

Family VOICES

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NSA Conference From A Parent's Perspective

MELANIE ROGERS, ARIZONA

Nate and I got back last night from the National Stuttering Association's Annual Conference in Fort Worth, Texas. It was the first conference we attended, and we had an amazing time. I have attended various business conferences in the past, but I have to say that the group of people we met at the stuttering conference were some of the nicest, kindest, and warmest people I have ever met at a conference! It was 3½ days of smiles and friendly greetings.

The conference welcomes all ages – from kids who stutter through adults who stutter and those who love people who stutter. I was extremely impressed that there were workshops and sessions catering to everyone's different needs and interests. Throughout

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Couldn't Be Better!

SHAWN CZERWINSKI, PENNSYLVANIA

This year's conference was by far one of the best conferences that I have ever been to. I noticed at the teen workshops this year the rooms were almost always full, even at the first workshop of the day. Sometimes there weren't even enough seats in the room, which has never happened at any of the teen workshops that I have been to in prior years.

My favorite workshop was the Teen Ice Breaker. I met a lot of really cool new teens who stutter, along with many of their siblings. My favorite game we played in that workshop was the 'human knot'. The human knot was a lot of fun because every time someone thought they were cheating in our group, it made it impossible for us to untangle and end up in one circle again. I also liked the toilet paper game

because we got to learn a lot of interesting stuff about everyone and by the time we were done I really felt like I knew all eight people in my group.

I don't think that this year's conference could have gone better than it did. Everyone that I talked to - especially First Timers - were excited and enjoying themselves. All of the First Timers that I talked to couldn't wait until next year and either said that they were definitely coming or were really hoping they could! This means that we must be doing something right. One thing that I'm sure everyone would agree with would be to make the conference a little longer!

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Shawn Czerwinski

Erie, PA, 19 years old

NSA Teen Advisory council Member shawnace101@aol.com

*...for kids and
teens who stutter,
their parents,
SLPs and others
who support them!*

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DNA, Dads and Daughters: A Perspective.

ROB DUFFIELD, PENNSYLVANIA



We're dads. We're programmed to fix things. It's irrevocably built into our DNA, more than our love or hatred of the designated hitter, our desire for an engine with more horsepower, our need to get rid of ALL of the crabgrass in our lawns, or even the quest for the perfect barbeque technique (HINT: it's timing - don't turn things more than once). So what does a dad do when presented with a kid who is "broken"? These tiny little

beings don't come with an instruction manual, and not having a manual is so much worse than those multilingual, poorly drawn pamphlets that inevitably come with our summer weekend do-it-yourself projects. At least with those instructions, some of the Swedish words bear a faint resemblance to English and you can almost, if you squint, make out where the thingamajig screws into the whatsit.

So you can imagine my confusion when my daughter, Katie, began stuttering around age 3. Surely there must be a manual for this. There has to be a way to fix it, right? My wife, Joan, and I jumped on the Internet and began looking around. Fortunately, we quickly

found the source of the problem. Unfortunately, according to the all-knowing 21st Century oracle, the problem was us. We talked too fast. And we talked over each other. And we talked a lot. If we just slowed down, listened, had long pauses where Katie could interject, her stuttering would go away. "Well, that was easy," I said to Joan. Surely this Jersey-born guy and his Philadelphia-born wife could speak slowly. Even if we were both raised in gift-of-the-gab Irish families. You know, the type of family where conversation was equal parts Formula I racing, fencing match, and blood sport. We can so do this, I thought. So Joan and I slooooooed down (This took more than one try. A lot more than one try). Only, Katie kept right on bumping away.

Well, there was still no manual available, so we took the next logical step. We went to an expert, in this case our doctor. Surely, the doctor would be able to tell us what was wrong and then we could set about the task of fixing it. Once again, we found the source of the problem, and we were told that it was...us. We were putting too much pressure on Katie. We were too demanding. If we could just relax about EVERYTHING, Katie would be just fine. This was nothing to worry about and it would just fade away if we could just relax. Have you ever tried to relax, knowing that something depended on your relaxing? That one did not come easily to any of us, but we managed to be MORE relaxed and that was going to have to be enough. But still, Katie stuttered.

So surely, I thought, there must be some sort of expert who specializes in this sort of thing. It was then we found the National Stuttering Association and I felt like Galahad finding the Grail. Surely these knowledgeable professionals with their years of training and experience would be able to cure my daughter. So we packed the family up and headed out to the NSA's annual conference in Atlanta. I was wondering, on the ride down there, just how long it would take to fix Katie, to cure her of this malady.

That was more than five years ago, and Katie still stutters. What I learned in that first conference, and what I am reminded of each year I go, was that she didn't need to be fixed because she wasn't broken. Like the kids, teens and adults I met at the conference, Katie is smart, funny, beautiful and talented. What is broken, what needs to be fixed, I am learning, is a society that treats people who stutter as less than what they are. And so, I am going to acknowledge the nature of my DNA, that the need to fix things is an integral part of that, and I am going to set about changing this society to a place where my daughter's voice can be heard, because she has a lot to say. ::

NSA Family Radio

Your Virtual Family Chapter for Parents, Kids & Teens!

NSA Family Radio is hosted by the Family Chapters Committee of the NSA. The mission of the show is to bring together kids and teens who stutter and their parents, siblings and other family members in a way that is convenient from all over the world! We will be sharing ideas, information, and providing support. Best yet, you can join us for a live conversation as the show allows you to call in and participate. In addition, all shows are recorded and archived in case you can't catch us live! For dates, times, and upcoming show schedule, visit WeStutter.org. JOIN US LIVE! Call (310) 807- 5072 or toll free number: 877-560-5873



Be sure to check out 'National Stuttering Association' on Facebook and 'WeStutterNSA' on Twitter today!

NSA Conference From A Kid's Perspective

NATE R., ARIZONA

Ft. Worth Family Chapter | Ft. Worth, TX

The first official meeting of the Fort Worth Family Chapter took place on May 17th at the TCU Miller Clinic. In attendance were 3 parents, 3 monolingual SLP's, 1 bilingual SLP, and 9 children – 2 of which are PWS. One family was English speaking and one family was Spanish speaking. The chapter had a very lively meeting. It was the end-of-year celebration with the highly contested 'parents vs. children' stuttering Jeopardy game. Parents were, for the first time, victorious! The kids of course want a rematch, which Chapter Leader Laura Overton is only too happy to set up for next year.

Dallas TWST | Dallas, TX

The Dallas TWST Chapter met Wednesday, May 25th, and were thrilled to have a new family in attendance, making 3 new families to join the chapter in 3 months! There were only 2 families in attendance at the May meeting due to final exams, so the Chapter Leader Shannon Beaty decided to save the planned topic for another night, and instead hold an open forum for the new family, so they could ask questions, share their stories, and get to know the group and what they are about. The teens broke off and had a social forum, led by TAC member Braden Barber.

Central NJ TWST | New Jersey

Seven people attended the June 3rd Central NJ TWST meeting, including both Chapter Leaders – Hannah Laday and Cassandra Pietrus – two teens, one grandfather, one SLP, and one adult PWS who attends our local adult chapter as well. The main activity for the night was a talk show called "WALK THE TALK" in which each person took turns interviewing each other as if on a TV talk show. The interviews began with general questions to learn about the person, but also included questions about stuttering from the interviewees' perspective. Everyone participated, and this activity proved to be fun and informative.

My name is Nate. I am 9 years old and live in Mesa, AZ. In July, I attended the annual conference in Fort Worth, TX. I went because I stutter. I've known about the NSA for less than a year. I was extremely excited to attend this conference because I've never attended a conference before.

There were lots of sessions for kids. One of my favorites was the roping session. A cowboy came to teach about roping. When it was my turn to try and rope a bale of hay, I accidentally threw the rope behind me and roped the instructor.

I skipped one of the kid sessions in order to listen to David Seidler speak. I thought it was interesting that when he was small his father and uncle told him that the bombs in London were actually thunder. He said they were very bad liars because there wasn't a cloud in the sky. When he got to America, he wasn't teased about his stutter, but was teased because he was from England. That really surprised me.

Another of my favorite sessions was the juggling session. I was astounded by how well Reuben juggled. At first, I was amazed that he could juggle 5 beanbag balls, but then he started juggling bowling pins. Then, he started juggling knives. It was really cool because he did not cut himself once while juggling the knives.

Overall, I really liked the conference. I think that people who stutter should attend. I feel that it's a great opportunity for people who stutter to be around so many other people who stutter. I hope to meet you all in Tampa in 2012! ::



International Stuttering Awareness Day

October 22, 2011

How will you advertise?
How will you educate?
How will you celebrate?

Bigger in Texas - Recap, Highlights and Thank-yous!

SARAH D'AGOSTINO, NSA FAMILY PROGRAMS ADMINISTRATOR



Recap & Highlights

Over 80 families! Over 90 Teens! More than 280 in families gathered in Texas and it was bigger than ever! As families filed into the orientation on Thursday morning, I knew it was going to be great. Lives were going to be changed forever starting right then and there. From that moment on, we supported each other. The closing ceremony provided a wonderful wrap up, with the high-

light being the words of Cynthia Greaves as she was “apologizing” to her son.

Other Highlights Include:

- Oscar Award Winner and Keynote Speaker, **David Seidler**, got to see the kids in action and hear from the teens. Seeing him interact with our members with such grace, understanding and humor was priceless.
- **Teen Workshops:** Walking into Chloe and Courtney’s JAM PACKED craft session with the teenagers! The Teen Ice Breaker had over 90 teens in attendance!
- Crying **tears of joy** and past pains and hope and crying and crying.
- **Parents Meet the TAC:** Pretending over the phone to be a rude employee of “Jet’s Pizza” while the TAC made parents stutter in a call to me. (We got ’em good!)
- Watching the kids do one **fun activity** after another: cowboys, horses & roping, interviews, cooking, juggling, art, races, games!

- Presenting to parents with **Russ Hicks**. We could do it with our eyes closed and hand behind our backs (but that’d be boring).
- **Tammy!** I wondered what was wrong with Tammy. How could she be so calm and seemingly enjoying herself? She has built a strong team of people who know what to do and how to do it.
- **Teaming:** Serious balloon tower competitions and saran wrapping families together for the race on Friday night.
- **Teen Advisory Council:** Meeting with the TAC on Wednesday night when I realized they were as committed, honored, excited as they claimed to be on Skype!

THANK YOU!

The conference success was the collaboration of work by countless individuals who care about people who stutter. There are too many to thank than will fit in the pages of this newsletter, but here are just a few. First and foremost, thank you to **Nina Reeves** who is my heroine, my mentor, and the NSA’s family support on the ground in Texas. Thank you to **Sarah Onofri**, who took on a huge leadership role with the kids. We love her! All the **parents** were there to support each other, but especially **Shannon and Kevin Beaty**, and **Joan and Dave Ross**, and our “sunshine moms”; **Helene Haus**, **Joan Duffield**, **Pattie Wood**, **Julie Whittaker** and **Julie North**. And of course, thank you to Tammy and the Board of Directors for this wonderful job I am honored to hold, and a special thank you to the Family Program Co-Chairs, **Stephanie Coppen** and **Sheryl Hunter**.

CONGRATULATIONS: NSA 2011 Awards

Braden Barber - Youth of the Year

Pattie Wood - Parent of the Year





Stutter Buddy Interviews

Interviewer: Sean F. (Vancouver, WA)

Interviewed: Maggie N. (Garland TX)

Is this your first NSA Conference? Yes

Do you belong to an NSA chapter? No

What grade are you in and where do you go to school?

6th grade, Abbett Elementary School

What are your favorite activities or hobbies? Collecting bottle caps

What do you want to be when you grow up?

Police officer

Do you go to speech therapy? No

What would you like people who don't stutter to know about stuttering? Just because you stutter doesn't mean that you can't make friends.



Interviewer: Maggie N. (Garland TX)

Interviewed: Sean F. (Vancouver, WA)

Is this your first NSA Conference? No

Do you belong to an NSA chapter? No

What grade are you in and where do you go to school? 6th grade, Alki Middle School

What are your favorite activities or hobbies? Riding bikes, playing games, sketching

What do you want to be when you grow up? Engineer

Do you go to speech therapy? Yes

What would you like people who don't stutter to know about stuttering? We are normal just like everyone else!

Interviews were conducted at the NSA's Fort Worth Conference "Who's Who - Letter Writing" workshop, where kids interviewed each other and became published writers! All of the interviews written by the NSA kids will be published in Family Voices throughout the year.

The workshop was lead by Alexa Jaworski and Jennifer Delaney. Alexa is a writer and an English as a Second Language (ESL) teacher. She is also a person who stutters. She has always enjoyed writing, and has worked as a newspaper journalist in the past. She is now a marketing writer for a financial company in NYC. Jennifer Delaney is a parent of a child who stutters and a First Timer at this year's conference! ::

Skype Therapy

DAN H, PENNSYLVANIA



Hello, my name is Dan. I am 13 years old and going into the 8th grade at Holicong Middle School in Doylestown, PA. Last year when I entered middle school I finally met a therapist - Karen O'Hern - who really understood stuttering. But, after one marking period of speech class, I was disappointed to hear that she would be moving to New Hampshire. Then,

after that, she was replaced with a therapist that I felt didn't have a strong knowledge of stuttering. We later contacted Karen for advice on how to cope with this transition. She had an idea of how I could still get helpful therapy with her...by using a video chat called Skype!

Since then, I have been meeting Karen every other week on Skype to do a session of therapy. During this time we have become friends and I really look forward to our sessions together. I have a great time because we don't just sit down and practice, we have conversations that have nothing to do with stuttering. Sure we have tools to use and incorporate but she doesn't mind if once in a while I forget to use certain tools. Also, she enjoys helping so much that she agreed to give out her e-mail, Karen.ohern@me.com, and if anyone who reads this likes the idea, they can contact Karen and try to find a time to start sessions like me. Skype sure is a wonderful tool to use for speech therapy especially when you don't have an SLP close to you. ::

Ask the EXPERT

GARY J. RENTSCHLER, PH.D.

Q: I've been bringing my four year old to weekly therapy sessions for his stuttering for almost three and a half months now and I'm afraid it's not working. Adam will be good for a couple weeks, but then all of a sudden he'll have a tough week where he's really dysfluent again. I don't know if I should take him to see a different therapist or what. Shouldn't this be going away by now? Signed, A worried mom.

A: Stuttering therapy with children is usually a process and can take some time. Variability (alternating periods of fluency and then stuttering) is typical of childhood stuttering. It's often very upsetting and can feel like the stuttering is getting worse when episodes of dysfluency return. Trying to look beyond the periodic variability of stuttering, we hope for the overall frequency of dysfluencies to diminish over the course of time. We see that approximately 80% of children recover from stuttering. Of those who recover, some children continue to stutter for as long as 48 months, while for others, their stuttering only lasts six months or less. But the duration of stuttering itself is not a predictor of eventual recovery, nor is the overt severity of the stuttering symptoms.

Stuttering usually (in about 70% of cases) begins by 3½ years of age. Statistics reveal that the younger the child is at onset, the better the prognosis for recovery. We also see that girls have a better chance of overcoming from stuttering than boys. It is common for stuttering to run in families. We see that the best prognostic indicator of recovery is having a relative who has recovered from stuttering.

Therapy for young children is usually focused on making changes in the child's environment that will

facilitate fluency. Parents learn to model slow, soft speech at home and try to minimize interferences and distractions to communication. For some children, it can be helpful if a parent repeats back with the child has said to confirm that his or her message has been successfully communicated. In some families, taking turns talking can lessen the competition for attention or competition to communicate among siblings. These and other environmental modifications are usually discussed and modeled by the speech pathologist as part of the therapy.

Children who stutter may have co-existing difficulties that can contribute to their stuttering as well. A higher than average proportion of children who stutter also have problems learning to make sounds; some may be delayed in their motor skills or coordination, which may add to their speaking difficulties. These frequently become additional targets of therapy.

You should be included in your child's therapy as parents spend considerably more time with their child than the speech therapist and usually have much more influence in facilitating their child's learning. Before you make a change, talk to your current clinician about your concerns. See if you might play a bigger role working in concert with the speech pathologist to better Adam's chances of improvement. ::



Stamily: Stuttering Family

MIRANDA SMITH FLORENCE, KENTUCKY

Coming to a National Stuttering Association conference with 800 plus attendees is overwhelming and scary. It's even worse when you come alone, without a family there to support you, make sure you are comfortable and okay, go to workshops and learn about stuttering with

you, laugh with you, cry with you, take you out to dinner, or even stop by and sit in at one of the teen workshops to learn another teen's perspective of stuttering.

My family is very supportive and I'm very close with both of my parents, even though they are divorced. However, I was raised without talking about stuttering. My parents never wanted to learn more or asked how stuttering has affected me. I went to speech therapy twice a month but my parents didn't go with me. When I found the NSA and decided I wanted to go to my first conference in Cleveland, my parents did want to

go, but only because they were afraid of me going to Cleveland alone at such a young age, and not because they wanted to learn more about stuttering, attend workshops, meet people, and support me as a person who stutters. So, I didn't let them come.

Fort Worth was my second conference. I did come alone again with no blood-related family there for support, but when I walked through the doors of The Worthington Renaissance Hotel in Fort Worth, Texas around 2 PM on Wednesday I saw that my family was there waiting for me in the lobby. My stuttering family, that is, or 'stamily' as I and others like to put it.

The welcoming and inviting sensation of the people of the NSA is amazing. Being tackled by Courtney Ross, a member of the TAC, before I could hardly even get out of the van in front of the hotel and then being greeted by familiar and even unfamiliar friendly faces while walking into the conference made me feel like I was coming home after a long year. I instantly formed new friendships, reconciled old ones, and cried with excitement and joy with the ones that I had stayed in touch with over the past year.

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Finding My Voice

BY COURTNEY R., NEW JERSEY



I attended my first conference four years ago in my home state, New Jersey. Going into the NSA conference I wasn't sure what exactly to expect but what I didn't expect was to fall in love with the National Stuttering Association and to meet lifelong friends that, over the years, would turn into family.



Up until this past conference in Fort Worth, Texas I didn't use my voice. I have never spoken in front of a group larger than three people. If exactly one month ago you would have told me that I would be introducing myself and answering questions to a room full of parents, I would have called you crazy. I was petrified of getting up in front of a group and saying my name, let alone answering questions that would take more than one word answers. This past conference was my first year on the Teen Advisory Council and I knew speaking was involved. I also knew that if I didn't feel comfortable, Sarah D'Agostino would never make me speak, and she didn't. Over the next few days she never pressured me, only encouraged me to speak up, and whether she knows it or not she actually gave me strength to overcome my fear of public speaking.

There were others who helped me overcome my fear of public speaking as well; the TAC, all my friends at the conference, my parents, and my sister. This year there were two people in specific that I've met thanks to the conference and who have really helped me, Chloe and Miranda. These girls have become my sisters in such a short amount of time and stood by me, whether it was before I was about to speak and going through a panic attack, literally sick, or when I was done speaking and I felt like a new person. These girls were there holding my hand through it all, and any time I had any doubt in myself they would be right there to make me feel okay again. Miranda and Chloe helped me find my words and my voice. I wouldn't have been strong enough to overcome my fear without the help from these two girls. Even though we live miles and miles away from each other, nothing will ever change the fact that these girls understand me best and will stand by me every step of the way with the rest of my journey with stuttering.

For me, stuttering is a struggle every day but just like anything else in life, having support and family who stand by you always makes it easier. Everyone who is a part of the National Stuttering Association is my family, and you all make my struggle easier. ::

Parent's Perspective *continued*

the conference, there were sessions set up for the kids ages 7–12, as well as teens. Nate got to meet a cowboy and his horse, practice his roping skills, learn how to juggle, and tons more! While he was in these sessions, I was able to choose from sessions geared specifically to parents, or I could attend sessions geared towards adults who stutter or sessions presented by researchers and those who work with people who stutter. I was a bit overwhelmed by all the choices, but I was grateful that there were so many!

It was interesting to be in groups of parents whose children stutter (and also may stutter themselves), but the research-lover in me also loved being able to learn about the research being done in the stuttering community. As an added bonus, we also had the amazing opportunity to listen to David Seidler (Oscar-winning screenwriter of *The King's Speech*) and were even able to get his autograph.

Nate and I arrived in Texas a day and a half before registration and had the chance to wander around Fort Worth and enjoy the sights. While the conference was wonderful and I hope we can attend as an entire family next year in Tampa – I think my favorite part was spending 6 days with Nate one-on-one. We ate out, talked a TON, enjoyed exploring the streets around the hotel, and watching shows about guns, cars, and insects (just like books - he prefers his television to be non-fiction.) It was an extremely special experience to spend all that time with just one of my children and get to know him a little better than before. Before leaving for Texas, Nate knew he wanted a pair of cowboy boots and a cowboy hat. On our first day there, he found both and was thrilled. He's trying to put on his tough cowboy face (photo on page 3), but trust me when I tell you his face was more often broken into a wide grin during our visit.

A couple people recognized Nate from his YouTube videos, and while he tried to act humble, I know it thrilled him. When we talked about the conference afterwards, he did say to me "I didn't really learn anything about stuttering – but it was cool to meet so many people who stutter!" I think that's what the conference is all about. The chance to be in a room filled with others that are like you in a pretty significant way. The NSA conference made that happen, and they did it wonderfully. ::

Stuttering: It's Not ALL of Me

MATTHEW C., GEORGIA



I remember the day when my mom was helping me with a language arts assignment. All of a sudden, I just couldn't hold it in any longer and blurted out that I no longer wanted to participate in any more sports or activities. That meant no more baseball, basketball, football, chess, taekwondo, or anything where I'd have to talk to others outside of my family. I decided that I only wanted to stay home and work on school assignments.

Obviously, that caught my mom's attention because she knew how much I loved doing all of my activities, and besides, what kid only wants to stay home and do schoolwork? She wanted to know the reason why, but it took me a little while to open up to her even though she should understand, as she also stutters. I wasn't sure whether I should say anything else about it because it made me really sad to talk about it, but finally I admitted that I was sick and tired of being teased because of my stuttering. I hated it when my friends, teammates, and others would mimic me and ask things like, "W-w-w-hy do you t-t-talk like that?"

I didn't know what to say when they asked me such questions because I didn't know myself why I talked like that. All I knew was that I felt very stupid and like an idiot when I stuttered. I mean, why couldn't I just talk like a normal kid? Why was it so hard for me to speak like everyone else? But above all, I wondered, what's wrong with me? I just wished that I could say what I wanted to say, when I wanted to say it. Why wouldn't the words or sounds come out like they were supposed to? I felt so trapped – like I was a prisoner in my own body – and I didn't know what to do.

Since it seemed like I wasn't outgrowing the normal speech dysfluencies that affect many children, my amazing teacher, Mrs. Kacmar, gently suggested to my mom that I begin speech therapy. My mom was so happy to hear this as she, too, was thinking it was time to do something about my speech as it sounded like my stuttering was increasing instead of decreasing like she had hoped.

Sometime after that, I began speech therapy with a wonderful woman named Mrs. Rowley. In addition to helping me learn different strategies to help with my stuttering, such as turtle-talk, easy onset, stretching, and prolongation, she has helped me to understand that my speech bumps are just a little part of me and not ALL of me. She has helped me to come up with creative ways to respond to others when they ask questions about my stuttering and even how to act when I am teased.

Even though my stuttering still bothers me from time to time, I have learned to accept it as a unique aspect of who I am. The biggest problem I have with stuttering is the frustration I feel when I want to say something and can't say it as fast or as clearly as I'd like to. Despite my speech struggles, I feel so blessed to have an amazing life filled with family, friends, and fun. Stuttering is definitely a piece of my life, but like the other pieces, it's just that – a piece! ::

Stamily *continued*

Friendships, however, are not all that I gained from this year's conference. I got a family. People who not only did everything that I wanted my own family to do, but who became a huge part of my life. Tom Scharstein proudly boasted to everybody he met that I was his daughter. Alex Rosenbaum stayed by my side almost every minute of the conference. His dad bought me lunch one day. Other people's parents that hardly even knew me told me I would make a great mother one day. People who I have known only a year told me they were proud of me.

One person and one family, however, made a huge impact on my life and on my conference experience this year: Dave Ross and his family. Dave was everywhere I looked; he was helping out with the First Timers' lunch, greeting new people, watching the keynote speakers, asking if anybody needed help, stopping in at several teen workshops to see what was going on, and just volunteering his own time to the NSA. He was there at almost every workshop telling me he was proud of me and that he loved me. Although Dave's hugs, "I love you's", and welcoming words made me feel like I was another daughter to him made me cry every time I saw him, he'll never really know how much all of that meant to me and how much better I felt knowing that I did have a real family supporting me at the conference, the Ross family. ::