



How did the MS Society first get involved in Second Life?

It really began with a conversation with some of the people who did some of the early building and architecture of Second Life. Really we were just talking about what it is they were trying to accomplish in this community where people came together and always looking at it from my perspective of people with MS and some of the obstacles they face.

They talked about a community where everyone is equal. There are no physical barriers in that world and that really intrigued us at the society as a space where everybody came on a level playing field. That generated discussions that started in 2006, to us actually launching a presence the following year. At that time there were six million in Second Life so the growth has been phenomenal.



What lessons did the MS Society learn in Second Life?

We really liked the philosophy behind what this site was trying to do and the way that it would bring people in. What I think we were surprised by is what people really wanted from the experience and so we went in really only promoting this a little bit online and some in the Southern California market. We ended up with people from around the globe participating. People from Singapore, Italy, UK, Netherlands and Russia coming together to participate in this event. Some of those people had MS and a lot of those people didn't have MS.

And on our sites we were able to then load things like video onto the site with the island so people can come in and learn something.

But what did we really learn is that we learned that there was an enormous need for people who have been effected by MS to have a global meeting place. So you'd go to our island and you find people. Somebody from Brazil talking to somebody in the United States about what their experience of living with MS was and what they had in common and what the different experiences were.



What is the Second Life experience on the MS Society island?

Because we didn't want to go into it with a lot of rules about how people signed up or got engaged. We didn't want to put barriers in the way of people becoming engaged and learning about Multiple Sclerosis and learning about our organization. Of all of those sorts of things, so we asked people if they'd register and let us know but we didn't require it.

So we actually know we had several thousand people who at some point were involved. We were able to track over a thousand individuals from over twenty countries who came together to get involved and talk about MS.

So what we realized was they wanted a forum for all kinds of things. Raising money was really secondary, what it really became about was connecting people who were really committed to this cause who wanted an international forum to talk about everything from Healthcare to management of the disease to finding somebody else with their circumstance. Just the myriad issues that people experience.



What have you done to bring MS Society events into Second Life?

Our first foray into Second Life is that: we have an event that, organization wide for us, raises around 60 million dollars. It's our Walk MS events where people go to sites, over 600 sites across the country and they get pledges and raise money for MS walk. Now everyone doesn't have that ability or opportunity to come and walk and we said what happens when we take that to a virtual world? Where in fact people can not only walk but people can fly.

So we launched into that to say can that be a catalyst to engage all kinds of people, not just people with MS to learn about MS. So we had our first event that really our Southern California chapter drove which was the MS fly event.

So people signed up online with their avatar, they got a cape with our logo on it and it was virtually a scavenger hunt which allowed us to leverage corporate islands the places that people visited to learn things about MS along the way and then back at a giant MS island at the end.

We really had no expectations of how this would go on the outside other than to say this is a growing environment which has a level playing field for all people to participate. And we wanted to see what would happen when we went to someplace that would have no boundaries to who could be involved.



How much effort does it take to maintain the MS Island?

Mostly we leverage that through volunteers because it really was once we were able to build the structure, it was really something where you could say for instance people with MS who for whatever reason have left the workforce. That have issues that they're facing with their MS that didn't allow them to work full time but they wanted to be engaged in other ways. And it's like well would you be willing to volunteer in Second Life now and meet with people or be a peer support person or have conversations or facilitate a room or work on building out the island in some way. So we've really tried to leverage that spirit of people online, sort of that true community building which means, this isn't just here for you to use, it's here for you to help build.



How is Second Life opening doors for web users researching MS?

What is the role that technology plays and how people manage their health and how well they do. And we found out that it's an incredibly significant role and that's now become the first place for information that people go.

As we all know now in the real world if something goes wrong with us or we're feeling something, rather than call somebody we go online and enter in our symptoms. Go to Wikipedia or Web MD or whatever it is and try and self diagnose and get our information before we take that next step. Well, same things true in people managing more chronic illnesses, that's their first instinct.

So, we need to make sure that people have a pathway. That they have quality information that is well vetted and researched, that they have confidence and then they have next steps to go to.

One of those next steps is people need to be able to connect with the same experience. For MS if I'm a mother raising two you kids and suffering from fatigue is my big issue,

how do I manage fatigue, it's just I don't know how to get it all done. I would love to talk to other mothers and solutions they're finding.

Second, that's where we can leverage quality information on our website to go to a discussion in Second Life or go to a chat room or go to what is your style. How do you want to gather and have information and be engaged and then there's a pathway.

For all the energy early on at this point to have come out of that and created connections with a few thousand people you look back from the short term ROI and you say well I don't know was that worth it, or could we have done something else. But if you look at it like what is your relationship going to be for the next 10-20 years with people. What is that community that you want to have and how do you have this and what are the forms you're going to build on to do that. Then I think you have a different viewpoint about this early on investment of figuring this out.

Figuring out how people want to use those environments, how to be relevant in those environments, how to be found in Second Life. All of those sort of things you know we're learning. We learned at six million we're a much more effective presence now that there are 50 million people in that. And if it grows at the current rate and there are 30-40 million people there, we're going to have had 5 years of learning behind us to build upon and maximize that environment for our cause to help people with MS.



How do corporate donors react to your presence in Second Life?

I'll just tell you this: I was in Prague a year ago talking about our efforts in Second Life at an International MS forum that actually had other global companies there who were invested in other research efforts. After that session it was so interesting how many of those corporate entities came up and said we think it's amazing that you have been out in that space already that we now see you in a different light.

So I think it's the difference of how you want to be viewed by your potential customers, your sponsors, your corporate partners. People really take a second look and say, 'wow you are really on the frontier of how people are communicating and connecting in the world now.' So we would be willing to have a conversation with you now because we actually think you'll bring something to the table that perhaps other non-profits wouldn't for us in terms of the added on benefits. They want to do it for the cause but they also want to do that cause in a way their customers know and care about.



Do you have advice for other organizations interested in Second Life?

Find the right partners. I mean, I really I have to go back and credit to us our volunteers and other organizations were early leaders. Go out and find those people, because I'll just tell you the people are early on to Second Life, they are passionate about this environment. They are so willing to share that information and lessons learned and shortcuts and things to do and not do, I would have no hesitancy to reaching out to people who have a presence in Second Life and saying would you share what you've learned and how do you do that. The other key I think is partnerships, don't think you have to do this alone.



How does the Second Life environment improve life for those with MS?

When people come back and say: you know, everyday when from the moment I get up to the moment I go to sleep I live in this chair and I go into Second Life and I fly. There's that sense of I fly virtually but there's a metaphor for I fly in terms of how I connect, of how I'm viewed, of how others see me, of how I'm validated. We've had people with MS come back and say it takes so much of the stigma that can be associated with having MS or anything away from that. And for people who live in rural areas in our own country who don't find other people with that experience. They come to this environment where it isn't everyday that you can talk to somebody from around the globe and find a common point to share on and I think that becomes something really remarkable that occurs there.