November 2013

Dear friends:

I want to take a moment of your time to report on yet another amazing Miles for Myeloma event. This year is the ninth year in a row we have gone on this journey, united by purpose and resolve. Our mission is clear: multiple myeloma is one nasty disease and it affects some awesome people, so let us get rid of this disease for good.

I continue to be humbled and overwhelmed by the determination and generosity of the people involved with this cause. Once again, a planning committee of patients and their family and friends met for hours to prepare for this year’s event. They managed every little detail. A core group of those individuals drove the route – more than 200 miles – five times to find the best and safest path for the 24 bicyclists who participated in this event. They marked every turn and managed to secure a police escort for us the entire first day and part of the second day. Once again, we had an RV traveling with us providing us the rest stops we desperately needed, especially after riding miles and miles against headwinds.

This event is becoming a pilgrimage to a place where humanity is manifested at its best. I am not the only one who feels this, as many who participated in the two-day ride agree with me. We all look forward to this spiritual journey to renew our resolve and faith in humanity.

We started in Niles, Michigan, where I was touched by the generosity of a Vietnam Veteran standing outside our hotel who emptied his wallet and gave all his cash to support the cause. The first day, we made our way through South Bend and LaPorte and ended in Monticello. The second day, we left Monticello and headed to Lafayette. We rode south into strong headwinds, but the riders stayed together, taking turn leading the pack and making what would have been an impossible day possible. I am proud to report that my son Rabi rode both days and stayed strong for the both days. This is remarkable as his first 100-mile ride was just three weeks before. What is more remarkable was that we had one patient who is getting treatment ride with us the entire 200-mile distance. Another patient was not able to take off work Friday rode with us on Saturday. And another patient who had a recent hip surgery rode with us on his recumbent tricycle for the last 15 miles. It is inspiring and sobering to see patients reject the limitation this disease may impose on their quality of life and refuse to live their life as anything but normal. (That is, if you can say riding 200 miles on a bicycle is “normal” 😇)

Miles for Myeloma 2013 ended at the NCAA Hall of Champions in downtown Indianapolis, where we were welcomed by more than 370 patients and supporters. This is an amazing victory lap for the riders and the volunteers who make this event feasible. We had a nice dinner and then a newly diagnosed young woman serenaded us with the song "That’s Life," telling us “I’ve been up and down and over and out, and I know one thing: Each time I find myself laying flat on my face, I just pick myself up and get back in the race.” It was a powerful song and fitting for anyone going through this nasty disease. After that, we had an open discussion with my IU colleagues Drs. Farag, Fausel, Roodman, Silbermann and Suvannasankha. I am glad to be part of a team of health care professionals who treat not the disease but the humans affected by this disease. The reason I say that is because we care about these patients as individuals with lives that have been turned upside down by a disease that we cannot currently eradicate. It is so important for us to help each patient reset life to its baseline so individuals can live life and seek their dreams for a very long time.

As part of our research discussion, we talked about the variability of the disease course among patients. It is clear that one-size-fits-all therapy does not work and we have tremendous need for personalized care. Our group has the expertise and the depth to provide such individualized care. In addition, we are busy studying the disease in the clinic though clinical trials with new drugs. In our IU laboratories, we are
focused on two major research questions: 1) how can we make it harder for myeloma cells to grow in the bone marrow? and 2) how can we enhance each patient’s own immune system to eradicate any residual disease remaining after treatment?

As I reflect on this year’s event, I do think that a sense of urgency is needed to get us to the finish line. Many people around the world are feverishly working on this disease. I am more optimistic than ever. I see the finish line of a cure for myeloma, and because we are almost there I think we need a big boost to get us over the hump. So, at the dinner this year, I pledged that next year, on the 10th anniversary of Miles for Myeloma, I will ride 100 miles for each year. Some of my fellow riders have already pledged to join us. Yes, we mean it: we will ride 1,000 miles next year and we hope to raise $1,000 per mile. We need this meet this $1 million goal so that we can make a difference now. Let us cure this disease so instead of having grueling events, we can just meet to celebrate life without multiple myeloma.

This year, I was glad to see my son riding with me for this cause, but I do not want to see my grandchildren doing this ride. I want this disease GONE as soon as possible. I know we can do it, and I never doubted the Mile for Myeloma community’s resolve and creativity. So, let’s get started on this final push. We have a year to get ready and to a find way to reach our goal.

For now, I wish you and your family health and peace in the next year.

Peace,

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Thank you for supporting Miles for Myeloma 2013.