



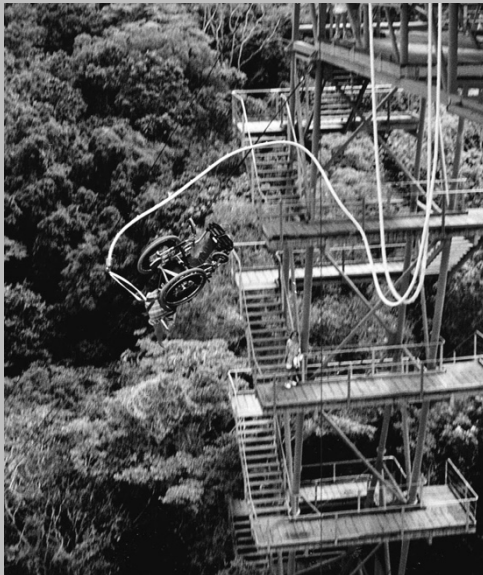
WHAT ARE YOU WAITING FOR? TRAVELLING WITH CIDP

by Director Jane Field, Toronto, ON

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I have always loved to travel, to experience other cultures, other landscapes, other ways of living. When I was 21, I travelled with CUSO, a Canadian volunteer organization, to Nigeria to teach English at a secondary school. I learned so much while I was there, far more than I could ever have taught my students. But one thing I found myself unexpectedly learning about was Guillain Barré Syndrome. Over a period of a few weeks I lost sensation and strength, first in my legs and then in my arms as well. I was very lucky that my respiratory system was not compromised that time. I returned to Canada and spent a year in rehab learning to walk and function again. When I was better, I went back to Nigeria to resume teaching, assuming I had put GBS behind me. I continued to teach and I continued to travel.

Eight years after my first GBS attack I had just returned from a summer in Nicaragua where I was helping to put electric lights in a school. Suddenly I was once again paralyzed, this time even more severely, requiring a respirator and 7 months of hospitalization followed by another year of outpatient therapy. At the time I was told this was a second attack of GBS, unusual, but possible. I didn't recover quite as well the second time and relied on a wheelchair for mobility for the next 15 years. But I still wanted and needed to travel. In fact, as soon as I was discharged from my 7 month stay in acute care before beginning outpatient rehab, I booked a flight to Mexico and headed off alone with my new wheelchair for a week by myself at the Pacific Ocean. It was wonderful. In the following year I returned to Nicaragua to help in a home for disabled children and discovered a very wheelchair accessible volcano in Costa Rica on the way. Next, I went to Europe as a mother's helper, yes, in my wheelchair - it's surprisingly easy to keep track of a two year old when she is happily riding on your lap! But, oh those old cobblestone streets do present a challenge.



Bungee Jumping in Australia

The following year I visited Australia, New Zealand and Fiji. While I was there, I was inspired to do a bungee jump in my wheelchair. I also went white water rafting and best of all snorkelling from a catamaran anchored overnight on the Great Barrier Reef. I didn't need to be able to walk to enjoy any of these pursuits.

In 1997 I was teaching adult literacy in Toronto when one day I woke up very ill with gastroenteritis. I went to the hospital to be rehydrated and returned home 16 months later. The illness had triggered (apparently) a third episode of GBS. This was the worst yet and even upon discharge from the rehab hospital I remained totally quadriplegic. I was breathing on my own, but unable even to turn over in bed without help, let alone feed myself or do any personal care. Gradually I learned to accept attendant care as the

foundation of my days, not the focus of my days. With attendant support I travelled to a conference in

San Francisco, visited friends in Massachusetts and spent Christmas on my own in Burlington Vermont, just because it looked like a nice place to spend Christmas and one of my attendants was keen to accompany me.

In 2002 just when I thought I had life as a quadriplegic pretty well figured out, I met Dr. Hahn at University Hospital in London Ontario. She told me she was sure I had CIDP and that she could make me better. After close to another year in hospital and after 15 years in a wheelchair I was walking again. One thing about walking is that it is very convenient and travel is simplified considerably. During the next 8 years my partner Hilary and I did lots of travelling - to England to visit family, to the Maritimes and the west coast to visit friends, to Arizona, Mexico and Iceland. I relished my ability to climb rugged hillside paths, walk behind waterfalls and hike in the English countryside. It seemed I had put CIDP behind me too, though I continued to take Prednisone and Imuran to keep me stable.

Whilst visiting family in England in 2012; however, I contracted the Noro virus and it triggered a fourth attack of CIDP. Once again, I was completely paralyzed. I spent a month in hospital in Bath and Bristol before I was stable enough to be flown home in a Lear jet with Hilary and a doctor, a nurse and a respiratory therapist. Not the kind of travel I would advise, though the Lear jet was fascinating. Then followed another seven months in hospital in Toronto.

I was discharged from Lyndhurst Rehab hospital in December of that year and immediately began planning a trip to Nova Scotia to spend Christmas with friends. Since I was still quadriplegic my partner could fly free on both Air Canada and Porter Airlines within Canada. My friend who is also quadriplegic rented a wheelchair accessible cabin on the Mersey River where we had a lovely Christmas together. The whole resort at The Mersey River Chalets is accessible. It was designed by several quadriplegic men so that in the summer even the canoes can be accessed with a hoist lift from the dock. Every cabin has a ramp and roll in shower. The thing about access is that once a place is made accessible it works for everyone. Universal access is a concept worth promoting everywhere we go.

Boarding a boat in Costa Rica



Following that trip, we went down to Florida in February to spend a week with my brother. There we rented a wheelchair that could go on the beach and into the ocean, though I struggled with the force of the waves. So we took the wheelchair to a lake with no waves - just alligators to contend with. We also discovered that all beaches in Florida have a beach wheelchair that can be borrowed at no charge.

I have continued to get better since 2012, though not to the extent that I did in 2002. I still need a wheelchair for any kind of distance, though I am managing to walk with crutches around the house.

No one can say if I will continue to improve or if I may even have another full blown attack of my CIDP. Life is short. Thus, in October 2015 Hilary and I travelled to South Africa, Zimbabwe and Botswana to fulfill a life dream for both of us to see animals in their natural habitat. We went on many safaris by boat and by land rover. We saw giraffes and hippos and rhinos and leopards and warthogs and cape buffalo, impala and elephants galore. The highlight was being able to ride an elephant on a safari. With much help to get on the elephant I found the ride gentle and easy. Much better than a wheelchair! It was truly a trip of a lifetime. I had researched tour companies on line and found a travel agent who specialized in arrangements for travelers with special needs. It was the smoothest trip we have ever taken and one of the most accessible. After all, no one needs to be able to walk to ride in a jeep or boat or even on an elephant. Everywhere we went people were kind and eager to assist me. All the places we stayed at were accessible - even our tent in Botswana!

Elephant Safari, Zimbabwe



I didn't hesitate to return to England for Christmas this year despite my last experience there. I can't blame England for my recurrence of CIDP. We rented a wheelchair accessible van and I took my power wheelchair this time. This gave me a lot of freedom to explore the coastal path in Cornwall, which is beautiful any time of year.

In February 2016 we spent two weeks in Costa Rica where we saw different wildlife - monkeys, crocodiles, toucans, sloths and more. We ventured into the rainforest and onto the beach at the Pacific coast as well as into the thermal springs at the Arenal Volcano. The resort even had ramps into the hot springs. In the rain forest we discovered a biological research station at La Selva that had inadvertently made 8 kilometres of trails deep into the forest wheelchair accessible. They built the paths to accommodate all the equipment they needed to bring in and afterwards realized people in wheelchairs could now experience the jungle. So, they went further than that and made a raised yellow path down the middle so that blind visitors too can explore the rainforest.

People ask me if I am not afraid of having another attack when I travel. My reply is that I could have another attack at home. Why not go out and explore the world now to the best of my abilities? I may get back to walking and I may not. What am I waiting for?