The making of an advocate

Interview with Alan Fernandez

We spoke with Alan, Associate Director at the Genetics Policy Institute (GPI), the organizer of the annual World Stem Cell Summit, to find out what led him to devote his career to stem cell advocacy.

How did you come to join the Genetics Policy Institute?

I started working with the GPI while I was at Burrill Life Sciences Media Group. Burrill was partnering the Stem Cell Summit produced by the GPI with the Harvard Stem Cell Institute in 2007. In building the network of supporting organizations and sponsors for that meeting, I decided to shift my career focus to nonprofit advocacy. GPI's Executive Director, Bernie Siegel, was obviously a 'man on a mission' and from that Summit in Boston, I felt firsthand that extreme sense of urgency. Where we have an emerging field of stem cells and regenerative medicine that could possibly cure previously untreatable diseases, how can we stand back and let a group with a minority position impose their will on the majority? Where is the collective compassion for the suffering and chronically sick? I decided that I could best live up to my potential and have a better life dedicated to stem cell advocacy, with the goal of changing lives for the better.

Where do you get your inspiration to be a stem cell advocate?

Dealing with those individuals and their family members afflicted with

chronic disease offers me continuing inspiration. In this journey, I have encountered some really compelling people. Steve and Barbara Beyer carry the spirit of their late son, Ben, whose bravery battling amyotrophic lateral sclerosis was memorialized in a documentary. The Beyers created ALS Worldwide, a wonderful grassroots organization, counseling families dealing with that horrible affliction. My good friend here in Palo Alto is Gary Dawson, who deals with immense physical challenges resulting from cerebral palsy. The Hempel family who created the Addi & Cassi Fund with their precious daughters afflicted with childhood Alzheimer's disease. There are a hundred more.

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Alan has focused his career on advancing stem cell sciences and the field of regenerative medicine since 2006. While working with Burrill & Company, he began working with the Genetics Policy Institute (GPI) on the 2007 Stem Cell Summit with the Harvard Stem Cell Institute. He then joined the GPI full-time in 2008. Alan's skills in business development and marketing were cultivated at companies like Dow Jones, Ziff Davis and Burrill & Company. Earlier in his career, Alan worked in technology and grassroots business communications, working for start-ups and mid-sized companies.

“ Advocacy is a participatory sport, not a cerebral exercise. People do things when they become emotionally charged and when they feel threatened that something important is about to be taken away. ”

You are known for being an 'international man': how does your background impact your work?

Each year, the GPI builds the World Stem Cell Summit from scratch and recruits organizing partners, sponsors, endorsing organizations and media partners from around the world, some 250 in number. In certain ways we are diplomats, circling the globe promoting support for our field. I am the son of an American diplomat, born in Chile and growing up in Romania, Austria, Switzerland, the UK and the USA. I started my career as an intern for Drexel Burham Lambert in their London (UK) office, lived and worked in New York City and eventually migrated to the Bay Area in California. I developed an interest early on in business, government, economics, policy, foreign countries, leadership and communications. It has been a fascinating journey.

What is one of our your proudest moments?

I started at the GPI as Director of Public Policy Outreach and was promoted to Associate Director in 2011. My role expanded to traveling to a number of

scientific and industry conferences. But it is when speaking with fellow advocates I feel that I have truly found my voice. Last year, I traveled to Peoria, (IL, USA) at the behest of a very brave patient advocate, Joan Snyder, who runs the Central Illinois Parkinson's group. I spoke to the audience about the need to build a powerful movement to address the obstacles facing our field. The ovation that day meant the world to me. I know I have found my voice and my calling.

The GPI has built a prominent coalition supporting embryonic stem cell research. Explain the role of the Stem Cell Action Coalition.

The Stem Cell Action Coalition springs from the Stem Cell Action Network, a group of grassroots stem cell activists present at the creation of the policy battles in 2002. The Coalition emerged as an important force in 2010 with the threat of the 'Sherley versus Sebelius' court case. Organized by GPI, the coalition includes 75 diverse organizations, scientific and medical societies, medical philanthropies, university programs and patient groups. Through letters of lawmakers, social media, press

releases and frequent policy calls with grassroots activists, the Coalition serves as a voice for the stem cell community and as an engine promoting the field of embryonic stem cell research at the federal and state level. The Coalition is grassroots activism at its best. It's about commitment to taking action and then taking action.

How can patients and industry combine to solve problems and advance the field of regenerative medicine?

Let's have some clarity. Advocacy is a participatory sport, not a cerebral exercise. People do things when they become emotionally charged and when they feel threatened that something important is about to be taken away. Those are motivating factors. The healthcare industry, including the emerging cell therapy companies, need to deal with financial and regulatory hurdles. Without the passion and sense of urgency of the patient community behind them, the road will be much longer and tougher for all. Working with patients, who see the future of regenerative medicine as salvation, the combined force can move mountains, by changing laws, forging innovative

collaborations and increasing public awareness. There has to be continuing communication and interaction and a broad recognition that we are one community. A few of our friends seem to forget that one day we will all be touched in some way by a chronic disease – statistics show one in three will be afflicted. We are sitting on technologies that may alleviate a huge amount of suffering for adults and children. If not for ourselves, let's make it happen for our kids, our friends and humanity at large.

You often speak about the importance of music in stirring the soul of an activist. How does music move you?

Consider a rock concert with 10,000 attendees all dancing to the music, all with their arms outstretched holding aloft a flame. Music does stir the soul. I grew up moved by the music of Simon & Garfunkel and John Denver and many others. My favorite is 'The Eagle and The Hawk.' Every time I listen to it I am energized.

“ Come dance with the
west wind and touch on
the mountain tops
Sail over the canyons and
up to the stars
And reach for the heavens
and hope for the future
And all that we can be and
not what we are. ”

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