

The New York Times
A Guide to Skin Disease Through the Eyes of a Boy
By DONALD G. McNEIL Jr.

"Hi, I'm Ryan. This is a story about what started happening to me when I was 8 years old. I wish I could tell you that this is all make believe, but it's real."

Ryan does not discover that he is a wizard among Muggles, or get to go to Hogwarts, or get a Nimbus 2000 broom and become a star seeker at Quidditch.

He does discover that he is different from the other kids in his class. He has vitiligo, a skin disease creating white patches on his face. And now the kids on his very prosaic, un-Hogwartian yellow school bus call him weird.

If Harry Potter's adventures are joyful skyrockets of the imagination for children who suspect they are somehow more special than the mere mortals around them, then Ryan's story is a depressing reminder that sometime in childhood most of us put in some years as mere misfits.

(My mother told me that she spent her childhood concealing from her parents the true story of her birth: that she was a princess and had been forced into her tedious life with them only because of a tragic hospital mix-up.)

Mostly, this is an 18-page "What is vitiligo?" primer, the kind that might be found in a doctor's waiting room. That is roughly one-fiftieth the length of "Harry Potter and the Order of the Phoenix."

Such primers are badly needed. Very few children have noticeable vitiligo, but those who do, like children with port-wine stains, albinism and other birthmarks and conditions, can suffer terribly from the teasing.

Vitiligo is especially difficult for black children, who can end up with faces, arms and legs in a very visible camouflage pattern of browns, pinks and whites.

In Ryan's case, it all starts with a visit to his dentist, who notices a white spot below his lip and suggests seeing a dermatologist.

Ryan learns that vitiligo is caused by the weakening or death of his skin's melanocytes, the pigment-making cells. It doesn't hurt or itch, but it's incurable and irreversible. A pale-skinned boy like him can conceal it by avoiding the sun.

There are other treatments, involving pills or creams that make the unpigmented skin more likely to tan, followed by ultraviolet radiation. But none are perfect.

By the time Ryan is 11, the patch has spread across his chin and cheek, and new ones are turning up on his legs. But he takes up skiing and dares to tan over the summer. It is much more evident when he returns to school, and his classmates mock him.

At his mother's suggestion, Ryan, who is now an expert, gives a classroom presentation on vitiligo, answering one question on all their minds: No, it is not catching.

By the end, reassured by his mother that she doesn't even see his patches, he has opted for acceptance. "I'm O.K. just the way I am," he proclaims. But in the thought balloon over head, he is imagining himself grown up, in a lab coat, working on a cure — superior to the mere mortals around him.

The book, meant to be comforting to a child with vitiligo and instructive to a thoughtless child without, can be ordered through the American Vitiligo Research Foundation, (www.avrf.org) or (727) 461-3899, or rikcinmay@acegroup.cc

Ryan

