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## My Perspective on Living with Ichthyosis

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From the time I was born with lamellar ichthyosis, my life has been something of a paradox: at once, everything and nothing is about ichthyosis. Born a collodion baby, my family was fortunate to at least have received a timely and accurate diagnosis of lamellar ichthyosis as the cause of my problems. However, the information my parents received in those early days about my ichthyosis was, at best, incomplete and often devastatingly pessimistic in terms of the quality of life I was expected to experience. It's no wonder they had doubts about what life would hold in store for me and decided it would be best not to have any more children, at least until they saw more of how things turned out for me. I didn't know the reasons for my parent's choice until later in life; all I knew growing up was that I thrived as an only child. When I first learned about birth order theory, I considered myself a lucky product of all the beneficial things that birth order theory suggests as hallmarks of only children: an innate sense of independence, strong problem-solving skills, and a tendency toward leadership positions. Even today, I can't imagine growing up (or wanting to) any other way.

My family, especially my parents and my grandmother, embarked on a trial-and-error quest in search of effective treatments for my skin that continues to this day. Early on, two distinct goals for any type of treatment emerged: (1) improve my appearance and (2) improve my physical state. From my perspective, the cosmetic aspects usually took precedence (and usually still do). Above all, I wanted to look normal. How I define "normal" has changed over the years. As a child, "normal" meant being able to go out in public, carry on everyday activities that most people take for granted, and not have all

sorts of people stop dead in their tracks, compelled to stare at me. I never had any difficulty responding confidently to people's questions about what was wrong with me. However, every time someone stopped to ask that question served as a disappointing confirmation that no matter how close to "normal" I thought I had gotten, I still wasn't.

Often, the cosmetic and the physical objectives intersect. For example, like many people with lamellar ichthyosis, the skin around my head is tight enough that it pulls at my eyelids and causes ectropion. Much to my ophthalmologist's relief, the consistent addition of a nighttime eye lubricant alleviated what was becoming a dangerous drying of my corneas. Much to my delight, this addition lessened the effects of the ectropion, making my eyes appear less red (and more "normal"). But, miss a single night and the difference is immediate—both in comfort and appearance.

Quite apart from anything having to do with ichthyosis, and like so many little girls for generations around the world, I fell in love with horses. My first regular contact with real horses started with weekly lessons when I was eight, and my interest has continued ever since. Therapeutic riding, hippotherapy, has become more commonplace in this country. I can't help but recognize the profound influence I believe horses have had, physically and emotionally, in my life. Besides inspiring in me the same Zen-like awe that millions of people before me have felt, handling horses gave me a sense of accomplishment and empowerment that I know has permeated all aspects of my life.



The daily and weekly routine to maintain my skin is labor intensive and involved, a constant trade-off between looking and feeling “good” yet not consuming so much of my life that my world becomes unhealthily dominated by it. The first time I was completely responsible for all aspects of my skin care was when I went away to college. I surprised everyone, most of all myself, by ultimately following my father’s footsteps into public accounting; very “public,” in fact—for many years I was a practicing auditor with a Big Four public accounting firm. Unlike some people with ichthyosis who struggle to establish themselves professionally (and attribute many of their struggles to others’ lack of acceptance of their skin), both my colleagues and my clients were well-educated and gracious; I’m not aware of my skin ever adversely affecting my professional aspirations. On the other hand, because so few people in the workplace ever ask anything about my skin, I sometimes find that I’ve worked with people for years, feeling as though we’ve come to know each other well, yet never have had a natural

opening to discuss what’s obviously wrong with my skin.

No one knows more about everything and nothing with my ichthyosis than my husband. Whether it’s scales in our bed, rescheduling plans at the last minute to accommodate a desperately needed bath, trying to cool me down when I’ve overheated (and, as a result, become wickedly cranky), or running out to the drugstore to refresh my supply of precious eye ointment (which I’d neglected to remember to replenish until just minutes before bed), he supports my incessant skin-related issues willingly and as though nothing could be more natural. He’s also picked up where my parents left off as my most ardent fan and staunchest advocate; he makes sure that I believe I can do anything. For instance, he decided several years ago that the world needed an Web site devoted to ichthyosis. As a network administrator, he handled all the technical aspects and I developed the content; together, we created [www.ichthyosis.com](http://www.ichthyosis.com).

Even now, my life is a rewarding mix of things related and unrelated to ichthyosis. We moved to Washington, DC about four years ago so that I could accept an appointment to the staff of the Public Company Accounting Oversight Board (more in the public eye than ever). I recently completed nine years as a board member of the Foundation for Ichthyosis and Related Skin Types, a beloved and critically important group with which I’ve been very privileged to be associated. I’m still trying to find more effective treatments for my skin, still pretending to be “normal.” All around, I’m having the time of my life.

Perhaps it’s the permanence of living with a severe but as yet incurable disease that forces me to find some conciliatory peace with my situation. But, given the choice, I’d change everything about my situation and yet nothing at all.