

# Ingrid's Story

by Ingrid Egger Stepan

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My goal is to take the fear out of having this treatment and for people to have hope and hang on: it's coming.

Well where to start? I was diagnosed at 47 years of age in Cranbrook, B.C. I had been having weird symptoms of not being able to lift my leg up onto a curb, and I would fall and both my knees were always a mess. I got stiff delivering fuel and supplies to the job sites (construction job). I could hardly walk sometimes and I couldn't get up or down off of the back of the truck anymore.

I was told by my family doctor that I had Parkinson's then ALS then MS. Finally, when I said I'm getting stiffer and stiffer, she typed those words into her search engine and it came out with stiff-man syndrome and said to check for GAD antibodies. I was also sent to her friend who is a cardiopulmonary specialist who had done a year of neurology during his residency and had seen a few cases of stiff-man Syndrome.

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He confirmed it, and tried to talk me into taking valium. I was very hesitant as my mother was and is a drug addict and I was afraid. I tried 2mg of valium in his office with him, and within 10 minutes I could move again. So he prescribed 2mg doses for me 3 x a day, and gradually we moved up to 5mg doses and I was taking 25mg a day. I was in line to see the travelling neurologist, but that would take 14months, bear in mind I still was only given 1 to 3 years to live.

I got on the internet and started to search for another Neurologist. I found one in Vancouver and I called them up and asked if they had ever heard of my disease: yes we have other patients with it. You need a referral. So, my doctor from Cranbrook referred me to the neurologist in Vancouver. I was seen quickly and the diagnosis was confirmed. The course of treatment would be IVIG, Baclofen, Gabapentin, and Valium. Well, the pathologist in Cranbrook would not sign off on my IVIG as I was already told I was going to die! So, I called the blood coordinator's office for B.C. and spoke with the head person. He said, yes absolutely I can have it and gave my doctor permission to prescribe it. They still would not do it.

We moved to Saskatchewan, a small town called Bengough, population 350. There I received IVIG every 8 weeks. After two weeks of being violently ill, I could walk again and dress myself. Up until that time, my two youngest kids (who were 9 and 11) were getting me dressed and helping me walk.

I decided that I would follow the advice of the patient care quality person for Cranbrook and asked why I couldn't receive this product at home. They assigned me a lady, who was supposed to look into it. I explained and gave her the names of all the doctors who have access to this product. She wanted to know who my source was that gave me that info and I refused to give it. I said to her you can look on the computer yourself and see who gets it. I had a lot of friends that worked at the hospital, and they gave me the info, some were doctors and others were nurses, one was even a pathologist.

Anyway. I went on to mention that I had worked for a medical supply company many years prior to living in Cranbrook and I understood the system, this stuff IVIG is flown in fresh every day, more than fresh fish. So, if others can have it and I have the approval why can't I have it?

We stayed in Bengough for 3 years. I bought that house off the internet for \$38,000 and we fixed it up nicely, and realized that education there was not adequate if we were going to give our two younger children a future! We decided to go to Ottawa where my husband had family and we knew education was good. I got a family doctor, a neurologist, and I was referred to Dr. Atkins who had done the other two stem cell transplant patients.

After a year of checking me out and getting approval from Health Canada I finally got to start my treatment. I am now post 5 ½ months . I got my stem cells back April 11, 2014, my new birthday forever.

I use to be a statue, or a popsicle, whichever way you want to view it. I was stiff, I had rational agoraphobia which meant I wasn't able to move if I was in large spaces or by myself. I have a wheel chair which is now put away. I have a walker and I watched my daughter use it to carry the laundry, lol, that's what I do with it now too. I have a cane and on occasion I do have to take it with me. I do experience some stiffness, they call it muscle

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memory and so I work hard to exercise and have my muscles believe we are different now. They say this can last up to a year.

Dr. Harry Atkins is now published in the American Journal of Medicine, and the first two patients are listed in there. I am not. However I am number 3 in Canada and number 5 in the world for growing my own stem cells then receiving them back.

I took 10 shots of Neupogen to stimulate my red blood cells to produce more. My stem cells were then harvested and I began chemo. I had 13 rounds of chemo, and 5 of AGT which is a serum made from rabbits. It ensures that it catches anything that chemo may have left behind, kind of like a mopping solution. I stayed in the hospital for 23 days. I was isolated yet not lonely at all. I had a lot of doctors, researchers, and nurses as well as others looking in on me daily. This disease did give me diabetes, so I had an endocrinologist as well as a social worker who ensured my husband and kids were well, a clinical physiologist to help with the rational agoraphobia, which now I can use an escalator or climb stairs. I can go out on my own and have used the bus to do so to get to medical appointments.

I'm free from a beast they said could not be cured. I see it as a cure. For now, it's an experiment and it's my understanding that once 20 people are done, it then becomes a form of treatment just like a cancer patient would receive and therefore should be covered by American insurance companies. As I am Canadian it did not cost us anything. We had to pay for parking and snacks.

I came up with a list of items that were very handy to have in the hospital and at home: unscented baby wipes, (I had a lot of diarrhea). I only threw up twice. Paper cups for the bathroom, I rinsed my mouth with salt water 3 or 4 times a day and as a result I never got sores in my mouth or throat like others have from having chemo.

I also suggest sanitizer in every room. I purchased a box of masks and put them on the back of the front door. The kids wore these out of the building and on the school bus, they had a baggy of them in their back packs. If kids had a cold at school, they put a mask on and changed it every 20 minutes. In hindsight, I guess I could have purchased better masks.

The type of chemo I had was called Cyclophosphamide. It is stronger than what is generally used on a cancer patient. I was also given a grocery bag full of any kind of antibiotic, antifungal, anti-anything.

I'm now down to two, Acyclovir and Septra. Acyclovir is to prevent shingles, herpes, measles, etc. The Septra I take once a day instead of 2 x per week and 4 in one day. It would make me throw up, so I take it my way, once per day. My numbers are not great I'm told, but enough to keep me home. I have IVIG once a month and it is used to prevent infection. I am still diabetic and may stay that way, although I have been able to stop taking Metformin, so I think that means I am now type 1.

I am married. We have six children ranging in ages from almost 30 down to 13 years old. We haven't seen our home in over 5 years. We don't know if we will ever get to go home. I have 3 children living in Cranbrook and a grandson. We have one daughter and her husband in Australia. We can only skype them.

This disease changed our lives. My daughter and husband became depressed. Our daughter tried to commit suicide twice, and has cut herself, so everything we own is locked

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up. Our son is withdrawn at times, and it's hard to know where his mind is at. My husband suffers terribly from depression and his family has no understanding of this disease other than, "I'm sorry you are going to die a horrible death." Who says that crap? Not once did they come over while I was in the hospital, our daughter did everything and she is only 15 years old. For her, this was overwhelming and may have contributed considerably to her wanting to die. She doesn't want to die anymore. The other day she spoke to someone in Bengough who said there is a rumour that I had died. Our daughter said really, well then she's a ghost because she is right here and cured. She had a big smile on her face when she said that. The kids see the difference. We all want to go home. We just need to know we will have a doctor and I can still get the remaining two treatments of IVIG before being vaccinated.

If you have any questions please do not hesitate to contact me. You must also know we gave up everything to be here in Ottawa, all our furniture, our home, our friends, our kids. We used up all our savings to stay alive until my husband found work. We will never regain what we lost, but our children have a mother and I am alive and I will get well. If you are interested, check out #2's site called Share a cell. [www.shareacell.com](http://www.shareacell.com) she is on a roll and I want to help. Cheers,

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