



ONE MOTHER'S EXPERIENCE

by Barbara Rahder

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It was odd for my 26-year-old daughter Micha to schedule our weekly phone call for a time when she knew I'd be going out to a friend's. But I called at the appointed hour and Micha, who was a doctoral student in California, began by saying, "I've got some bad news." I could feel my body bracing. She told me she'd been to the campus health clinic earlier in the week and described her symptoms: pins and needles in her hands and feet, tripping, falling down, dropping things and, most recently, falling over sideways on her bike when her legs refused to pedal. But Micha played rugby. She biked over mountains. She could run for miles. How could this be? My heart was pounding and my mind racing. Micha described how the young doctor had turned pale and fled the room in search of someone more experienced, how the doctor's panic had frightened her, how she'd been referred to a local neurologist, and how she hoped she'd know more soon. Tears were streaming down my face as we spoke, but it wasn't until I'd hung up and driven over to my friend Anne's, that I collapsed, falling to my knees and wailing, barely able to get the words out to explain why I was so distraught. Micha knew that I would need the support of my friends to cope with her news and had scheduled our call accordingly. I wondered, not for the first time, who was the parent and who the child.

Thus began eight long months of tests and speculation, an agonizing wait for a diagnosis and potential treatment. As Micha's symptoms ebbed and flowed, each wave seemed worse than the last. I was barely functioning in my job, but had a loyal secretary and a few close associates who knew what I was going through and helped me stay mostly on schedule, at least at work. At home, I lost the ability to keep myself organized. I missed dentist appointments, showed up at the doctor's a day early, dragged the wrong bins to the curb, and forgot to pick up my in-laws at the airport. It wasn't that I didn't have a calendar. Somehow, I managed to write down every single one of these appointments on the wrong day or at the wrong time. All around me, I was recreating the chaos I felt inside.

When CIDP was finally confirmed, and IVIG proved effective, the relief was overwhelming, however short lived. Within weeks, her symptoms recurred, worse than before. In the months and years that followed, Micha maintained a two-day once-a month cycle of regular IVIG treatment, but with a number of scary glitches along the way. At first, I'd get weepy whenever she had a treatment, but eventually I got used to the schedule and just felt a little raw on her treatment days. At the same time, I was in awe of my daughter's strength and maturity. Clearly, this illness wasn't going to stop her. It wasn't even going to slow her down.

Before Micha flew off to do her doctoral research in the jungles of Peten in northern Guatemala, we were assured that her student medical insurance would continue to cover her IVIG treatments while she was abroad. We knew that we'd have to pay out of pocket and then get reimbursed by her insurance, but lucky for her, I thought I had enough savings to cover this short-term expense. Micha also checked out the availability of healthcare services in Flores, Guatemala, where she'd be living, and arranged, in advance, to go to a local clinic where a doctor could provide treatment. But nothing worked quite as planned.

Shortly after she arrived, she caught the worst cold of her life. It cleared up miraculously fast as her immune system kicked into high gear. Within days, however, she was unable to climb the stairs to her apartment. Her first treatment went roughly as we'd imagined, but turned out to be less than half the amount of IVIG she actually needed. Instead of recovering, she continued to decline. Her neurologist, back in the US, prescribed large quantities of prednisone, but rather than helping, the side effects quickly became debilitating. Unable to sleep or concentrate or get around on her own, she phoned me in desperation. I persuaded her to fly back to the US for treatment.

The following month, Micha organized a full IVIG treatment for herself at a hospital in Guatemala City. She basically walked in, introduced herself to the neurologist, told him about CIDP and persuaded him to treat her. She received excellent treatment there. Twice. The first time, she was required to stay in the hospital overnight because they were unfamiliar with the disease and wanted to be cautious. Everything worked smoothly, so she was treated as an outpatient the following month. Having already paid out over \$50,000, however, I was running out of savings and still had received no indication of when I would be reimbursed by Micha's insurance. We had to switch tactics. Instead of continuing to receive treatment in Guatemala City, I paid to fly Micha back to the US every month where her insurance paid upfront for her treatment. After a year and a half of fieldwork in the forests of Peten, and almost monthly flights back and forth to the US for treatment, Micha completed her research and returned to California to analyse her findings and write her dissertation.

At some point during the next year—as she was busy teaching, writing, and coaching rugby—she was informed that she was going to lose her health insurance because she would soon exceed her lifetime coverage (\$400,000 US) under the students' plan. Initially they said they'd cut her off at the end of 2012, which was, in fact, the last treatment they paid for upfront. But in January, after they finally reimbursed me for the cost of her treatments in Guatemala, the insurance company moved her cut-off date from December to the prior September, claiming that she now owed them for three months worth of IVIG expenses!

In response, Micha did several things. First, she came back to Canada to re-enroll in OHIP (with a three-month wait for coverage under the mobile worker program). This allowed her to continue her studies in California, to apply for other types of emergency medical insurance in the US and, most importantly, to help organize to change the healthcare policy offered to University of California students. The students at Santa Cruz, Berkeley and other campuses wrote letters, created petitions, held protest marches and demonstrations, lobbied the UC Chancellors and members of the Board of Regents. And they got media attention for the plight of students, like Micha, whose studies were in jeopardy because of their lack of healthcare coverage. Micha spoke at rallies, met with officials, and was interviewed by CNN, among others.

During the three-month wait for her OHIP coverage, she struggled through a long period without needed treatment, at one point becoming bedridden and so weak that she was unable to feed herself. Ultimately, she had to have treatment regardless of the cost, so we solicited donations from friends and family and got support from a local medical charity, as well. Her rugby team provided homecare.

When her OHIP coverage began, Micha moved back to Toronto, as planned. To my shock and dismay, however, the earliest she could get an appointment with a neurologist was another four months away! This meant no way to schedule her regular IVIG treatment, as we'd anticipated. Our family doctor was unable to help. Micha's health was deteriorating and I became frantic, again!

Then, one night I went to the GBS/CIDP Foundation of Canada website, found Susan Keast's email and wrote to her. She responded that same evening and was tremendously helpful and reassuring. By the next week, Micha had an appointment with Dr. Brill and, soon after, was enrolled in a study.

Unfortunately, the experimental treatment did not work for her and she had to drop out. It seemed we were back to square one! I know I emailed Susan again for help and don't really remember how things got resolved, but somehow Micha was able to go to Toronto Western Hospital for regular treatments after that. I am so thankful for Canada's healthcare system and also for Susan Keast!

As it turned out, the political organizing and pressure that students put on the University of California paid off, too. The Chancellors voted to change the students' health insurance plan, so that there is no longer any lifetime limit on their healthcare costs. Micha was able to return to UC Santa Cruz, complete her PhD, and is now an anthropology professor at Louisiana State University in Baton Rouge, where she continues to receive IVIG treatments for two days every month...at least as long as Obama's Affordable Care Act is still in place.

Barbara Rahder and her daughter, Micha, are dual Canadian/US citizens. Barbara is a retired environmental studies professor.