



*Nancy Gianni with daughter, GiGi*

## GIGI'S PLAYHOUSE

One woman's mission to help children  
and families living with and learning  
from Down syndrome

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BY NANCY GIANNI

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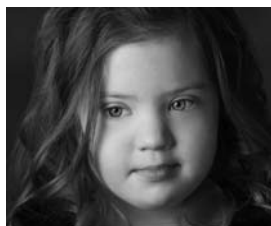


Above: *Annabelle Shepard*  
Right: *Kelvin McLaurin*



*{South Barrington resident Nancy Gianni had a child with Down syndrome and thought that her active life as a mom of four was over.*

*She soon learned that nothing could be further from the truth. Nancy was inspired by her daughter, GiGi, and turned her fear into a plan to change the way people view individuals with Down syndrome. As you will see, it has become so much more. This is their story.}*



*GiGi Gianni*

## BACKGROUND

**W**hen my daughter, GiGi, now 5, was born with Down syndrome, I thought my family’s life would change forever. About an hour after she was born, the doctors suspected she had Down syndrome. Panic welled up inside me but I was afraid for anyone to see it. As soon as my husband and I made eye contact, I said, “If anyone can handle this, we can.” He agreed and said, “Can you imagine what better kids Isabella and Franco will be because of her?” I knew we were going to get through this together.

Don’t get me wrong — we were petrified! I cannot even begin to tell you the total fear and devastation I felt. Everything they were telling us about Down syndrome was so negative. Suddenly, no one had eye contact with me anymore, they had the door to my room closed, and they kept sending in the clergy. If this was happening to us already, what was life going to be like for our children?

I was afraid to bring GiGi home and start this new life. When people first came to visit, there were hugs of sympathy, not congratulations. They would tiptoe towards the bassinet and be afraid to look inside to see what she would look like. When they did look, they saw this beautiful, little baby and were shocked. People always exclaimed “Oh my gosh! She is adorable!” I don’t know what they were expecting to see, but finally people started to realize she was just a baby.



Above: *Sara Bak* Top left: *Christine Ancel*  
Bottom left: *Vince Ptaszek*

## LIFE WITH GIGI

There are still many misconceptions about Down syndrome. The average age for a mother to give birth to a child with Down syndrome is 28, and it occurs in one of every 733 live births in the United States. When GiGi was born, we learned she had two holes in her heart. We were told that 30 percent to 50 percent of children with Down syndrome have heart issues. Most of the heart conditions can now be repaired, but it still scares you. She had open-heart surgery at 4 months old to repair the holes and there was no stopping her after that.

Once we were settled and got back into a routine at home, I realized GiGi was more like my other children than she was different. Some things took her longer but she always got it and never gave up. She inspired me every day and I promised her I would make the world a more accepting place for her and those with Down syndrome. With my husband by my side, we went out to recruit board members and raise money. Five of our original board members were from the Barrington area and all of them have children with Down syndrome in the Barrington school district. My son, Franco, drew the GiGi's Playhouse logo, and in just five months we opened the doors to the first Down syndrome awareness center in the country.

## THE PLAYHOUSE

The mission of GiGi's Playhouse is to spread positive awareness about Down syndrome by providing programming, education, and support to individuals with Down syndrome, their families, and the community. The goal and ultimate vision of GiGi's Playhouse is to celebrate the lives and showcase the talents and potential of individuals with Down syndrome. Though

educational programs and activities for each age range are the draw for many parents, simply having a place to go is powerful in itself. My first support group meeting for Down syndrome was in the corner of a sterile room at a hospital. This propelled me to create a place where families could come for resources and networking, where children and adults with Down syndrome could be the leaders, and where we could celebrate our diagnosis. What a difference it has made to have such a place, especially for new parents.

The fragile state of a new parent is what prevents many of them from being able to see the joy in Down syndrome. But once they step into GiGi's Playhouse, they hear "Congratulations" instead of "I'm so sorry." They are immediately met with parents who have been through the same thing they are going through and who have wonderful lives, something you don't think is going to happen. By helping a new parent, a sibling, or a grandparent view their new child as a baby and not a diagnosis will forever change the life the child will have. It will, in fact, change the world the child grows up in. A major benefit of the Playhouse is the self-esteem the children gain. There are more than 20 educational activities and programs for infants and adults and everything in between. Each is designed with a specific purpose. Many of the programs are facilitated and developed by therapists and educators. The children are strengthening their gross and fine motor skills, speech and language development, and social skills — all while having so much fun they don't even realize it! All of the skills are structured in a way that they can be transferred into the classrooms. Our 3-to 5-year-old group gets children ready for preschool/kindergarten; our Teen Tastic group facilitates friendships with peers while working on fine motor and physical activity; and our Hispanic



*"i have a voice" gallery*

and Polish groups bring families together to reach a population that may not be receiving all they can for their children due to language barriers. The most popular is our renowned Literacy Program, which offers free tutoring.

We are tutoring hundreds of children from ages 2 to 26. Based on documented research from experts in the field and with help from a developmental therapist, the Literacy Program at GiGi's has quickly grown with its proven success. They learn how to read in the manner they learn best: focusing on whole words rather than individual letters and sounds. This summer we also successfully piloted a new program with phonics that will be added to the curriculum in early 2009. All materials are custom-made for the child and teach the parents how to practice at home. This program, which has gained international awareness, allows many children with Down syndrome to remain mainstreamed at the level of their peers and not play "catch up." The popularity of this program has opened literacy satellite programs in addition to GiGi's Playhouse locations. We receive calls daily from around the country about the program — how to use it, how to start one, how to make materials. We have helped to bring this teaching technique to India, Ireland, Puerto Rico, and all across the United States.

Children with Down syndrome wear their diagnosis on their face. Unfortunately, this means they get stereotyped and judged. GiGi's Playhouse works hard to prepare children for school. When they enter kindergarten with reading skills because of the Literacy Program, the outdated stereotypes some may have about children with Down syndrome are proved wrong and these children get a fair chance. The literacy program also helps to develop speech and language skills, something that is so important when you enter school.

My favorite part about the Playhouse is that you do not even have to step inside to be touched by its magic. Families from around the world use our Web site not just for the resources but as a place to belong.

## THE FUTURE

Having GiGi is a true love story. It started out with devastation and fear and ended with a love unlike I have ever known. I am just glad that GiGi's Playhouse has turned into a place where parents can see the other side of Down syndrome and make an educated decision. The limitations that are presented in books, online, and even from the medical profession are outdated. They told me that GiGi would be hard to potty train (what child isn't?), yet she was trained the same time as my other children. The more they say she won't do, the more she steps up to the plate. She works hard every day without a complaint, so how can I not do the same for her? It is always at the end of the day when I carry her to bed that I remember how truly incredible she is. While sleeping, you can really feel the weight from the low muscle tone (a feature common in individuals with Down syndrome) that she carries daily, but you would never know it. She wakes up with a smile and works hard all day.

The Playhouse is truly miracle run. From the day I first started thinking about opening a Playhouse, the miracles started to happen and they haven't stopped yet. When we first opened, I was playing dress up with an 8-year-old girl named Christina at the Playhouse. All of the pretty, pink clothes were small and she kept trying to make them fit. I told her that I would somehow get some bigger ones. Then, my daughter, Isabella, told me that someone was at the Playhouse's doors. There was a woman from Barrington with her two



(Left to right)  
*Thomas Balsamo, Nancy Gianni,  
Jenni Von Tobel, Steven Bagby,  
and Lisa Schuh.*

teenage daughters holding Nordstrom bags and she said, “I don’t know if you could use these costumes and dress up clothes because they are big. They are high school orchesis, skating, and drama costumes.” Christina went running around with a huge smile and a big purple boa and a dress that was too big. Miracles like this happen all the time.

Though the miracles may seem disguised at times, they are a constant reminder of why we must continue. The “i have a voice” traveling gallery is an example. Barrington photographer Thomas Balsamo came to me to collaborate on a project about Down syndrome. I felt so honored but I was in the middle of opening two new Playhouses and restructuring our entire organizational structure, so I told him I simply did not have the time for a big project. When I picked GiGi up from preschool the next day, I was told that some parents were “concerned” with having a child “like that” in their child’s classroom. We were only a few days into the school year and the teacher said “this was said strictly because your daughter wears her diagnosis on her face.” It was like a knife in my heart.

I sat there and listened as they told me that they had sent a social worker into the room who was so impressed with GiGi and her ability to read three letter words, be potty trained, and listen to directions. I couldn’t hear any more of the conversation because I was so numb. As we were driving home, with GiGi’s Hannah Montana CD cranking, I looked into the back seat and watched her singing every word to every song, and my heart broke. Why couldn’t people just see her as the beautiful little girl she is? As soon as I got home, I called Thomas and, together with renowned advertising creator Steven Bagby, the “i have a voice” project was born. The gallery and accompanying book features beautiful portraits that capture the depth and very essence of individuals with Down syndrome. Appropriately titled “i have a voice,” this awareness campaign truly sheds light on the boundless potential and incredible spirit of individuals with Down syndrome.

My biggest fear when GiGi was born was for my other children. I now know that I could never teach them the life lessons that she does every day. They have learned patience, tolerance, empathy, and how hurtful words can be. They are so proud of her and make sure she tries everything we do. She is spending the summer playing T-ball, boating, wave running, swimming, listening to her brother’s iPod, dancing, and playing with her friends. Not only is she learning to read a book a week at the Literacy Program, but she’s reading before my other children did.

Now, less than five years since its’ inception, there are four GiGi’s Playhouses in the Chicagoland area (Hoffman Estates, Plainfield, McHenry, and Chicago) and a literacy satellite in Westmont. Calls come in daily regarding opening more across the country. At the opening of our McHenry location, the president of the Down Syndrome Organization in Nigeria visited with her 22-year-old daughter who has Down syndrome, and became interested in opening a GiGi’s Playhouse in Nigeria.

The growth of GiGi’s Playhouse is phenomenal, not merely in size, but in reach. The mission has also grown into a national awareness movement that is being swept across the country. It is more than I could have ever dreamed.

Sometimes I think the Playhouse mission is just too big for me and then another miracle comes along and I know it is all going to be OK. I have signs all the time telling me that no matter how hard it is to have these Playhouses, it must continue. GiGi came up to me while writing this and asked what I was doing. I responded wearily, “I am trying to write something.” She gently kissed my hand on the keyboard and hugged me, and I felt the strength to go on. She continually inspires me to do things I never thought I could do and I thank God for her every day. ☺