

C Living and Working with Cancer

Perspectives from Patient, Caregiver, and Physician

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“My hope is that I will be invited back next year to speak at IHPM’s Seventh Annual International Conference,” announced Steve Avey before he departed center stage to walk out into a world of uncertainty – facing the greatest challenge any of us could face – radical medical treatment for a life-threatening illness.

So it was on Friday, Oct. 19, 2007 in Scottsdale, AZ that Steve returned – this time with the added contribution of his lovely wife, Colleen, to share their miraculous journey together as patient and caregiver.

Very few words were needed in closure by Dr. Philip Hagen, Medical Director at the Mayo Clinic, representing the physician in the three-person panel session introduced by Dr. Pamela Thomas, Director of Health & Wellness at Lockheed Martin Aeronautics – who led a pilot employer program for the working caregiver at Lockheed. The audience then played its own special role at the conclusion of this emotion-filled hour – rising to give Steve and Colleen a standing ovation.

Steve Avey states:

For those of you who missed my presentation last year at Lake Las Vegas, I would like to tell you about my illness. In August of 2005 I was diagnosed with Stage 4 Mantle Cell Lymphoma (a Non-Hodgkin’s Lymphoma). The prognosis for this disease has been pretty grim and so it was important that I be treated aggressively with chemotherapy in an attempt to get me into remission.

Over the next nine months I was given three different chemo regimens. The first two were unsuccessful, but the third one worked. In May 2006 I was given the great news that I was in complete remission. That would be an interim step, however, as the only known treatment that would give me long-term remission would be a stem cell transplant. In some cases stem cells can be harvested from a patient and injected back into them after what they call an ablation treatment. In my case they could not harvest my own stem cells because my body’s bone marrow was too beat up to produce them. They next test-

ed my siblings for a DNA match, but were also unsuccessful.

The Mayo Clinic next tried the National Donor Program, which has five million potential donors. Unfortunately, there were no matches. Finally, after months of waiting, they found a suitable donor in Europe through the International Donor Program. We obviously were ecstatic with the news that I could begin the next phase of treatment that would give me my best shot at long-term remission.

Let me introduce my best friend, my caregiver and my lovely wife, Colleen. Together we will be telling you about our journey together to bring me to the miraculous health I enjoy today.

Colleen

Thank you. I am not thrilled to be here – Steve is the public speaker, I am not. But I am thrilled to have him next to me, strong and healthy again!

Steve

Rather than do separate formal talks we decided to just dialogue with you and each add comments where it seems to make sense. On Nov. 16, 2006 I underwent a stem cell transplant at the Mayo Clinic Hospital in Phoenix, AZ. I wanted to clarify what a stem cell transplant is since Colleen and I both needed a little educating on it. A stem cell is an immature cell in each of our blood streams that can mature into the kind of blood cell the body needs at the time. It could become a lymphocyte to fight infection or whatever is needed.

In the old days we did a lot of bone marrow transplants where you had to remove substantial amounts of bone marrow from the donor. That was very uncomfortable. Researchers found that you could kill a person's bone marrow and replace it with your own stem cells or an appropriate donor's. Those stem cells will migrate to the bones and make the host a whole new bone marrow. The trick is that you have to keep the patient alive while they develop a new immune system.

Colleen

As everyone knows things often do not go as planned, and so it was with Steve's transplant. The first glitch was when I came down with a cold right before he was to go into the hospital. We went to his doctor and I didn't shake hands because I was fighting a cold. The doctor was very concerned about that, so he actually put Steve into the hospital that evening to get him away from me and to hydrate him well before starting the chemotherapy. My plan to be with him at this critical time had to change.

Luckily, we have very supportive children and two of our married children live in the valley, so I went down and took care of our grandchildren in Chandler and my daughter and son and their wonderful spouses took turns going to the hospital to be with Steve 24 hours a day. I did all I could to get rid of my cold quickly, but I actually missed the five days

preparing for transplant and the actual transplant itself.

The night of the transplant my daughter and daughter-in-law phoned me during each step of the procedure with updates on what was happening and how Steve was doing. I felt very bad I couldn't be there, but very grateful they were there, and they felt like it was a very special bonding time they got to have with Steve. Our daughter, Carmen, wrote down a lot of Steve's hallucinations during the week and we were able to have a few laughs about them; you really need to be able to laugh sometimes to release the tension of it all.

Steve

Overall, the transplant was successful in that my body accepted the new bone marrow graft with only a few problems. The team was diligent in looking for graft vs host disease, which is where the new bone marrow graft fights the body and can cause some real problems. My reaction was relatively mild as I developed a rash over most of my body for about two weeks, but it was managed by Colleen applying a steroid cream all over me twice a day. It went away in several weeks, and I was released from the hospital after 40 days – just before Christmas. It felt so good to be home again even though I did not have much energy to do much and had to be careful interacting with people.

I had some setbacks along the way to my recovery. In January I was readmitted to the hospital. I was going to tell you that this was one of the few times I did not appreciate my caregiver.

Colleen

I need to defend myself here. When we went into the hospital for Steve's daily checkup on Jan. 24 they went through all the usual questions about how Steve had been doing over the previous 20 hours since he left the hospital the day before. He was answering that everything was fine and I was trying to catch his eye to get him to be completely honest.

I had been very nervous the night before because when he came home from work he was so chilled he could not stop shaking. I warmed blankets and rice pillows for him and he changed to very warm clothing, but he continued to be chilled. I knew Steve was avoiding me, so finally I just told the nurse myself. Sometimes the caregiver just has to speak up even if the patient doesn't want them to. The doctors were worried so they decided to re-admit Steve to the hospital. I got a real glare for that one.

Steve

There were two things in my blood counts they did not like, combined with the chills from the night before. They did a chest x-ray on me and three hours later they let me know I had pneumonia. I could not believe it. How could I have pneumonia when I did not feel sick? The problem was the team did not know what kind of invading organism was causing it. They gave me anti-bacterials, anti-fungals, and anti-

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virals to cover all the bases. I was on substantial doses of immunosuppressants to keep my body from rejecting the new bone marrow graft. Unfortunately, these drugs also made it more difficult to treat an infectious disease.

Colleen

Steve just kept getting weaker and losing more weight and they were getting quite concerned. On Feb. 2 he started getting confused and couldn't answer questions the occupational therapist asked him. By afternoon he was thrashing around and moaning in his bed and it continued all night long. We asked many times what hurt, but he could not answer us.

By morning his knees and elbows were worn raw from all the thrashing; he knew his name, but gave his birth date when asked his address; he knew I was his wife, but did not know my name. They did an EEG and he had a lot of distorted brain waves and could not count to three.

During all this our children and some dear friends were such a support. They kicked me out to rest and took care of Steve for a few hours, even rubbing his feet for hours to calm him down. The nurses were also so incredible; even when Steve was out of it and became belligerent they continued to treat him with total respect and professional care.

Steve

Because of Mayo having excellent neurologists on staff, they did some great consults and ran some tests and determined I was having a reaction to one of my immunosuppressant medications. Once they stopped it, my neurological functioning returned to normal.

Finally, after being in the hospital for three weeks, they got the results back from some cultures they had done and they came into my room saying, "We have some good news and some bad news. The good news is we found out what you have and we can treat it. The bad news is, it is tuberculosis."

Colleen

I was shocked because I thought tuberculosis was a third-world country disease and I could not figure out how Steve could have it living in a fairly sterile environment we had been working so hard to maintain.

Steve

They believe I had contracted it many years ago when I was working as a pharmacist, treating TB patients. As long as my immune system was intact, the TB remained in check. When I went through the transplant, the TB took over.

In early March I was having some chest discomfort and they again ran a battery of tests. From an echocardiogram it was determined I had some slight pericarditis, which is an

inflammation around the heart. With appropriate medication they were able to get rid of the pericarditis and the discomfort it was causing.

In April 2007 I was being treated for the TB and I began having more discomfort in my chest. I felt like I had a cracked rib or pulled muscle. I was coughing fairly consistently because of the TB. From x-rays and more tests they determined I had gotten an RSV infection, which is an upper respiratory virus. Not a big deal unless you are immune compromised. I was treated with Rotoviron for 10 days. The treatment required me to be inside a plastic tent for two hours at a time, three times a day. The infection was cleared and I returned home again.

Colleen

On April 18 we went into the hospital for all the regular procedures; then the nurse practitioner over the transplant unit asked to speak to me in the hall. She told me they had discovered that on top of the TB Steve had contracted the RSV again as well as another infection called parainfluenza-3. They were very concerned and afraid that they could not get Steve through this one. I couldn't really grasp it at first because he had looked so much sicker at other times.

She explained they have nothing to treat parainfluenza-3, that normal people's immune systems just have to take care of it, but because Steve was so immunocompromised they did not think he would be able to fight it. She apologized for being so blunt about it, but she had always been honest with us. She was compassionate, but did not have much hope of him getting through this.

I tried to stay calm and go back into the room and not let Steve see how scared I was. Once they told Steve they had to admit him to the hospital again I told him I needed to go home and get some things and let the kids know. I left and started calling our children and asking them to start praying. We discussed having a family fast for Steve and decided we better have it on Friday so we could get the word out to our family and friends the next day. I went home and got on the computer and sent out a mass email to all our friends and family, giving them the latest diagnosis and asking all who wanted to join us Friday for a special day of fasting and prayers that Steve's immune system would kick in and he would come through this great trial. We had many more people join us that day than we dreamed would, and we are so very grateful for their support.

Steve

When the transplant team came into my room to talk to me they looked more somber than I had ever seen them. They told me this was serious and that there was a possibility I

would need to be put on a respirator in order to support my system. They told me it would all be handled according to my wishes and they would do all that they could to keep me from suffering. They were very kind and compassionate, but were also being honest with me.

I had somewhat of a restless night that night, but on Friday morning when I woke up, I felt this tremendous feeling of calm and peace. I knew everything was going to be alright. Although I still had this nagging cough, I felt reasonably well. As the day wore on, I seemed to improve instead of decline. So each day went over the weekend. When my transplant team came back in Monday morning they were very impressed and I think surprised that I was sitting up in bed and smiling. We had been extremely blessed and we believe our prayers had been answered.

In the months after that, I continued to do well and gain strength. I was slowly weaned off of my immunosuppressants. Once I got completely off of them, I felt even better and I slowly gained more weight and my appetite returned.

In June I was released by the Mayo team to return to my community oncologist with a clean bill of health and a brand-new immune system. As we left the hospital that last day the nurse practitioner from the transplant team stopped us and said, “Steve you are our miracle boy, I hope you know that!” We do know that.

One day in late July I came home from work and Colleen was getting some well-deserved R&R with our 13-year-old son up at a lake in Montana – it was Colleen’s sister’s family reunion. When I got home from work, I opened the mail and found an envelope with a handwritten address to me from the Mayo Hospital. I wondered what it was, so I opened it and found a letter from my donor across the pond. We did not know anything about her, other than that she was from Europe somewhere and that she was young.

Colleen

You have no idea how much we love and appreciate this generous young lady who gave Steve a chance to have his life back! We definitely want to meet her in person some day. I am so grateful for her as well as for our family and friends and the wonderful doctors and nurses and Mayo who got us through this very difficult time in our lives and I am thankful to the Lord for His miracles and strength that carried us through the very worst parts.

Steve’s thoughts about the process:

I have been well cared for during the entire process.

I was given the opportunity to be a decision-maker through all of my treatments, which made me feel more in charge of my life.

I have a wonderful wife who really stepped up to the plate as a caregiver and got me through some very difficult times.

I am so grateful to the companies that developed some pretty amazing drugs to help me through the process – Ritux-

an, Zofran, Lorazepam, all of the old chemotherapy drugs that actually came together and worked, the antibiotics, the anti-fungals, the anti-virals, and a host of other drugs that made it all work.

Today, I am taking one acyclovir twice a day and a Protonix as needed, plus all of my TB meds, which I take on Monday, Wednesday, and Friday.

I have been given extra time. I do not know how much, but I am healthy, getting stronger every day, and I am working nine hours a day again.

I rest a little more than I used to. I don’t run outside in the heat anymore. I might start back now that our temperatures are getting down below 100 degrees.

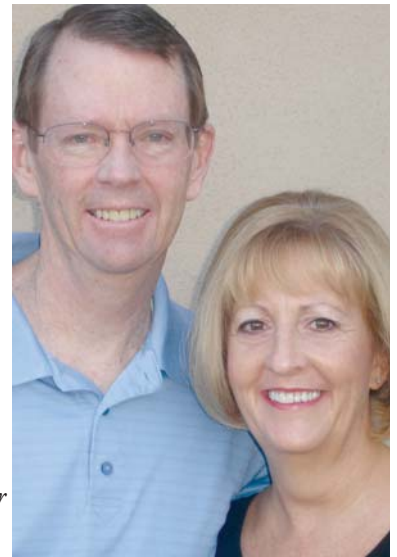
I take the time to enjoy my family more than I ever have.

SUMMARY

One of the most striking things about Steve’s remarkable story is the way he kept going back to work all through the course of his extended treatment, proving what is often said about cancer patients – that no one wants to work more than they do. Steve’s determination to keep getting back to work is a critical measure of his progress and the quality of his life.

Steve Avey is not just a medical “miracle boy,” in the words of the nurse practitioner at Mayo; he’s a dramatic example of why the health of people like him is one of the best investments we can make. Both his employer and our society are better off for having made this investment in Steve – restoring him to his full capacity as an executive, a husband, a father and a grandfather. **HPM**

Steve Avey, VP, Managed Care, Partners Rx (a Pharmacy Benefit Management company in Phoenix, Arizona), has more than 25 years of experience in pharmacy with a diverse background in retail, long-term care and management. With a focus on managed care pharmacy, Steve has worked directly with employers in designing and implementing their prescription drug programs.



Colleen Avey is a Para-Educator at Pinnacle High School and works with special needs students to assist in many levels of their educational development with an ultimate objective of enabling them to graduate.