a family photograph from the past that might illuminate her daughter's present.

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: Folklore, Family and the Mystery of Our Hidden Genes Details**

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## From Reader Review Beyond the Pale: Folklore, Family and the Mystery of Our Hidden Genes for online ebook

### Kate says

After her daughter was born with albinism, Emily Urquhart began researching the genetic condition through the lens of her own field of study, folklore. She looks at historical western folklore, for example, people with albinism in "freak shows" or remote communes (there are stories like this for many conditions with particularly recognizable phenotypes), and the heartbreaking contemporary stories from Tanzania of the power and wealth to be attained through magic done with the body parts of a person with albinism. These tales are widespread and directly contribute to the kidnapping, mutilation, and killing of people with albinism, which has only recently been acknowledged and fought against; the first conviction for such a crime was in 2009. People with albinism have been seen as ghosts, angels, and bad omens throughout history. Urquhart also looks through her own family's history to track the gene for albinism through the generations, finding pictures and stories to link her daughter with her family from 100 years ago. I really love the approach of juxtaposing folklore and storytelling alongside history and science - it always makes for a very interesting perspective on any topic, and this one in particular.

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### Debra says

Given that I am Canadian, it is ironic that I learned about this extremely well-written, non-fiction, Canadian book from the very British Jen Campbell, author, poet, and Booktuber extraordinaire. Thank you, Jen!

Urquhart's moving and informative book recounts her adjustment after her first child, a daughter, is born with albinism. The book is part memoir, part travelogue, part journalistic investigation, and part folkloric study. I highly recommend it. Urquhart seems to have inherited more than a little of her mother's (Jane Urquhart) talent for fine writing.

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### Jen Campbell says

This has a massive personal connection for me. Will chat about it in my August wrap up. A wonderful read.

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### Rebecca says

In December 2010, the author's first child, Sadie, was born with white hair. It took weeks to confirm that Sadie had albinism, a genetic condition associated with extreme light sensitivity and poor eyesight. A Canadian folklorist, Urquhart is well placed to trace the legends that have arisen about albinos through time and across the world, ranging from the Dead Sea Scroll story of Noah being born with blinding white skin and hair to the enduring superstition that accounts for African albinos being maimed or killed to use their body parts in folk medicine. She attends a NOAH (America's National Organization for Albinism and Hypopigmentation) conference, discovers potential evidence of a family history of albinism, and even makes a pilgrimage to Tanzania to meet some victims. It's all written up in as engaging present-tense narrative of coming to terms with disability: to start with Urquhart is annoyed at people reassuring her "it could be

worse,” but by the end she’s ever so slightly disappointed to learn that her second child, a boy, will not be an albino like his sister.

(Emily Urquhart is the daughter of novelist Jane Urquhart.)

*I was delighted to win a copy in a Goodreads giveaway.*

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## Jess says

Read this review and more on my blog!

I feel like this year is the happiest I've felt with my reading habits for the longest time. When you step into book blogging it feels as though you must read what everyone else is reading, not because anyone else tells you that but because, naturally, you want to join in when other bloggers are really excited about a book they've been reading. I *really* tried, but I don't read primarily YA so a lot of the books that are very popular in the book blogging community tend to pass me by. For a while that bugged me, and now it doesn't because all that matters is that I enjoy blogging and I enjoy reading.

This year I've really gotten into non-fiction. For a while I was convinced non-fiction just wasn't my thing. When I was younger I was interested in stories, in fiction, I wasn't interested in reading a memoir. As I got older most of the non-fiction I read I encountered at university, and when you associate non-fiction with essay writing it can be hard to seek out non-fiction purely for enjoyment's sake. Over the past year or so, however, I've really begun to enjoy non-fiction. I love non-fiction centred around history and historical figures - I'm a huge history nerd - but I've also enjoyed reading some literary criticism and memoirs, and recently I read and enjoyed *Beyond the Pale*.

I had no idea whatsoever that this book existed until I saw Jen Campbell mention it on her YouTube channel and it sounded fascinating. I knew very little about albinism, but I had encountered it a little during my MA while I was researching witchcraft, and the idea of a folklorist exploring the beliefs surrounding albinism and looking into her own family history sounded right up my street.

Emily Urquhart's writing style is very readable. When she's discussing the early stages of her daughter's diagnosis and the different types of albinism there are it could have been easy for me to get lost - I'm not scientifically minded at all - but I was never confused, nor should I have been. This book isn't a science book, it's a memoir and a travel book and criticism all rolled into one, and while albinism is the focus Emily pays so much more attention to the people with albinism than the condition itself. Everyone she meets is treated with such respect and her daughter, Sadie, is just adorable.

There's a real spectrum of beliefs in this book, from the biblical suggestion that Noah had albinism and therefore the condition is associated with being the child of an angel in Christian theology, to the more heartbreaking realities in Tanzania in which people with albinism literally live in fear of their lives. Some of the stories may be a little hard to read but they're worth reading: it's incredibly important that we don't remain ignorant to some of the atrocities that people with albinism are forced to face on a daily basis.

I really enjoyed this book. It satisfied the craving I've had for non-fiction all year, and once again reminded me to continue to broaden my reading habits. The only reason I gave it four stars rather than five was because I was hoping for a little more along the lines of folklore; after a while it seemed to disappear from the narrative completely other than the times in which Emily reminded us she's a folklorist, but I still really enjoyed reading about her trip to Tanzania and her research into her family history.

Super interesting read, I highly recommend it!

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## Adrienne says

"Beyond the Pale: Folklore, Family, and the Mystery of Our Hidden Genes" was not quite what I was expecting. This book is a memoir of a mother who has a daughter with albinism, or who is an "albino," but the author says that term is not politically correct. I wish she would have told us what people with this condition prefer to be called, however, the author used the term "albino" throughout the book. The author shares her story about having a child with a disability (people who have albinism tend to have low vision (difficulty with sight) and their skin burns easily and quickly). I was curious to learn more about albinism, having only covered a snippet of information about it being a genetic condition from my 9th grade biology class. The author tells us of her struggles, her fears, and her hopes and dreams for her daughter, visits Tanzania to learn about the suffering of those with albinism in remote areas (they are perceived as magical beings, and their body parts are wanted for potions and such). The author learns that people with albinism can live happy, fulfilling lives, as she spends time with people with albinism in Tanzania and as she researches her own family tree to find relatives that also manifested the recessive gene mutation. This is a great memoir of a mother's acceptance and love for her child, albinism or no, and the journey she took to learn more about it, both scientifically, in her family, and in folklore. I was expecting it to go more into the folklore side of things, but the author kept that concise. I found it interesting that she explored the urban legend of the Albino Colony in New Jersey, as well as the urban legend of the "witch" with white hair who would tend a garden in the middle of the night in the rain. Included in the book is a poem describing the latter legend, as well as family photos from the author. Her daughter is beautiful with her fair hair, and I found it to be an encouraging book for those who have or know someone who has a condition or disability. The book is encouraging in the fact that it states that those with albinism, and others, can have happy lives. One of the author's relatives with albinism was an early chiropractor, for example.

This is a book for those who want to learn more about albinism, who are interested in memoirs, especially those about mothers and children, and for those looking for hope in a time of circumstance. This book kept my attention throughout, although there were times, for me, it seemed the story dragged on a bit describing the life of a parent. As I have no children, that part didn't interest me as much personally, but it did contribute to the overall memoir and the story of a mother's endless love for her child, so it was an important part of the story, my personal interests and experiences aside. It was a good way of "showing, not telling" about her experiences as a parent of a child with albinism. Others may relate more to the parenting, and may see how much they have in common with the author's parenting experiences.

Overall, I recommend this book; it was a pleasant read, and I learned a lot: about parenting, a mother's love, albinism, and overcoming adversity. If the author wrote a sequel detailing her daughter's journey growing up and going through the teen years, as well as beyond, or if Sadie herself would write a memoir, I would love to read that as well.

I received "Beyond the Pale" for free from a Goodreads First Reads Giveaway.

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## Louise says

I received this book from the Goodreads First Reads program. This is a fascinating memoir about a woman learning about her daughter's genetic condition- albinism. I particularly enjoyed reading about her experiences in East Africa. Although 'enjoyed' seems like altogether the wrong word. The atrocities that are

happening over there, even in contemporary times are reprehensible. I am very glad to have read this at the same time as 'Born too White', a BBC documentary aired, which also focused in on Tanzania. Hopefully media like this will raise awareness of albinism and what life is like for those born with the condition.

The author also goes into detail about her ancestors, some of whom, as she discovers, also have albinism. All the while, she describes how her daughter is learning and developing. She also describes her fears over her daughter's future and eventually comes to the understanding that she will have to shift her perspective on the world to appreciate what her daughter's future will look like.

I'd really recommend to anyone looking for some lively, yet touching non-fiction.

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### **Karen M says**

Such an interesting book! I'm glad I finally picked it up as I learned so much about albinism and how it affects people around the world. I loved how Urquhart tied her research into folklore -- it really does show how fiction and myths can help us understand something that is very real.

I'm reviewing this book for the GritLIT blog tour, so stay tuned for a longer review later this week!

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### **Yaaresse says**

I have been dithering on posting these notes. I read books, and then I say what I think about them. The notes are mostly for myself, but the GR model means saying things in public. If I want to use the site, that's the trade-off required. At the same time, I know that on the other side of this book are a probably very nice (and definitely emotionally-invested) author and a little girl growing up in the computer age who really didn't have any say in being the subject of a book.

So, here goes. And it's going to be a long one, I can tell already. So I'm going to give a down-and-dirty short recommendation first, then get all verbose and mouthy.

Short and sweet: If you are a new mother who knows absolutely nothing about albinism or what to expect or if you feel like no one has ever faced what you *think* you are facing, buy the book. Read it. Learn from it. But before you do that, go to the NOAH site at <http://www.albinism.org> and download their information package which will clearly and calmly explain this family of genetic conditions. (There is more than one type of albinism.) If you are still confused and have questions, make an appointment with a low-vision specialist who can give you practical, informed answers. Once armed with facts, read this book and enjoy. Most of all? Stop panicking.

If you're someone who enjoys reading memoirs about parenting or about first world people who travel to third world situations and seem to feel like they have some connection to what's going on there because of one fairly superficial commonality, you will likely enjoy this book, but be warned that parts of the book describe violence toward and mutilation of children. Don't expect *Eat. Pray. Love*.

Now for the long version:

This book and I got off to a rough start before I ever began reading it.  
(view spoiler)

## Hannah says

I am fairly conflicted about this book and I have mostly myself to blame for that. I did not really read the description before requesting it and going mainly off the title of the book, I expected the folklore part of this book to play a bigger role. And I would have loved that book (the one I imagined in my head I mean), I am sure of it. Using something as personal as the birth of one's child with albinism as a stepping stone to discuss larger themes of folklore and discrimination and mystery? Yes please. And the book did do that, in part, but not in any kind of depth. This is especially sad considering that Emily Urquhart has academic experience in this area of research and it could have been glorious! The parts where she talked about different myths were definitely my favourite but I think they could have been more fleshed out and the conclusions drawn a little bit more researched and less on the nose.

On the other hand, who am I to tell her how to write her story? A story she obviously mostly wrote for herself and for her daughter to make sense of her now changed world. It is heartwarming to read of all the things she does for her daughter and the book gives a clear sense of how much Emily and her husband adore their daughter and want just the best for her. I do enjoy reading memoirs, so I was also fine with her telling the story of her daughter's first few years.

Where the book did lose me was in the weird structure - Emily Urquhart does jump from topic to topic and does not tell the story chronologically either, and sometimes that got a bit frustrating to read. I also was not the biggest fan of the visit to Tanzania - while I enjoyed reading about the myths and also the dangers faced by people with albinism in this country and learning more about Tanzania, Emily Urquhart's reasoning why she just absolutely had to leave her daughter behind to explore the connection she has with people in Tanzania (as a mother to person with albinism), was not convincing for me.

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I received an arc of this book curtesy of NetGalley and Jacaranda Books in exchange for an honest review. Thanks for that!

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## Philippa Mary says

A very interesting book about a topic I knew very little about. It is written really well and is easily accessible - you don't need any prior knowledge of albinism. Please go read this book! I highly recommend it.

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## Amy | shoutame says

A wonderful read exploring the many cultural beliefs and understandings surrounding albinism.

This is a non-fiction book focusing on a subject in which Emily Urquhart has poured her heart and soul. Having given birth to her daughter Sadie, Emily quickly discovered there was something that set her daughter apart from the rest - she had albinism. Being a passionate folklorist, Emily took it upon herself to discover everything there is to know about albinism - from all over the planet.

What I loved about this book was the unfaltering determination from Emily to unearth the secrets of her

family so that she could one day share them with Sadie. You see Emily and her husband come to terms with the fact that Sadie will always be impaired in some way or another - but they combat that with pure courageousness and open minds. It was a truly eye-opening read and I would highly recommend to all, I had never read anything to do with albinism before and this one definitely taught me a lot!

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### **Birgitte Bach says**

Interessant bog, men jeg synes ikke den var særlig godt formidlet.

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### **George says**

Quite disappointed by this I had really high hopes for this book. I thought there would be more facts and folklore surrounding albinism but what it mainly felt like was following someone coming to terms with being a new mother with some different challenges than your 'standard' new mother and listening to a friend's aunt walk you through her findings on ancestry.com. The only parts I found interesting/enjoyable were the medical facts and the Tanzanian perspective. Perhaps I should have looked into this more and I would have been less disappointed.

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### **Kaitlin says**

I'm giving this book a 3.5\* rating which seems a little harsh in my head, but I think it makes sense. This is quite a short book and it is a non-fiction all about Albinism, folklore, and the way Albinism is treated and seen worldwide. When Emily (the author) had her baby (Sadie) she was born with Albinism. This is a genetic disease that affects people when two genes are mixed in the baby. When Sadie was born Emily had no knowledge of her family history with Albinism, and so she started trying to find out as much as she could for both herself and Sadie, so she could help and explain things to her when she got older.

What I liked about this is that it's brutal and raw and not afraid to be. Some parts of the world Albinism and people with the condition are looked down upon as less than human 'zero-zero' in Tanzania. These places are dangerous places for people with this condition to live, because witch-doctors and people believe that the bones and body parts of Albinism sufferers are potent with healing properties. Many young people with the condition are brutally attacked and sometimes murdered by people trying to steal their body parts... This is a horrific reality.

What I found a little less engrossing was the fairytale element. I had hoped we'd see a lot more of that than we did because of how it was pitched, but it seemed to me that we really didn't get to see very much at all. Whilst I enjoyed the looking at the nasty side, and the good side of conventions in Canada (where they live) I wish the folklore and fairytale side had been brought in more. Maybe that's just me, because I enjoy that sort of thing, but I definitely wouldn't have wanted any other part missed out to put that in, so I guess what I'm really saying is I wish this was longer and could have gone more in-depth.

I learned a lot from this story and I am very, very glad I read it. It's both lovely, terrifying and enlightening, and a story I really enjoyed, but that they lived. I would certainly read more by this author, and I enjoyed the experience of this one, I just wish there had been more. 3.5\*s from me :)

