Foundation for Ichthyosis & Related Skin Types

June 20, 2023

To whom it may concern:

I write this letter to share my testimonial and gratitude for the outstanding Rare Earth team we worked with in May 2023--Connor, Ryan, Alex, and Serena. The stakes were clear: climbing the Grand Canyon would present very serious risks that needed to be taken seriously. But, the payoff was also clear: this could exponentially inspire and connect our community, if everyone made it out safely.

Foundation for Ichthyosis and Related Skin Types (FIRST) is a nonprofit patient support organization dedicated to improving lives and seeking cures for people with ichthyosis and similar skin diseases. We have a long history of raising funds and running programs to empower our community.

Ichthyosis comprises 28+ diseases which affect the skin regarding sun sensitivity, heat management, and the ability to sweat. The diseases are rare—each year only about 200 babies are born in the US with a moderate to severe case. Ichthyosis is also highly variable among individuals, making it hard to predict a person's best course of treatment, physical abilities, and personal sensitivities.

Preparation
The Rare Earth guides' preparation was thorough, thoughtful, and all-encompassing. A few weeks before we left, the NPS announced the N Rim was closed. The guides re-configured our route and presented options that were well-matched to our group. Then, in the canyon, the guides were physically and mentally prepared to complete the journey while focusing on helping everyone around them, whatever that might entail. All the gear we needed, plus first aid, food, and I'm sure countless other things we never even saw, appeared as if by magic--an enormous amount of work that can only look effortless if experts are involved. Indeed, all the logistics for travelling, camping, and trekking with 17 people went off without a hitch.

Adaptability
With so much planning, rigidity is expected. However, this group of guides was extremely flexible. Connor was adaptable from the very start: the re-reroutes due to N Rim closure, accepting a 10-year-old, and willingness to revise plans and protocols around ichthyosis. We live in a world that is very much not made for people with ichthyosis. But Connor made the time to meet and listen to us, then he spent more time learning about ichthyosis on his own, and then he met with the guide team to brief them in on ichthyosis and potential adaptations. The net result was an experience wherein people with ichthyosis felt completely free, safe, and cared for—pre-requisites for doing your best in a grueling physical challenge. Finally, the guides also pivoted and created a completely new menu of options for us for the second day, based on reading the needs of the group.

Soft skills
The guide team took Connor's lead on ichthyosis issues. They all showed up informed, caring, and comfortable around those of us with different skin. Ichthyosis affects many aspects of camping and hiking including handwashing, Purell, cooling towels, shower times, sunscreen application, and more. Beyond just being educated on what to expect, it was clear to me that these guides were really, simply, good people. Their care was evident, and their personalities sparkled. When you are facing uncertainty and used to judgment about your skin, it can make a huge difference to see 4 individuals beings completely themselves, joyfully working very hard, and supporting you unconditionally. They set a tone of acceptance, understanding, and belief in others and themselves. Their energy was inclusive and contagious, and I'm sure it's responsible for many of the miles we powered through.

In closing, the care and knowledge from Rare Earth guides made us feel supported, informed, and capable. We made it through the canyon, raised $70,000, and learned how to test our limits. Our memories of the canyon will be treasured forever and I daresay we all wound up inspired to be better humans after spending a few days in the care of Connor, Ryan, Alex, and Serena.

In gratitude,

Denise Gass

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Director of Development, FIRST