

Chapter 1

A Healing Journey with a Thousand Echoes

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ABSTRACT

In this personal account, the author describes her engagement with the healthcare system and the insights she gained during her struggle to restore her health. It also chronicles how this life-changing event prompted her to help educate others diagnosed with similar diseases and to form an active community for sharing and expanding medical knowledge. After a synopsis of the author's medical journey in the Introduction, these topics are woven into three main sections: Medical Evidence, Complementary and Alternative Treatments, and the Influence of Technology.

INTRODUCTION

Like many patients, I thought life was going along fine. Sure, my job wasn't very fulfilling, but it did pay well. I was worried about my two daughters who had graduated from college and were trying to find their way in life, not unlike many young adults. I was living with "Paul" and that relationship was alright, but not great. I was eating the standard American diet along with a daily dose of chocolate and way-too-frequent french fries, had redecorated a few rooms in the winter with insufficient ventilation, cleaned my

home with the volatile products one finds on the supermarket shelves, and had sprayed some plants with pesticides. I was oblivious to the increasing toxicity of my lifestyle. That is until I caught what seemed like the flu, after getting chilled on vacation during the July 4 holiday in 1992, and my physical resilience gave way to a disease I couldn't ignore, although I tried.

After that vacation, I had trouble getting out of bed and just collapsed after work, thinking the fatigue and lack of vitality would go away with rest. The bruises that mysteriously appeared on my arms were odd but would go away too, I thought. I became more suspicious when I bumped my thigh on the edge of my bed and noticed a black and

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blue mark the size of a grapefruit. I became more alarmed when I bit my tongue and it didn't stop bleeding for what seemed like way too long. The little things I tried to get back to normal, resting, traveling to San Francisco to breathe the bay air, eating more vegetables, were not helping. It was then that I decided to go to a doctor.

I wasn't anxious to have a deep involvement with the medical profession. In my late twenties I had my thyroid removed when the lumps in that gland were found to be cold nodules with a small amount of papillary cancer. In my late thirties I had what might have been a seizure, partly due to poor regulation of my Synthroid dose, replacing the functions of my missing thyroid. The Dilantin prescribed for the seizure made it difficult for me to concentrate or do my computer job and I was included in the corporate down-sizing. It took me years after discontinuing that medication, plus some experiments with vitamins and diet, to feel myself again and rebuild my career, in time for the flu and bruises to consume my life.

The hematologist I consulted told me I probably had idiopathic thrombocytopenic purpura, ITP. He wrote it on a piece of paper since there was no possibility of my remembering those strange words. He explained that my body was attacking my platelets as it would attack a virus or bacteria. ITP was in the same autoimmune category as multiple sclerosis or lupus, diseases I had at least heard of. And, like those diseases, there was no definitive cause, although sometimes the low platelets were linked to various environmental toxins.

Since I didn't have many platelets ($6 \times 10^9/L$, or 6,000/mL) my blood would have difficulty clotting and there were insufficient platelets to plug up the holes in my veins and arteries. All this made logical sense given my symptoms. I was glad to have an explanation I understood.

When I questioned the prognosis, he said the disease was fatal in a small percent of cases, but most times it could be managed with treatments. However, when he talked about the treatment options I recoiled. The first choice was prednisone,

and I knew from a girlfriend who had taken the drug for her asthma that it could change your personality in addition to other unwelcome side effects. After he mentioned the usual second-line treatment, a splenectomy, I was disheartened. I'd already lost my adenoids and tonsils as a child and my thyroid as a young adult, and the loss of each of these may have solved some problems but certainly caused others. I wasn't anxious to lose another organ, especially one that was healthy.

I finally did agree to the prednisone, despite the difficult side effects, since it seemed to be the usual first-line recommendation for treating ITP from what I read on the Internet, and a splenectomy was certainly lower on my list of preferences. However, the prednisone barely raised my platelet count and caused more than the usual share of problems.

I didn't know it at the time, but this was only the beginning of a series of treatments, including several courses of IVIg (immunoglobulin G), a splenectomy, additional rounds of prednisone, colchicine, Danocrine, vincristine, and a Prosorba A column that resulted in another series of treatments to manage the side effects that included possible damage to my digestive system, a suspected seizure, tachycardia, a possible heart attack, and a near-death experience. I was a walking pill box.

Unfortunately, despite everyone's best efforts, none of the treatments succeeded in keeping my platelet count much above 5,000/mL for more than a few weeks and their cumulative destruction left me bald and so weak I could barely walk up stairs. From my diagnosis in August, 1992 to February, 1993, I spent 51 days in the hospital, was on short-term disability from my job, and felt I had no life.

As the treatments my hematologist recommended continued to fail and the side effects mounted I began to look outside of the medical mainstream. If I wanted to live to see the children my daughters wanted and be able to ski again, I clearly needed to change course. I had consulted a naturopath with mixed success when attempting

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