

Creating a Network of TSC Patients and Families in Japan

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TSC Salon Chubu

Since 2012, I have hosted meetings for families of individuals diagnosed with a medical condition called tuberous sclerosis complex. It was a condition that I had never heard about until my son's diagnosis with it when he was six months old.

TS, as tuberous sclerosis complex is commonly called, causes benign tumors to form in the brain, kidneys, skin, and other organs of the body. The brain tumors often cause seizures and delays. About half those with seizures also develop autism. The kidney tumors grow in size and number and must be monitored regularly. The skin tumors can be disfiguring.

There are about a million people around the world who have been diagnosed with TS. It affects one in six thousand newborn infants.

In the case of TS, access to information can mean the difference between uncontrolled seizures and a severe intellectual disability or seizures that are controlled and a mild, or even no intellectual disability. It can mean avoiding losing all or part of a kidney. It can even impact the severity of the autism diagnosis.

I am a TSC parent who was born and raised in the United States, but has lived in Japan since 1983. My understanding of two languages has enabled me to access to information on developments in places outside Japan and given a perspective that 10 or 20 years ago, or even more recently, Japanese parents did not have.

In the United States, parents have created broad-based networks with the Internet and have had access to the knowledge and experiences of others for the past 20 years. Even before then, there was a strong national organization in the United States that hosted conferences and regional meetings, provided support for newly

patients and their families, and supported research initiatives. Today the online networks are international, though most are conducted in English. The largest, run by the US-based TSAAlliance, has upward of 8,000 members.

By contrast, in Japan, small, private online groups started by parents or patients who want to share their own experiences are the norm. The idea of staying informed is considered important, but hasn't been a priority.

Japan also has a TS organization that a parent set up in the late 1980s. The organization holds an annual gathering for TSC patient/families in Tokyo, so people in and around Tokyo have had an easier time connecting. Nevertheless, for some reason this did not develop into broad-based networks, online or otherwise.

Until 2012, only a handful of physicians were interested in and knowledgeable about TS. As a result, the average patient/family had limited or no access to information on new treatments, unless they understood English fluently and could use the Internet.

Because English is my native language and because I am the type of person who feels that knowledge is power, I had stayed abreast of developments outside Japan and seen what a difference information could make in parents' choice of treatments. I wanted to share what I knew with Japanese families but had no vehicle to do this. Back in 2000 or so, a few TS moms and I formed the central Japan chapter of the Tokyo organization. The meetings, which started out as quarterly events but eventually were held less and less often, drew about 10 or 15 people. Ultimately, however, interest flagged and we disbanded. However, many of us

kept in contact, and these connections became the basis of a new series of gatherings from 2012.

The year 2012 was a turning point for TS families and patients in Japan. A new medication called *everolimus* was approved for kidney and brain tumors. Meanwhile, clinical trials had gotten underway in 2010 for a skin ointment. After years of quiet, new treatment options suddenly became available. This was the impetus behind the establishment of the Japan Society for Tuberous Sclerosis Complex. And it became a factor behind changes in parents' and patients' understanding of the importance of accessing information.

The main actors of the Japan Society for Tuberous Sclerosis Complex were physicians and researchers. One of the researchers who founded the society was closely linked with a number of groups for cancer patients. And perhaps because of these experiences, he sought to get patients and families involved in the new society. I had taken my son to the clinical trials for the skin ointments and thus had a connection with what was then one of a handful of TS specialists. I was also in touch with a TS mom in Tokyo who had been raised in the United States and whose son was part of the clinical trial. This is how I came to be asked to be part of the Family Committee in the academic society.

After joining the society and becoming part of the Family Committee in 2012, I started having patient/family meetings in Nisshin. I decided to use my home as the venue because I wanted people to feel at home and get a break from their normally hectic and stressful lives while they made connections and exchanged information.

When the meetings began, interest in the new medication among the people attending the meetings was high, but there was a dearth of information about it. This has changed gradually, thanks in part to the website for families created by the producer of the medication and thanks to the growing number of doctors who have become interested in TS.

Soon after the establishment of the society, at the end of 2012, the first TS clinic in Japan opened in Tokyo at East JR Hospital, with one day a week set aside for TS patients. In 2013, Seirei Hamamatsu Hospital created a team of doctors dedicated to TS. It was not a TS clinic, but a sort of Japanese adaptation of this. This

was our second hub and it was amazingly not in Tokyo or Osaka, but right around the corner from us. (Hamamatsu is about an hour and twenty minutes away from my house.) Interest in TSC among physicians throughout the country had been sparked.

Our links with Seirei Hamamatsu have been strong. Soon after the announcement, I met one of the doctors from Seirei Hamamatsu Hospital at the annual Tokyo gathering. A few weeks later, he got in touch with me and asked whether he could attend one of our Nisshin meetings. He said he wanted to find out about the lives of patients outside the hospital and find out about the problems they were facing. I had never encountered a doctor quite like this. I wrote back and said I would love to have him there and also hesitantly asked whether he would be willing to answer questions from families and patients at the meeting. He said yes.

This was a turning point in our Nisshin gatherings. In December of 2013, we had another gathering/medical consultation at my house. This time Dr. Hitomi Sasaki, a urologist from Fujita Hoken Eisei Hospital in Toyoake, agreed to come and meet with patients and families. Fujita was the third hospital in Japan to create a TSC team and also happened to be located right outside Nagoya.

Word about the Nisshin meetings gotten out, thanks in part to the notice on the Society website and also word of mouth. This time an even larger number of people attended. There was no room to move around in my dining room. It was crazy, but in a way exactly what I'd been dreaming of.

During the meetings at my house, people always chipped in and helped set up and clean up the room. But one woman in particular—Risa Hori—took the initiative in making name cards, thinking through some of the finer points in the schedule. After the December 2013 meeting, she offered to help in planning, and since then we've done everything together. Her support has given new shape to the meetings and today we have become both good allies and friends.

Our next gathering in June 2017 drew 30 families and more than 70 people. During the meeting, I handed out a questionnaire and asked whether anybody would be interested in joining a planning committee. Almost a dozen people said yes! After the meeting, we met to discuss future directions for our group. I also

spoke about how I wanted to use the Internet so people throughout Japan could access information and have support. Our meetings had begun drawing parents whose children had been newly diagnosed and who came with tears in their eyes because they were so happy to find the group. But the reach of the group was still local (regional), and this bothered me. Two weeks later, Risa contacted us and said she'd designed a website. As it turned out, she was at one point a computer instructor and knew had to create and maintain websites.

A month later, we launched the website, which Risa named TSC Salon Chubu to mirror the cozy "salon-like" atmosphere of our Nisshin meetings. We decided to make the website an independent initiative rather than part of the Family Network Committee of the Society because we wanted to have the freedom of content.

In the coming months, Risa monitored the site, added information regularly, and did everything in her power to raise its ranking on the Google list so that people, especially people with a new diagnosis, could find it easily and get information immediately. In the year and a half since its launch, about 6,000 people visited the site. Currently, it comes up number 63 when a search with the Japanese for "tuberous sclerosis"; number seven with "tuberous sclerosis" and "family"; and number one with "tuberous sclerosis" and "gathering." Its rise up the Google ranking ladder has been steady and quick.

The development of our Japanese network has followed a very different course from that of the United States. In the United States, the national organization was patient/family driven and it grew to encompass physicians, researchers, and other specialists. Here, however, the newly established TS society and vision of one of the founding members of involving families was pivotal in the formation of our network. The support shown by doctors of the newly established TS teams at hospitals in the area gave our meetings credibility and added momentum to the network formation.

Parental initiative has, by contrast, been limited. It is difficult to predict what the shape of the network will be in the future. The annual gathering will continue to bring people in central Japan together and let them get second opinions on treatments and other problems from the TS specialists and other families. The website, meanwhile, will hopefully continue to serve as a lifeline

for newly diagnosed patients and their families throughout the country.

We've come a long way, but still have a large distance to travel. What I would like to do in the future is to create an online forum where families can share their knowledge and experience. I think Japanese shy away from airing their troubles in public and still prefer the security of small private groups, where they can post anonymously. It will be difficult, but hopefully a way can be found.