

# Patient Perspective: Molly Dushnicky

I can't tell you much about my initial diagnosis of polyarticular juvenile idiopathic arthritis. That's because I was only 18 months old when I was diagnosed. My mom tells me the same story I have now heard so many times from my own patients — I had started walking, and then I stopped; it was hard to bend my knees to get me into my sleepers; I was such a happy baby, and then, I just wasn't.

My name is Molly, I am 33 years old, and I have been living with arthritis for the majority of my life. I am also currently in my final year of a pediatric rheumatology fellowship at the Hospital for Sick Children in Toronto, and I cannot wait to continue a career as a pediatric rheumatologist and be able to give back to a community that has given me so much.

As I am sitting here writing this article, I am reflecting on my life with arthritis and the challenges I have faced. Growing up with a chronic disease and being constantly told to slow down and take it easy drove me to be even more active. I never took it easy. I grew up playing sports, pushing myself to keep up with all the other kids, and always wanting to participate in literally everything. Even if I was in pain, I always wanted to keep going. In that sense, I'm grateful for my arthritis; I'm a stronger person because of it. Now, I am an active soccer player, curler, and skier. There are still many days where my arthritis doesn't allow me to do the things I want to do, but for the most part, I can, and I'm always grateful for that.

It has exhausted me — despite all my knowledge of the disease now, I continue to have hope that one day I might come off medication, that one day I would not have to think about all of this anymore. It's hard to not have hope, even if all my medical training tells me that at this point, I'll likely always have to deal with my arthritis. When I was younger, I would have disease-free periods, where I was able to come off all medications. Then I would have a flare. Every time that I've needed to restart medication, to increase or change my medication, to go for another joint injection, it's emotional and tiring. I sit



Dr. Molly Dushnicky with her husband, Tim Wright, and daughter, Charlie.

here now as a budding pediatric rheumatologist, constantly having conversations with families about changing treatment plans, and all I can say is, I get it.

Let's take a moment to talk about something — none of the medications we prescribe are particularly fun to take. I've been on most of our standard gamut of therapy at some point, from non-steroidal anti-inflammatory drugs (NSAIDs) and steroids, to all of the conventional disease-modifying anti-rheumatic drugs (DMARDs), to an assortment of biologics. I can't think of a single one that I've enjoyed being on. Some of them just taste terrible, and some, like methotrexate, have tiring side effects that interfere with the high-level functioning I need to continue my career goals. Finally, weekly or biweekly injections — not fun, it's as simple as that.

It has frustrated me. The world of pediatric rheumatology has come a long way in the last three decades. Growing up, if I told someone I had arthritis, I would quickly get told that "arthritis was for old people". The medications available to treat my arthritis 30 years ago were limited, and I have damage from joints that just wouldn't respond to those medications. I encountered barriers in sports, in school, and at work, because my illness isn't always "visible". When I am at my most frustrated, I think about the progress we as a rheumatology community have made. Our knowledge and awareness of rheumatic diseases in children is constantly growing, thanks to so many amazing patient advocates and charitable organizations. The treatments for rheumatic disease have improved so much, and the number of children who now experience joint damage is much lower than when I was young. There is still so much room for improvement, but it's important to reflect on how far we have come.

Most importantly, my arthritis has motivated me. When I was young, I used to wish on stars that my arthritis (back then I called it "my-thritis") would go away forever. Now, I don't have to wish. As a physician and researcher, I work with other patients just like me regularly and help



Snowboarding at Mont Tremblant, Quebec.



Dr. Molly Dushnicky and her daughter, Charlie.

improve their disease activity. I participate in local, national, and global research aimed at improving outcomes in pediatric patients with rheumatic disease. Through my experience, I have a unique perspective on areas for improvement. For example, I grew up in Thunder Bay, Ontario — a city with no pediatric rheumatology care, a 14-hour drive from the closest centre in Ontario. I am thankful to have had an amazing adult rheumatologist provide most of my care when I was growing up, but that was a unique scenario, and today, most adult rheumatologists in Northern and rural communities simply don't have the capacity to care for pediatric patients. Although the pediatric rheumatology community continues to try to improve access to care, with outreach clinics and telemedicine care, to be frank, the care these patients receive just isn't the same as someone who lives in downtown Toronto. I have recently been involved in work with the CRA highlighting that there are geographical barriers to accessing care across the country. More recently, I've become a member of the Ontario Rheumatology Association (ORA) Northern Ontario Committee, with a personal goal to improve access to pediatric rheumatology care for all Northern patients through my career.

Further, I know the importance of a strong transition to adult care. Although I didn't undergo a standard transition to adult care, when I was in my early twenties I left Northern Ontario for graduate school, moving away from home for the first time. My lifelong rheumatologist referred me to a rheumatologist in my new city. Shortly after my move, I continued my routine bloodwork like the good, independent patient I was trying to be. The following week, I received a call from my new rheumatologist's office instructing me to stop my methotrexate because I was neutropenic. I asked if I had an appoint-

ment and was told to be patient and that I was on the waitlist. Months went by and I stayed off my methotrexate because no one told me otherwise. I still had no appointment. Then I started to flare. I continued to call to try to obtain an appointment, but was told the same canned line that I was "on a waitlist" despite trying to communicate that I was flaring. I was 22 years old, living in a new city alone, and unable to get dressed or brush my hair in the morning, with no rheumatology follow-up in sight. Eventually, I spoke to my previous rheumatologist back home, who told me to restart methotrexate and go for more frequent bloodwork for now. I was lucky to be able to maintain that connection easily. Mine is just one of countless stories of the struggles of young adults during this transition. Now, I aim to improve healthcare transition in pediatric rheumatology and, to date, have been involved in several transition-to-adult-care projects and initiatives, including building transition toolkits, helping establish transition readiness assessments, and publishing multiple articles in this field. I love what I do every day, and I am so grateful to have the opportunity to change more lives than just my own.

To all my rheumatology colleagues out there, I'm here to remind you that whether your patients and families are frustrated, exhausted, challenged, or motivated, we need to be here to support them. Dealing with chronic disease can be a roller-coaster ride, and it's our job to help patients with both the challenges and the successes of their disease and do all that we can to help each of them achieve their dreams.

*Molly Dushnicky, MD, MSc, FRCPC  
Pediatric Rheumatology Fellow, Hospital for Sick Children,  
Toronto, Ontario*