



Cohen Syndrome Newsletter

A newsletter published by *DDC Clinic for Special Needs Children*

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Wow! Here at DDC Clinic, we cannot even begin to put into words our excitement about the recent National Cohen Syndrome Family Meeting. To say it was successful is an understatement! Attended by 13 families—both local and from across the U. S., including Maine, Massachusetts, Kansas, Virginia, Mississippi, Kentucky, Pennsylvania, Colorado, and Alaska, the event exceeded all of our expectations and we are excited to begin planning future events.

The first speaker of the day was Elias Traboulsi, M.D., Cleveland Clinic Foundation. Dr. Traboulsi is board certified in both ophthalmology and genetics. From him, families learned about the multiple vision problems that affect children with Cohen syndrome along with current treatments and research implications that may benefit them in the future.

Gary Stotsky, a speech pathologist from York, Pennsylvania, with 35 years of experience in helping children with special needs communicate better, ad-

ressed the issue of using alternative communication devices, such as picture boards and computers, to help enhance communications skills of Cohen syndrome patients.

Guests listened to Dr. Wang speak about primary healthcare issues for children with Cohen syndrome and common findings among them including neutropenia (low white cell count), anxiety, “super-hearing”, and central obesity. He also spoke of the need for reduced dosing of medications in some children.

The day ended with Dr. Wang leading a family discussion session focusing on parent observations and the daily management of symptoms and issues involving their children.

Families gathered on the following day for a picnic and the opportunity to spend more time together visiting and sharing ideas and strategies to help their children.

Several families took the time to write and share their thoughts and comments with us. Thank you! We wish we had the room to publish these letters in their entirety. We are so amazed and moved by your heartfelt stories. Following are excerpts from these letters that sum it up better than we ever could!



Iva Byler (Ohio) writes:

(Friday’s meeting) not only gave me ideas but also re-

alizations of Cohen’s and my daughters. Cohen’s has been a struggle not only for my daughters, but for myself as well. The support and the experiences shared amongst parents was valuable.

I no longer feel it is my daughters and myself struggling with Cohen’s, I know I have both the medical and the group support I need to do the best for my girls.

From Jan Waite (Maine):

... I wanted you to know how much Wilson and I enjoyed our time in Ohio. We are still talking about it!

What a wonderful opportunity to share information and connect with so many awesome people with whom we have so much in common.

We learned a great deal from each other and began some very special relationships.





From Krista Mayfield (Kentucky):

My parents, Jacque, and I all had a wonderful time—we are still talking about the trip and all the people that we had the pleasure of meeting. I think for us the best experience that we had was that we got to meet other kiddos just like

Jacque (something that we had not experienced). I personally . . . felt like I was at home. It was, and has been, the only place we have ever been that we didn't have to "explain" Jacque. She got to be who she is, and we didn't have to hope that she would fit in—or have to tell others what she does or doesn't understand—SHE JUST WAS. This was, and still is, the greatest feeling I have ever had. It still brings the tears and goosebumps. And for that I thank you. The parents that I was able to meet and talk with have been a great resource to us. To hear of the challenges that they had experienced helped give me an idea of the things that lie ahead for Jacque.

. . . now that I know about . . . the possible difficulties that may be ahead, I can be better prepared as an advocate for Jacque. (KNOWLEDGE IS POWER). This calls for yet another THANK YOU!

What a wonderfully blessed event this was. Not only did we learn new information from doctors that are very passionate about their work, but even more so about our kiddos. And, of course, we got to meet each other!! We have so much to give each other. Shared experiences and a place where we just UNDERSTAND each other, a place where we don't have to ex-

Sonja Delano (Colorado) writes:

I very seldom stray far from home, so going to Ohio for the conference was a big thing for me. It was also one of the most wonderful experiences of my life. For the first time in almost 22 years . . . I was able to see other children like mine. That may sound silly, but for someone like me who diagnosed her own children after years and years of research and genetics appointments, who was constantly yearning and hoping for answers for 20 plus years, who searched every time she was in public for faces like her daughters', it had a tremendous positive impact. When Dr. Tsai officially diagnosed them, I wanted to see pictures of other children and adults for comparison just in case it was a "too good to be true" thing. After waiting so long for answers, finding out what had happened to them seemed too good to be true.

There was one mother there who has three daughters with Cohen syndrome. One of her daughters speaks, the other two do not. My Debbie speaks, Ashley has never spoken. There was a girl there who looks so much like Debbie, except she was

thinner and she was much more developmentally appropriate. For me, that was looking at Debbie if she had "more", I don't know how else to explain it. It was not a sad moment, but a happy one. I got to see Debbie in a new light, if that makes any sense. The conference did something for me that no doctor could ever do—confirm in my mind that the girls' diagnosis was correct. There is great peace in that.

For me . . . it was the support of the other families that meant so much. In all of this I have been alone. Sure, there are support groups here, but it is not the same as having the support of others who know EXACTLY what you are talking about. As I drove back to my hotel that night, I cried. At the hotel, I cried some more. This time it was with relief that while we are few, both us and our children, we know exactly how each other feels. We are not alone.

I know that the next one I will be bringing Debbie and Ashley so they can meet others like them. Maybe they won't know the difference, but I will.

Ellen Mast from Mississippi sent her list of top highlights from the meeting:



- Seeing all of the families that put forth the effort to travel the many miles to attend.
- Listening to the professionals who gave us their input on the retina degeneration, use of Vitamin A, neutropenia, truncal obesity, etc.
- Visiting and eating Saturday at the picnic in Burton.

Carrie Hintsala (Alaska) wrote about the decision to add low-dose supplements to her daughter's diet "if there is a slight chance that the progression (of blindness) will be slowed."

Faith and hope. In life, at the end of the day, that is really all there is. I have faith that God will give us a miracle, either we will learn to deal with the blindness, or Cheyanne's eyesight will not deteriorate to the point of blindness. I guess that is where the "hope" part comes in.

Meeting other parents who share that same hope has inspired me.

Cheyanne and I were so pleased to be invited and cannot wait to come back and visit with the other families that so unselfishly shared their children with the group, as well as the people who made it all happen.



Thank you to United Way Services of Geauga County whose generous donations partially funded the event. We are so grateful for their participation.

Thank you to our guest speakers and their generous donation of time and knowledge. Their interesting and informative talks were greatly appreciated.

Thank you to Kathy Maxwell, R.N., of Rainbow Babies and Children's Hospital, who graciously donated her time to help with the event on both days and helped sponsor the delicious lunches we enjoyed each day.

Thank you to the teachers of Sunny Hope School who graciously spent the day with our Cohen syndrome children. The kids really enjoyed the many activities they had arranged throughout the day.

Thank you, Leah Nye, for your time spent in organizing this event. We know how much you care about these children and their families and appreciate your efforts in ensuring a wonderful time was had by all!

Most importantly, we would like to thank the families who participated in this event. You are wonderful! Thank you for your time and dedication to help make this event such a success. This event would never have happened without your steadfast support. We feel truly blessed to have met all of you and consider ourselves richer for the experience. It is an honor to be involved with such an amazing group of people!



Now that the First Annual National Cohen Syndrome Family Meeting is over, we have had many families express their interest in keeping in contact with their new friends.

In that light, we are asking for your permission to put your name on a Contact Reference Sheet that would be sent to our list of Cohen Syndrome families. If you would like your name to be listed on this sheet, please fill out the following.



Name

Phone / Cell phone

Address

Email address

City, State, Zip

Other information you would like included

Please return to:

Leah Nye, DDC Clinic, P. O. Box 845, Middlefield, OH 44062

Thank you!

