

Living with Multiple Myeloma for 22 years

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Received Date: May 04, 2018; **Published Date:** May 09, 2019

Could You Tell our Readers about Yourself?

I was very healthy; at least I thought I was, rarely taking time off from work to deal with minor colds and physically in good general health. I had a strict routine of working out at a gym for 15 years. I had a family of three children a 16 yr. old and twins who were 11 when I got officially diagnosed, so it was a traumatic event for everyone in my immediate and extended family to be laid up and not my usual self.

How did You React to the Diagnosis

In terms of my introduction to M.M, I was not officially diagnosed until April 1997. In April of 1995 it was found that I had a plasmacytoma on my thoracic spine. Obviously, the small lump on my back was strange, but I thought the related pain and discomfort was a result of a skiing injury from two months earlier. Since I have had recurring back pain for most of my adult life, I assumed this would work itself out. After a visit to my family doctor and an acupuncturist, who discovered the lump, I revisited a prominent neurosurgeon that I had used for a lower back laminectomy in 1991.

He ordered CT scans and a MRI and discovered after a ten hour surgery that I had a cancerous vertebra (solitary plasmacytoma). That however was not a M.M diagnosis. I was relieved that radiation and not chemotherapy was in order. I mended for four months at home. That was my

introduction to what would become officially Multiple Myeloma, the third and rarest type of blood cancer at that time. So here it is April 1997 and my blood counts and marrow biopsy were indicating a change in condition. However, with levels which were not indicating any major change in my general health, nothing but x-rays and bone scans were needed to keep track of the now true diagnosis. A second opinion in June confirmed the first opinion and talk of smoldering myeloma was mentioned. So along with monthly Aredia infusions I was followed as a new cancer patient. However the disease took a very aggressive turn for the worst and by Dec of 1997 I was receiving radiation on my lower spine after two months of pain and an MRI showing multiple lesions not indicated thru simple x-ray technology. I was furious with my doctor. This was my introduction to chemotherapy and the end of my "patching up my disease". A second and more devastating surgery was needed to fuse discs and repair my vertebra. Months of recovery followed.

To be introduced this way to M.M was physically and mentally challenging to a young person between the ages of 45-47 with a family, a very active lifestyle and a deep commitment to my sales position in my occupation. I was out of work in various stages of recovery for five months, being bed ridden for two of those months. Learning to walk with a half body brace and a walker was to be a sad state of affairs for myself and my family and friends. I was a burden to my wife and caretaker.

Outline of Treatment

It was time to stop this cancer systemically. While recovering from surgery I was receiving four months of V.A.D infusions (Vincristine, Adriamycin and dex). I decided to undergo a stem cell rescue and go for the best treatment known at the time for a person my age and general good health. This induction therapy worked wonders on the M.M and in July of 1998 the stem cell rescue was to be a new beginning.

It was even done on an outpatient protocol, with visits to the hospital for as needed transfusions but with recovery at home. The transplantation of stem cells in M.M was rather new and exciting but very emotional. The new language of cancer along with procedures I never dreamed of occurring to me and the collateral effects on everyone was stunning. How unlucky was I?

However after four months out from transplantation, my protein levels were back on the rise and I was upset. I could not have any more damage to my body! Alpha interferon was self-administered for 14 months and dex was added in after a year for 18 months. I never could enjoy a drug holiday without the myeloma rearing its ugly head. In February of 2001, I found myself on V.A.D again. A conservative maybe antiquated protocol but it seemed to work for me. With conversations about another transplant or a try at a new drug, thalidomide which was becoming popular was brought up. With side effects I was wary of (quality of life) I was hesitant.

Revlimid Trial

I began my journey with a trip to the Mayo Clinic (MN. US.) to get some second opinions. The doctors told me about two trials of two different types of drugs: the Revlimid trial at Dana Farber (MA.US.) and the Velcade trial at St. Vincent Hospital in New York City. Since I lived in Philadelphia PA, US it was not that much of a stretch to travel to these centers. I was just getting my life back together and the Velcade trial required me to be in New York twice a week for infusions and going to disrupt my life, particularly at the office. I took pride in doing a good job and being on site. The Revlimid trial, on the other hand, involved an oral medication and required less of my overall travel, so I decided to go to Boston.

The trial itself was rather easy. The phase 1 stage tested efficacy at 50mg. per daily dose and lasted 30 days. I broke at in a rash as expected. Phase 2 started at 25mg daily dose. My blood counts dropped as expected but not

to dangerous levels. The particular event that stuck in my mind at the 30 day mark was that I was sitting in a hospital room on the Dana Farber campus the morning of 9/11.

I could see the air traffic from Logan Airport from my window. I thought it was a beautiful fall day in New England, until I turned on the television. It really was an ugly day in American history. At the end of the day, I drove back home only to be detoured around New York City. The signs flashed that the city was closed to all types of traffic. It was a horrendous and fearful day for everyone, but a life turning event for me.

I continued going to Boston for six years, in the phase 2 trials, achieving a result I never thought was possible. After 4 years on Revlimid I showed no signs of myeloma. I was in complete remission. The newest test (Serum Free Light Chain Assays) a much more particular, finite blood test was being used to track my M.M. At that time my serum protein electro-phoresis was getting harder to evaluate in my blood and urine. Presently I take 10mg of Revlimid and 12mg of dex (1x /wk) to let's say "put out any brush fires". That seems to be an ongoing situation, and not too probmatic. I have recently added bi-monthly Velcade.

What did You Feel about Your Breakthrough

Although I was able to find a trial with a drug that matched well with my body chemistry, I was watching my fellow peer group members in my support group at home becoming sicker and sicker leading to quite a few deaths. I wished this trial could end with a quick FDA approval but it didn't. It was very disturbing to see people I knew passing away. It was sad and very eventful for me.

I heard "you are so lucky-how did you do it? I wish I could have done what you did" and I said back "I wish you could have done it also." I know some trials can move along faster, but that was the way it was. I had no control over this situation and that was how it played out. So it was kind of bittersweet in a way.

I was unlucky enough to get M.M, not knowing where it came from or what I did to get it. I was certainly lucky enough to find a drug treatment that meshed well with my body chemistry and basically stop the progression of Multiple Myeloma. Nevertheless, it was devastating to my mental and physical being because it struck twice on my spinal cord area and spinal vertebrae which has constrained my life quite a bit.

You Co-Founded a Support Group

When we established our own support group, apart from the general cancer wellness center, we met at my house and discussed how this disease is being spoken about and how many people in our area might need our help. We were a diverse group of people, maybe five couples, patients and caregivers. We needed to be more specific about what we had, apart from other cancers.

As a result, we decided to get our own facilitator and develop our own agenda and to advocate and raise money. The mission statement of our group is to provide up to date information and treatment options. We collect and maintain an online resource center to help meet the financial, medical and counseling needs that seem to be pressing. We do sponsor fundraising events, which is our Miles for Myeloma 5k which just completed its 11th year.

In the eleven years we have done this, we raised at least \$1.5 million. That might not be a huge amount in the general cancer cause, but we are proud of our grassroots effort. In the past, money has gone to the International Myeloma Foundation and the Multiple Myeloma Research Foundation, with the I.M.F. distributing funding for junior grants. The Leukemia Society received money for patient support projects. We feel very good about the work we do and giving back to the community. Presently we are a fundraising arm of the I.M.F.

We offer support through shared experiences and certainly provide a shoulder to cry on. At our core, we are a networking group to spread reliable information, though certainly not medical advice. We bring in speakers who speak about finance, social security, general health issues and the latest on new drugs and treatments. Each year after the ASH conferences in America, we have a doctor from our main supporting hospital come to the group and discuss what has developed over the last year. Again the most important point is that we do not give out medical advice, but we do lead people to information they can rely on and interpret for themselves and most importantly take back to their doctors for further discussion.

You have seen

Well the field has developed through the introduction of new novel agents, which can be used upon initial diagnosis. I know all cancer drugs have side effects and degrees of toxicity, but it seems so much more civil than the drugs which I took. The new novel drugs provide different approaches to treatment and provide a vast new meaning for hope and good results.

Stem cell rescue, of course, is still part of the protocol if desired by those who choose it. I am pioneering the long term maintenance of staying on my therapy drugs. It is amazing that so much money has been poured into blood cancers, particularly M.M for research in the last 10-15 years. It feels like zero to infinity in just a short amount of time and that is gratifying.

What are Some New Developments

Where we used to talk about Melphalan and steroids as the “gold standards” of their time, we are now speaking about immunotherapies and targeting agents and gene editing with more clinical trials available to more patients. I was not aware of clinical trials before I went to the Mayo Clinic. It is certainly easier to find out about such developments now. Also the vast amount of drugs that can be used alone or together to create synergies of unparalleled possibilities brings, hope maybe where there was none. Synergizing Revlimid with dex and Velcade.

How do You Feel about Pricing?

This is a tough question because the elephant in the room is medical costs. I am aware of the expense of some drugs (I receive Revlimid for free since I participated in the early stages of its use), but expenses can be daunting. I know there is financial help for those who need it and that is great. I also know that cancer is devastating to the mind, body and pocketbook.

I know that patient empowerment is a big thing and we stress that at our meetings. That has come a long way since my journey started. It will continue to be important so patients can be part of the decision making along with their health providers and be informed as to what is happening with their treatments. An enlightened patient is a good patient and makes for a better team work approach to their care. It must be said that careful reading and proper sources of information are very important.

When I was initially diagnosed my boss said to me “Hey shark cartilage-I hear that that can rid of cancer” or someone said to me “wear magnetic bracelets, I think that cures cancer”. There are people in the depths of despair that might reach out for anything. Maybe 20 years ago this might have been true (I hope not now), but this is what I went through with friends thinking they were helping.

What is next

I do like to speak one on one with newly diagnosed patients that come to our meetings. We still have two or

three families per month that are new to the M.M. community or want to be brought up on new developments and ideas or quality of life issues they may be facing. To be part of this medical revolution is terrific.

Closing

There is no cure now, but we are getting close, and interest in knowledge is expanding. We get our largest crowds at the meeting following the ASH conferences and I find that amazing and uplifting. Personally I want to stress that the mental and physical challenges of getting cancer at any age is traumatic. I was stricken at a relatively young age with M.M. and I can attest that without the support of family and friends it is a long haul

back to recovery. It affected our family life, the way I felt about myself, what I thought to be important and what so many other cancer patients are dealing with.

Life flips 180 degrees and there is little or nothing that prepares you. It really affects the commitments you make to your family and society. For me, in particular the effects of this orphan cancer will remain forever in the faces of those not here today to see the giant steps we have taken to make Multiple Myeloma more like a chronic disease or a curable one and not the death sentence it once was. I want to be part of the solution, a beam of light to those new to the journey.