



# Complex Child E-Magazine

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## Starting a Nonprofit Organization: The Example of SWAN by Amy Clugston

When seeking out an organization for support, most won't realize just how these organizations get started. A brief history or overview doesn't get at the heart of the inspiration or the challenging steps that it took to get there. I will tell you the story behind the organization I started, Syndromes Without A Name USA (SWAN).

### **Lorna's Story**

It all started 13 years ago when I gave birth to my first child, a little girl we named Lorna. She was born with folded over ears and measured 4lbs 13oz in weight, 17in long, and 11in in head circumference, despite the fact that she was a full term baby. We later learned some of the terms for her small measurements, intrauterine growth restriction and microcephaly.

After coming home from the hospital three days later with feeding issues, colic, and a heart murmur, it was apparent that something was not right. Once we saw a cardiologist who found a hole in her heart, we were referred to the genetics department.

That was the start of our diagnostic odyssey that we are still on today, 13 years later. Of course, over those years we have added many signs and symptoms. As we added symptom after symptom, seeing doctor after doctor and still had no diagnosis, there was a growing need for connecting with others who were experiencing the confusion of an undiagnosed world.

### **Reaching Out and Legalities**

I searched high and low for people like my daughter and me. After I created an e-mail group and a website to share resources and stories, I finally felt like I wasn't alone in the world. A few years later, I found an organization in the UK, Syndromes Without A Name. I was so excited, but supporting me and other Americans over the oceans wasn't an easy thing to do. As a result, I set out to create SWAN in the USA. I had the support of those in the UK to use the same name, but creating the organization was up to me. I had no experience with starting an organization but had the desire to do my best not to let others feel alone like I once did.

The first step was to gather a few people together to form a board of directors, which was difficult since people were spread all over the country. I then contacted a lawyer who does pro bono work for organizations. He helped us with a set of bylaws and the papers needed to become incorporated and get an employee identification number. We then had to modify the bylaws to fit the needs of the organization, which took a lot of research time looking at other organizations' bylaws.

After receiving the approval of our articles of incorporation and an employee identification number we could then file to become a tax-exempt nonprofit 501c3 organization. This took a great deal of time and preparation, especially since I had no experience on how to complete all the forms.

Completing these steps was really only the beginning of SWAN USA, however. There was much more work to be done to create a successful organization.

## **Challenges**

There are a lot of challenges in creating a successful organization. Not only do you need to create a functional board, set up goals and objectives, create a strategic plan, and find funds, but you also need to meet the needs of the families and children you support, all while finding the time to do it. I have to remind myself and others that I'm doing this all voluntarily. I'm not getting paid, and I still have to take care of my family. Having a child with extra medical and educational needs is time consuming itself, and with two other children I can stretch myself pretty thin. It is important to find other dedicated people who believe in the mission and are willing to share in the duties. The challenges are hard and can be prevalent, but the rewards to me outweigh the difficulties.

The rewards may seem small to some, but not for me. I take joy in seeing new people come and make connections. Sharing and providing resources so at least one person won't feel so lost is calming to me. When I see a child get a diagnosis after years of searching it touches my heart. As medical professionals take interest in undiagnosed children and create research programs, I become very hopeful. Knowing what is possible and striving to make it possible may provide a sense of accomplishment. These are all reasons I continue to do my best to create and provide the resources and services that will better the lives of children living with a diagnosis that is yet unknown.

If you find the mission of SWAN USA of interest, you may be able to share in these rewards. If you are interested in creating an organization dedicated to another subject that you may find rewarding, you are welcome to contact me and I will share with you the knowledge I have gained in this process.