

## Record

290

## File Number

10261

Author: Somoza, Mary

Title: Taking Charge of Life

Original source: Exceptional Parent, April 1999, p31-

Resource type: Written

Publication Date: 1/4/1999

Publisher info: Psy-Ed. Corp

**Abstract**

Mary Somoza is the parent of teenage twins, both of whom were born with cerebral palsy and high support needs, including multiple medical needs. In this article, she tells how she found it necessary to 'take charge', searching out and co-ordinating the multiplicity of professionals in her children's lives. Even more than that, she talks of the fight to obtain the services her children needed, and in doing so, she shares strategies that she has learnt over time, saying "I began channeling all my negative feelings into positive action for change". Mary has become a committed advocate for children with disability. **Keywords:**

**Advocacy, Families**

# Taking Charge of Life

by Mary Somoza



The Somozas (back row from left); Gabriella, Mary, Oliver, Gerardo (front row from left) Anastasia, and Alba.

**F**ifteen years ago my twin daughters, Alba and Anastasia, were born. Both had severe quadraplegia cerebral palsy, and both had multiple medical needs. My husband and I were both immigrants to New York City—he from Central America, I from Ireland. We were without close friends or close—or even extended—family nearby. As an aspiring photographer, my husband was working long hours as a waiter along with trying to build his business. Our son, Oliver, was a year old when the twins were born. Our home had more infants than adults!

The girls spent their first three months in incubators in the hospital. Once home, I knew from their severe rigidity that something was wrong. Our therapists, however, kept telling me, “they’ll grow out of it.” When Alba and Anastasia were 8 months old, our pediatrician directed me to the services of United Cerebral Palsy. There, the diagnosis was made.

## In the beginning

My life was consumed by the quest for the many services our girls needed to survive. It was a lonely, sometimes desperate, mission to find where and how to get help. I quickly became aware that unless I could master this maze of social and medical services, I would never be able to care for my children at home.

Things were not hard; they were dreadful. There were no early intervention services at that time. I had to become my own case manager, searching for and finding the appropriate clinics, therapists and specialists—doctors, audiologist, ophthalmologist, neurologist, orthopedist, gastroenterologist—and coordinating the visits and cross consultations. My life was a blur of around-the-clock caretaking and crisis management.

Having to hustle for transportation, orchestrate my twin’s acceptance by the Medicaid program, and secure a home health aide for a few hours a

*continued on page 32*



President Clinton welcomes the Somozas to Washington, D.C. in 1993. (left) Anastasia, (center) Mary, and (right) Alba.

*continued from page 31*

week, made exhaustion my constant state of being. My chaotic life would occasionally stabilize, only to plunge into mayhem when funding was cut from vital programs and services abruptly stopped. It seemed I spent at least half of my time lobbying just to keep services I had struggled to find. It was a very difficult time. I often wonder how I got through those early years.

Our financial situation also began to bottom out. Everything—our income and the sale of anything of value—went to medical bills. We were forced to move twice.

#### **Who's in charge?**

We were constantly turned down for services. I appealed these rejections—sometimes two or three times—until I got what was needed. Every system we dealt with seemed to be designed to be a temporary solution, whether it was Supplemental Security Income, homemakers, hospitals, therapies, or clinics. Every time we lost a service, I would ask who the decision-maker was and write in a complaint describing how horrible the system was. With each default, I became more and more angry. And the angrier I became, the more I was willing to fight the systems blocking my daughters from care.

One day, I got smart about the letter writing. Instead of assailing the person immediately in charge, I asked who was in charge of the "no." And who did that person report to? And that person? Then I directed my letters to *all* of them,

driving my correspondence upward through the many different layers of leadership within a system's administration. Beyond that, I turned to and wrote the government officials connected with that particular system. Usually I could identify them just by asking.

Then I started including copies to the local media. This power-level scatter-gun approach worked wonders.

With my letters, I began channeling all my negative feelings into positive action for change. From these seemingly endless rounds of letters, as well as articles in *United Cerebral Palsy's Washington Watch* newsletter, I began to become a known entity to organizations and politicians. A request for me to testify before Congress during the reauthorization of the national child care act came at a prime moment. I had just been to an international conference and learned how far advanced European countries were in aiding families with children with cerebral palsy. I was angry. And I let Congress know it. I declared that as far as its outlook, policies, and practices directed towards children with cerebral palsy were concerned, the US was as a third world country.

Soon after 1993, New York's Governor Cuomo appointed me to the Early Intervention Coordinating Council. My work in helping design the state's first early intervention legislation included a plea for respite care. One official asserted that legislators—bureaucrats who do not have a clue as to what daily life is for a family with a child with cerebral palsy—would equate respite care with babysitting. I offered to "lend" my twins to the first one who did so. My voice—representing so many family voices—was heard. New York's early intervention law was the first state law to include respite care. Still on the state council, I was appointed to the local early intervention council in New York City in 1994.

#### **An "expert" mom**

I have become an "expert" mom, whether advocating alongside parents in special education, sensitizing professionals who work with families like ours, or fighting in the political arena to secure the rights of people with disabilities. I am often asked to speak to groups of parents; students at schools of physical, speech, and occupational therapies; hospital staff working with children with disabilities; and, increasingly, professionals and families in the area of special education. I take enormous pride and pleasure in imparting what is often principally common sense tips to our community.

Our girls were 8 when New York State's early intervention legislation passed. Our family, and others like us, finally had a source of knowledgeable and professional information not only for living each day, but for planning for the future. Early intervention has made a dramatic improvement in the delivery of services to families. Today, I am happy to say that, though we still struggle, things have improved considerably.

In 1996, I ran as an independent for the school board in District 2 to help reform special education. It was the American democratic process in action. While others had as much as \$60,000 in campaign financing at hand, I had a phalanx of parents of children with disabilities who were committed to the issue and willing to stick up campaign posters, canvas door to door, and, otherwise, get out the vote for their candidate. I won—the only independent in New York City's 32 districts to do so.

#### **Parent power**

As our children grow, something new is always entering the fray for any parents—especially for those with children with disabilities. When our girls were tiny, it was identifying and securing services. Early intervention was critical. School time came and special education and inclusion were vital topics. As Alba and Anastasia became teenagers, hormones, menstruation and boyfriends came into the picture.

A Special Educational Supplement of EXCEPTIONAL PARENT Magazine.

Essential to every age, every challenge, every crisis, are the connections we have formed with other parents of children with disabilities. If their children are the same age, we have worked together to solve problems. If their children are older, we receive great information and ideas for anticipating and planning for "what next?!" If their children are younger, we can help them avoid some of the pitfalls we hit. These parent-to-parent connections come naturally: in clinic lines, pre-school pick-ups, and all the other occasions when we parents are shepherding our children with disabilities through life.

The connections between our children are as important. We have made great strides in the schools with inclusion: children with and without disabilities working and having fun together in the classroom. As children grow older and socialize outside of school and without adults around, however, those with disabilities are often excluded. While we work to extend inclusion to movies, shopping sprees and long, intense discussions of soap opera plots

behind bedroom doors, it is important that children with disabilities have the opportunity to expand their social horizons with one another.

Today, our girls are 15 and fully included in ninth-grade classrooms at the School of the Future, a public high school in Manhattan. My youngest daughter, Gabriella, is 11 and in sixth grade, and Oliver is in 10th. Life is as hectic as any other family that boasts three teenagers and one "wannabe." My husband is a full-time photographer, a path that Anastasia is quite interested in following. She received her own camera at Christmas and takes a pretty fine photograph. On the other hand, Alba, our computer whiz lives and breathes bits and bytes.

My family life is what I would now call exhilarating. I am running for

re-election, hoping to continue my work on the reform of special education. I have four terrific children, a wonderful supporting husband, a cat who insists on eating my important papers, and the VIP of the family—Fayette, our Labrador. It doesn't get much better than that! **EP**

*Mary and Gerardo Somoza live with their children Oliver, Alba, Anastasia, and Gabriella in New York City with four-legged family members, dog, Fayette, and cat, Boston. Mary is a committed advocate for children with all disabilities. Along with her early intervention and school board positions, she serves as a state advisor to the Interagency Coordinating Council for Infants and Toddlers with Disabilities, and as a member of the Advisory Council to the Office of Mental Retardation and Development Disabilities. In her "spare time," she is a student of political science at Fordham University.*

### LESSONS FROM AN EXPERT MOM

- Join with other parents for ideas, support and building "parent power."
- Find out "who's in charge" at all levels: in the office, in government, in the media and make your voice heard.
- Don't give up! Keep those letters flowing.

**Disorders associated with cerebral palsy will be discussed further in this six-part series.**