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The **AUTISM** magazine  
TAP INTO IT.  
**perspective**



Modern Day Explorers



Becoming a Den Leader



P.A.C.E. Place

The Fight for Autism Awareness

# Candyland

# THE QUEENS AUTISM MEETUP

By Cheryl Ocampo

Courage, I have learned, means taking a risk for an unknown cause. Courage is all that I have come to know as a single parent with my youngest child living with Autism Spectrum Disorder (ASD). I received the diagnosis of autism for my daughter, Zariah, in June 2005 - right before her third birthday. After the initial shock and devastation of such a diagnosis, I knew eventually that I would have to accept it, so I could help her. However, I was always such a timid and introverted person; I did not know how to go about being a voice for myself, let alone my own daughter.

In the past, I had always been more of a follower than a leader. I was always heavily influenced by my peers, thus oftentimes making some poor choices. I struggled with a lot of anxiety and stress coping as a single parent, and I just wasn't sure if I had the strength to be able to cope with raising a developmentally disabled child. I was terrified. I thought, "I don't know anyone else who has a child with autism. Where do I go for help? Where do I go for support or education? What do I do first?" I felt so alone. I felt like no one understood what I was going through.

I remember asking the neurologist who diagnosed Zariah how I should go about learning about this disorder. He just directed me to his website to read more about autism. Although it was a good resource, I felt like it wasn't enough, so I went online to search for more resources. I searched for any and every book on autism that I could

find. I searched online for support groups or parent workshops in my area



of Queens, NY, that could give me some kind of direction. To no avail, I

kept bumping into a dead end. I felt like I was beginning this journey with no map, no compass and no support, but I knew I had the strongest guidance in the world that would take me to where I needed to go and beyond. I had hope.

Although the beginning of my journey resulted in many dead ends, I knew that I could not get discouraged or give up. I knew I had to be my daughter's biggest advocate, because no one else would be. I found that the internet housed many valuable websites dedicated to autism awareness, and continued from there. When I searched for support groups for parents in my area, I was discouraged to see that there weren't any within reasonable proximity. Zariah was in a routine, and having to travel 15 to 50 miles would be next to impossible during a weekday. Whatever resources were out there for support, I tried them. It was always something: There was no support system for this specific type of special need because no one was fully aware



**Cheryl and Zariah**

of the disorder yet; I had to pay an outlandish fee in order to get the support I needed; I had to be a resident or a member of a certain borough or district, school or facility; or the organization could not accommodate the time frame I was available. I was bumping into obstacle after obstacle, but I managed to still keep going.

I pressed on learning as much as I could about autism. I collaborated with my daughter's preschool and the members of her care team, all who had constant interaction with her every day. I observed their strategies and techniques and brought the same into my home. I asked questions all the time, and I asked the therapists for recommendations on how I could help my daughter. I continuously observed the tools they used for Zariah in school and then researched them online, such as PECS (Picture Exchange System), then implemented them at home in order to remain consistent. I practiced, practiced and practiced some more what the therapists had asked me to do at home with Zariah. I rearranged my whole life in order to accommodate her special needs. For example,

I placed a PECS board with a schedule where Zariah could see what she had to do every day. I labeled rooms in the home that she frequently visited, such as the bathroom, in order to help her transition better. I made sure to do my best to attend school meetings and workshops as much as I was able.

**My goal with the group is for all of us to help one another by sharing our experiences. Our motto is: "Empowering ourselves. One parent at a time." It is important for the autism community to come together to help one another, because the journey of autism can be a very long and lonely one.**

I made sure to stay on top of school, all the while doing my best to bring in a reasonable income by working at home and continuing my own education. I made sure to search for services through various agencies for

Zariah in order to help ease our lifestyle a little better, such as a home care attendant, respite, and special needs activities after school and during the summer. Each minute of gained knowledge turned to an hour. An hour turned into a day. A day turned into a week. Now, here I am almost two years after Zariah's diagnosis and I now have a little bit more confidence in holding her hand along this journey, just because I was willing to take the risk of studying a disorder I had never heard of.

In November 2006, a little over a year after Zariah's diagnosis, I decided to turn my unfortunate event into something positive. Although not a master of the mysterious disorder, I formed The Queens Autism Meetup designed to serve parents of children with autism in the Queens, NY, and surrounding areas. The Queens Autism Meetup is an online forum where parents of children with autism meet online and in person in order to network with one another for moral support and resources. We also get together to share family-oriented events, such as picnics and play dates. The group is still fairly new, with 21 members so far. My goal with the group is for all of us to help one another by sharing our experiences. Our motto is: "Empowering ourselves. One parent at a time." It is important for the autism community to come together to help one another, because the journey of autism can be a very long and lonely one.

I make no profit from this group, and all of my time and money spent is out of my own leisure and my own money. Since I made the choice to stay at home with Zariah almost two years ago (until I can find a specialized nanny or home care attendant), I have a very limited income. However, even with limitations in my income, I know the information I have learned thus far from my journey into autism could possibly be priceless to a parent who may have just begun their own journey. Looking into Zariah's eyes every day and seeing her progress, I had a

strong desire to help someone else. Although there are no monetary benefits, I believe being able to help these parents through my moral support is more valuable than money. I know that these parents will mentally and spiritually carry what they gain from this group for the rest of their lives. What these parents will learn, will in turn help their children grow and mature into the best possible adults they can be.

I've learned through life that the only thing we truly own is the knowledge we gain. Therefore, the knowledge I have gained

learning about this disorder is one I want to share with as many parents as I can possibly reach, so that they will not have to go through as many obstacles as I went through in the beginning. I feel that the more support these parents can get in the beginning, the better equipped these parents will be in order to get the help they need for their children.

I do not limit my group to any city or borough. If parents are willing to travel the distance to meet with us, then they are more than welcomed to do so. Those who reside

further can still benefit from the online resources through my message board. The Queens Autism Meetup is also open to any professionals in the field who would like to contribute their services in any way. The Queens Autism Meetup is open to friends and loved ones who have someone in their life with Autism Spectrum Disorder. Any which way autism has touched someone's life, The Queens Autism Meetup welcomes them.

I've always told my members that I don't have all the answers. If I don't know something, I will do my best to steer them into the direction to which they can obtain the information they may need. Overall, The Queens Autism Meetup is about all the parents who want to help their children living with autism. I always make sure to let them know that it is THEIR group as well. It is so important for group members to share whatever resources they may have or come across, because that information may be able to help another parent.

Initially, I thought autism was my worst enemy. I was angry at it for taking normalcy away from my child. But as time went on, I realized that autism has been a very special gift to our family. Autism has opened my eyes to things I would have never even thought of seeing through typical circumstances. Something happened to the timid and introverted person who was just a follower and seldom a leader, because now all I see in myself is someone who has a strong voice for the daughter who has limited speech. I speak Zariah's voice every day. The Queens Autism Meetup is the pathway I created in order to help other parents do the same. **TAP**

*Cheryl Ocampo is a freelance writer. She lives in the Queens, New York, area with her family. She is a regular contributor to The Autism Perspective (TAP) Magazine. To learn more or to join The Queens Autism Meetup, please go to: [www.autism.meetup.com/290](http://www.autism.meetup.com/290). You may email Ms. Ocampo at: [cocampo76@aol.com](mailto:cocampo76@aol.com) for comments.*



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