

EXPERIENCE—FRED CAPEL, MINNEAPOLIS PRIORITIZING CHILDREN’S RIGHTS

In his struggle to care for his son who was born with Down syndrome, Fred Capel discovered a tragic truth — few states have services available for disabled children. So he started a foundation to provide for children with Down syndrome across the nation.

I was born and raised in New York City. As a kid, I always wanted to play professional baseball.

When I was introduced to Nichiren Daishonin’s Buddhism in May 1984 by a family friend, I was told that I could “get anything I wanted.” My lifelong dream reemerged. I started practicing Buddhism, and began a career playing semi-professional baseball with the Indianapolis Storm for more than 12 years.

I met a young woman in 1991 from a Central Park community activity and found out that we had a lot in common — going to the theater, sporting events and traveling. Believe it or not, the main thing we had in common was that we were both SGI-USA members.

We married in 1992. Both my wife and I wanted a family and chanted that our children would be healthy and happy. My son, Travis, was born in 1995 with Down syndrome.

Named after its discoverer, J. Langdon Down, in 1866, Down syndrome results when a person inherits all or part of an extra copy of chromosome 21. Trisomy 21, the inheritance of an entire third copy of this chromosome, accounts for 95 percent of Down syndrome cases. This extra genetic material leads to too many enzymes and proteins. This, in turn, distorts normal metabolism and development.

We both were devastated with the news. My wife couldn’t handle the stress of having a child with Down syndrome, so she left Travis and me soon after his birth. My own family disapproved of my Buddhist practice and they felt that it “was the reason Travis was born the way he was.” I also found out that Travis, at the age of 5 months, would need to have heart surgery. I had to face all of this alone.

Turning to my Buddhist practice for direction, I determined to chant 5 million Nam-myoho-enge-kyo that his surgery would be an absolute success—I did, and it was! During this difficult time, I had applied to New York State for services for Travis. I received a letter explaining that services for children with disabilities were being severely cut. Two days after I received that letter, I watched the world champion New York Yankees baseball team get a ticker-tape parade in their honor. I was angry that the monies spent on that parade could have funded services several times over for children like Travis.

Since I had full custody of Travis, I determined to move to a place that would be better for the both of us. I received funds and decided to move to Arizona. Again, I had registered for services for Travis. I received a letter stating that under Arizona law, there is no entitlement for developmentally disabled children to receive services. I made many phone calls to private and public agencies. No one could help my son and me. I felt like the government wanted me to give up on Travis — to put him away in a facility.

Travis is a very sweet and kind child, who loves music, Barney the dinosaur and watching sports, especially football. I could never let Travis go somewhere where people would not care for and about him as I did.

I then knew what my mission had to be—to provide services for every child with Down syndrome across the nation. Physical therapy, speech therapy, special education and Independent Living Skills would be provided right in the child’s home rather than having to go to an impersonal clinic setting. For older children and young adults, I would find a way to provide services through the creative arts, job placement and paid vocational training. I also wanted to provide a helping hand to parents so that no one would ever go through what I did. I chanted for the wisdom to do something. The result was that I started The Foundation for Children with Down Syndrome.

In the beginning, I had no money or support from anyone. I was on welfare and was angry and upset with everybody’s misplaced priorities again.

When I would have these bouts of anger, I would chant a lot and read Nichiren Dai-shonin’s writings and SGI President Ikeda’s guidance. One day, I read these words from President Ikeda and they are with me still: “In the journey of kosen-rufu, things will not always proceed smoothly, but we are eternal comrades. People who come together in good times, but desert one another when the going gets rough are not comrades. Turning a blind eye to the suffering of others using the rationale that ‘it has nothing to do with me,’ is not the spirit of comrades. True comrades share both suffering and joy!” (*Faith Into Action*, p. 219).

I chanted a tremendous amount for the foundation to become a recognized nonprofit, tax-exempt organization and it did, on Aug. 21, 1997. During my journey to make the organization strong, I supported Travis by becoming a contractor. There were times that we were homeless and had no food for some time. I determined again to succeed.

So Travis and I moved to Minneapolis. Upon my arrival, I chanted intensely. I called my senior in faith in New York for encouragement. He said to just follow President Ikeda’s guidance by getting involved in the community. I did just that. I became the leader of my block club, and was elected to the board of directors of my neighborhood association. I began to receive a salary from the foundation as I had organized a regional office (which still exists) in Arizona before my move.

When the “Treasuring the Future: Children’s Rights and Realities” exhibition came to Minneapolis, I made sure that I supported that event with all my might. As I became more involved, I began to understand why President Ikeda had supported this exhibit. It was shocking to me that there were two countries that do not have a Children’s Rights Bill—Somalia and the United States. To me, it was clear that there was a link between children who have various needs (disability, poverty, hunger and access to education) not being able to get the services they deserve and the fact that there is no Children’s Rights Bill in the U.S.

Through many efforts over the past three years, the foundation is now a nongovernmental organization with the United Nations. My goal with this NGO designation is to fight to provide services for people with Down syndrome, as well as for a Children’s Rights Bill for the United States.

I recently met with the mayor of Minneapolis, Sharon Sayles Belton, to talk about the foundation and how it can help parents and children with Down syndrome in Minneapolis. Ms. Belton was one of the dignitaries that attended the opening of the “Treasuring the Future: Children’s Rights and Realities” exhibition and was very familiar with SGI-USA through a practicing family member. With Mayor Belton’s assistance, I now have a person who is putting together a solid business plan for the foundation, which includes a building for it and seed money to run it. Services are planned to start in Minneapolis this summer.

Because of my efforts, I was nominated for a prestigious honor, The Minneapolis Award, and (former) Senator Bill Bradley has recognized me for my accomplishments on behalf of Children with Down Syndrome. Because of my faith, I can look into Travis' beautiful brown eyes, see his smile, and know that people with Down syndrome across the United States will become self-sufficient in the 21st century.