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Online inspiration helps fight arthritis

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Peter Marshall celebrates the success of his fundraising trip on the summit of Mount Rainier at 14,411 ft. Handout

Two weeks back from his honeymoon in Hawaii, Peter Marshall was told he had an extremely rare autoimmune disease with no known cure. When given that shocking news, he says, the feeling of isolation was profound. “It can be pretty scary when you don’t know what it all means.”

A seasoned triathlete and Iron Man competitor from Vancouver, Marshall was diagnosed with Wegener’s Granulomatosis (WG) at the age of 31. The disease affects one in 100,000 people. “It started out with chronic symptoms like sinus infections, then acute joint pain. Then I started coughing up blood and ended up in intensive care.”

Two weeks earlier Marshall had been feeling relatively okay, he says. Still, he considers himself lucky, because he was diagnosed in time to receive treatment for his condition — including 10 months of chemotherapy, and high doses of steroids and other immune suppressants.

In this new reality, he found that online communities helped him gain a perspective on his illness and some inspiration in the process. “It’s not often you will meet anyone with the same disease,” he says. “But I’ve been able to connect with a few people online and hear their stories about what they have gone through.”

In fact, it was an online forum that inspired him to launch his own fundraising project. “I found a woman who had the same disease and had climbed Mt. Everest. That gave me the idea that I could still do something really big and challenging and give back to those who helped me.”

Last year, he developed a 12-day “Autoimmune Expedition” which included his friends and

family, and something he would do with reduced lung capacity. The mission: cycle to and from Mt. Rainier (500 kilometres each direction), and a 10,000-foot vertical climb to the peak. “One friend and myself were the only two who made it to the summit,” he says. “We were also the only ones carrying the gear.”

He celebrated this incredible accomplishment with a six-day back-country hike in the Yukon with his mother.

The Autoimmune Expedition raised more than \$14,000 for The Arthritis Society, which worked with him to publicize the site and manage donations. “I chose to raise money for them because what I have is lumped in with so many arthritis conditions, I felt they could use the money to help with research projects for this group of rare diseases.”

The expedition was also to support the work done by his rheumatologist, Dr. Jason Kur, and colleagues at the Vancouver General Hospital UBC. Kur says Marshall’s efforts have been invaluable in raising awareness. “Those are the stories that bring a human face to conditions that are often overlooked.”

The personal connection is especially critical for younger people since autoimmune-related diseases such as rheumatoid arthritis can affect people of any age, Kur says. In fact, the highest number of referrals for his clinic are patients between the ages of 40 and 50. “There just isn’t a lot out of information out there publicizing their conditions. And there are not a lot of spokespersons.”

Standing in the way, Kur says, are psychological barriers. “People are shy to talk about their conditions. We have perceptions of historical depictions where there was a lot of disfigurement, so there is a lot of stigma attached to arthritis. But that’s simply not the case anymore.”

He believes communities such as The Arthritis Society’s brand-new site, ThePain.ca, can help to remove the stigma and encourage people to communicate about living with arthritis. “It can be hard for people, especially with rare diseases, to get plugged in with others. But they need to know that treatments and outcomes are much better today.”

Advancements have made a dramatic improvement in both quality of life and mortality rates, he adds. “Autoimmune diseases (such as rheumatoid arthritis) are an area where modern medicine has had one of the biggest impacts in terms of survival and quality of life. People need to hear that, especially because early diagnosis and intervention are key. Many people are living near-normal lives with the treatments available today.”

Marshall is more than ready to share his story on ThePain.ca to reach out to people like him. “It’s definitely a good way to develop a sense of community and learn from others. People need to know that having this type of disease isn’t the end — and that they’re not alone in their battles.”

In fact, even through Marshall’s lungs have permanent scarring and he now has asthma, he’s thinking seriously about returning to the triathlon scene in a year or two. “I probably won’t be doing an Iron Man again. But I definitely want to stay active. I just have to learn how to pace