

# Orchid Press

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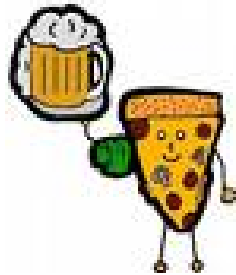
## My Kind of Town, Chicago is!

The 2008 annual meeting of the Androgen Insensitivity Syndrome Support Group-USA will be held on **July 25<sup>th</sup> - 27<sup>th</sup>**, in **Chicago**. We had been working on Las Vegas. However, as many of you know, our dear friend and potential hostess, **Cherie Thorpe**, fell ill. While Cherie is getting back to full strength, Las Vegas has been put on hold until perhaps another year.

This year's conference will be held at the **Four Points Sheraton O'Hare**, 10249 W Irving Park Rd., Schiller Park, IL 60176. The cost will be \$99 per room per night. **Call in-house reservations at 847-671-6000**. State that you are with the **Women's Support Group**. The hotel offers free parking and free transportation to and from O'Hare Airport.



There is a lot of interest in this year's meeting, and it looks like it will be very well attended. In addition to lots of time for sharing and getting to know each other, a program featuring wonderful doctors and speakers will round out the weekend. The conference offers a chance for your questions to be answered and discussed by experienced and knowledgeable professionals. Don't miss this chance to develop lifelong friendships with other women and families with similar interests and concerns. We hope to see you there!



## Keepsakes & Tchotchkes for a Good Cause

Every year, the conference hosts a silent auction to help raise money for our scholarship program. The scholarship program offers a chance for individuals and families to attend the annual conference that might not otherwise be able to afford to attend. Some of the big hit items in the past have been handmade pottery, a handmade quilt, artwork,



jewelry, orchid-theme items, and much more. Please bring your silent auction item with you to the conference. Your item can be submitted to the auction at the conference registration table.

- Tryla Brown

## Returning to the Annual Meeting

When I received the meeting info in the mail last year, I had serious doubts I'd be able to attend. Summer is quite busy (I know everyone can relate), and weekends were booked tighter than a Denver airport hotel in a blizzard. But, having missed the past two meetings, I knew I had to clear the calendar and head to North Carolina.



Nothing beats the face-to-face contact of an annual meeting. It's a huge benefit to be part of the email circle, getting to know orchid sisters and sharing life's experiences. However, there's a special spark to attending a meeting.

Catching up with old friends and meeting new members is like a homecoming. There never seems to be enough time to catch up with everyone, but the opportunity to be immersed in a weekend of informational sessions, social hours and dinners is invaluable. Plus, the southern charm from our beautiful Orchid Sister Nancy made everyone feel at home. When you receive your info packet in the mail for Chicago, be sure you clear your calendar and book those tickets. Make it a special summer holiday ... Orchid Day! And, don't forget to inquire about scholarships. The organizers can help get you there!



- Joyce Henning

## Parents' Feedback on Raleigh Meeting

For the second year in a row, there were special breakout sessions for teens and young adults at the meeting. The girls had their own private hospitality room and a late breakfast every day. They met with Charmian Quigley, our very special endocrinologist, and with Stephanie Sanders, a sexuality expert returning to us by popular demand, and they got to ask questions and share experiences with their peers.



Several girls who attended in 2006 returned for a second meeting. They worked together to set up a safe and private chat area on Facebook (for more information on the private chat area, email [katieDOTbaratzATgmailDOTcom](mailto:katieDOTbaratzATgmailDOTcom)). They loved their Saturday night sleepover. Our young orchids are bonding and blossoming beautifully!

There was a special Ask the Doctor session for parents to discuss parenting issues unique to children who have AIS and related conditions. Special sharing sessions for parents were a big success.



A Moms & Daughters event, initiated by adult women, provoked tears and laughter on both sides as mothers and daughters grew in understanding each other. We now have a cohort of Fighting Grannies ready to shake up the boomer generation - watch out!

All parents are encouraged to join the parents' email circle to share experiences and advice. Contact either Arlene Baratz at [abbaratzATgmailDOTcom](mailto:abbaratzATgmailDOTcom) or Coleen Bohlen at [cbohlenATshawDOTca](mailto:cbohlenATshawDOTca)

- Arlene Baratz

## The Oprah Experience

Forget my first kiss, my college grad, and my acceptance letters to medical school. I can (roughly) pinpoint my most exciting moment to 4:03 PM, EST, on Friday, September 21, 2007, the moment my mother and I appeared before millions of viewers on the Oprah Winfrey Show.



Everything up until that point was a blur: the pre-show interviews, filming the lead-in montage in my West Philly apartment, getting picked up at the airport in a stretch limo, making a mess in the dressing room (only to be told I was no worse than Paris Hilton had been), even sitting with Oprah on the soundstage and answering her

questions. It wasn't until I was sitting in a living room with 20 newly-minted med school friends watching myself on TV that the enormity of my choice sank in, that the girl standing before America and declaring that she had a Y chromosome and undescended testes was me.

Only part of the exhilaration of those 10 minutes of air time comes from the personal pride I felt in going so public. I'd told people before--friends, family, even rooms full of strangers at Planned Parenthoods and local

colleges--but this was different. Now everyone knew: my boyfriend's grandparents, my teachers, even the lady who developed my Christmas photos. It took more strength, courage, and self-confidence than I could, or can, actually claim as my own. This, then, is why the flood of complimentary emails, phone calls, and cards I received after the airing seemed so, well, and odd.

My appearance was not a testament to my ability to cope with my diagnosis, but rather the love, support, and encouragement I felt every time I disclosed to a new friend, voiced insecurities to an old friend, or shared more of my story with my boyfriend. Most importantly, as I know you saw in the eyes of my beautiful mom, there is no way I would have been able to do what I did without having been raised by amazing parents who never gave me any indication that I should feel embarrassed or ashamed about who I am.

So what was it about that show that made me feel so proud? **You**. By 4:10 on that Friday,



*Our gal Katie signs her upbeat emails with love and "jazz hands"*

emails and phone calls from many of you began pouring out of the woodwork. You told me stories that brought me to tears. Some of you had just told childhood friends about your AIS. Some of you bonded over the show with your children, partners, and parents. Some of you felt inspired to rejoin the

email circle. Some of you used the show to talk about your bodies at yoga and church retreats with women you'd never met before. Some of you felt like you could use the word "testes" for the first time.

Both the parents' and the adult email circles heard from brand-new members who finally found the group and all the love and support that it shares. To know that I was a small part of that blossoming of our tiny but tight-knit community was the most wonderful experience I've ever had. That feeling alone is worth more than anything else I got out of going on Oprah. Except maybe the chance to high-five Oprah because I do, indeed, have a vajayjay.

- Katie Baratz

## PAIS Roundtable in Raleigh

At the 2006 Annual Meeting in Bloomington, I found myself in PAIS session filled mostly with confused and frightened parents grappling with the questions of how to best provide the right care for their newborns and

young children manifesting intersex/DSD characteristics that were not easily identifiable with clear answers for medical intervention.

As one of only two or three (we think) affected adults in that session, we commented that it was not the kind of experience that we were hoping for where we could share our stories with others that would easily relate to and understand what we had been through. This idea was the conceptual seed for the PAIS session that we hoped would take place the following year in Raleigh and would be hosted by none other than Nancy Evans, whom I sat next to in the Bloomington session.

Well, with a modest but mighty turnout of four of us in attendance in Raleigh, we handily managed to double the number of those who participated as affected adults from the prior year in Bloomington! That's progress for you! We not only managed to double the roster of attendees,



but having turned what was originally intended as a one hour session easily into two and almost a third, we easily managed to double the time spent in this session as that is what organically unfolded as what the dynamic called

for. Regretfully, we had to part with one of our attendee's, Nancy, who had to return to carry on with her duties of running the meeting at the next agenda timetable came up. We sure missed her in that second hour as we continued to break down personal barriers and defenses allowing for deeper sharing of personal accounts of our own struggles and successes in navigating the unique circumstances of living with the partial (or related conditions) of AIS. While we all agree with the common bond and similarities we share with our other AIS sisters in the majority, we recognize the dimensions that are not universally shared with the others that warrants the distinction and the need for those affected to be given the opportunity to come together and learn more about each other in hopes of seeing ourselves reflected and accepted.

It was a small and intimate group and yet a very profound experience in personal growth. Those of us in attendance would probably agree that it was the very modesty of our group size that allowed for the level of intimacy that created a safe environment of trust, support, and

understanding that paved the way for the transforming effects of disclosure to take place. It was an amazing two hours to say the very least.

I am so thankful to Nancy for pressing for this session to be scheduled with a time slot in the agenda and to the AISSG-USA Board for approving it and responding to her plea. Lives were changed in these two hours and that I am certain of.

I hope that everyone that has or will attend an annual meeting has the opportunity to experience the connection and personal growth that the four of us were fortunate enough to have shared with each other.

With "PAISano" love to all of my AIS/intersex/DSD & related conditions Orchid Sisters out there.

- Cynthia Johnson

## Sisters Experience Sweet Tea & Grits

Arizona sisters, Diana Esparza and Carolina Johnson, attended the 2007 annual conference and will never forget their experience. Diana admitted that they are very close as sisters and best friends but were not in the habit of talking with each other about their very distinct experiences regarding their gonadectomy surgeries and dealing with their subsequent internal feelings. Attending the conference opened up the lines of private communication between the sisters and Diana learned so much about Carolina's experience never previously discussed. Diana discovered that Carolina's overall medical experience was more traumatic than her own and regrets not being more protective of her sister back then.

Diana is one year older than Carolina and she was the first of the sisters, at 17, to deal with doctors and genetic counselors and learn that she had a "syndrome." The sisters would not find out the name of their syndrome until later in their mid-30s because talking about their experiences (at 17 and 18 years) was not encouraged in their Mexican-American household. Years later, now with their own respective households, the sisters felt more comfortable in opening up with each other in discussing AIS. When talk about the Raleigh Conference was brought up, they both agreed to attend and became excited about the



prospect of learning all they could and coming in contact with other adult AIS/DSD women.

Carolina felt a great sense of empowerment and excitement at attending the yearly conference, so much so, that just days before leaving for Raleigh she disclosed for the first time to her sister-in-law about having CAIS. Her sister-in-law, a nurse, was very encouraging, compassionate and understanding. Because of that disclosure, Carolina's sister-in-law knows that she can count on Carolina and Diana to provide outreach and to assist in educating their medical



community or with providing referrals in the event of encountering AIS/DSD adult patients or parents of AIS/DSD children in Arizona.

Diana and Carolina returned home to Arizona with so much information, lasting friendships and encourage other AIS/DSD sisters to attend. Diana says, "You won't regret it!"

## Welcome AISSG-USA Directors & Officers

Please join me in welcoming the superlative 2008/2009 AISSG-USA Directors and Officers!



**Marissa Jaye** will be taking over as president, a big job to be certain, but I have no doubt that she will do it incredibly well. I am always so happy to see an email from our amazing Marissa. I know it is full of heart, love and conviction.

**Tryla Brown** will be serving as Secretary. I am always amazed at Tryla's drive and determination. She is a force, all 5 foot 2 of her! I am so happy to see her continue serving AISSG as she has done for so many years.

**Aimee Owens** will be joining the Board; a beautiful and happy thing is always said by Aimee. She is a wonder and a joy.

**Cynthia Johnson** will also be on the Board; a vivacious, vigorous and verbose welcome to one of my favorite ladies.

And **Carolina Johnson** rounds out our new members. Carolina warmed my heart the first time I saw her face. I am so excited to see her jumping in with both feet.

Fabulous and funny, **Susie Denard** returns as Treasurer. Amazing and artistic, **Diana Esparza**; the incredibly dynamic, **Jeanne Nollman**, and the multi-tasking/multi-talented, **Arlene Baratz**, return to complete the second year of their term as Directors.



Leaving the board are Nancy Evans, our amazing and wonderful North Carolina conference planner, board member and newsletter maven. She is always a source of strength and a light to the group. Cherie Thorpe, I can almost guarantee, will be right back to work as soon as she is fully recovered. Nobody can keep that amazing woman down.

I'd like to take this opportunity to also give a shout out to the following wonderful gals who continue to serve our community:

The hilarious and wise Cindy Stone is our Webmaster. Never shrinking from a new task or new contact, Joyce Henning is our Adult Email Circle Administrator and frequent Hotmail account maven. The dramatically diligent Kathryn Gallagher is always willing to lend a hand at the Hotmail account. The marvelous and musical Eden Atwood is our Parent/Adult Circle Liaison.

I will be retiring my spot as President. I have loved every minute of the work, and I am so excited to see Marissa take over. Love to all,

- **Rebecca Baughman Kerns**

## Raleigh Sweet Tea & Grits Recap

Our 2007 annual conference started out with a great need for sweet tea and other cold drinks as the temps were in the 90s. Orchids had starting flying into RDU Int'l Airport on Tuesday, with the majority coming in Thursday night. Other orchids motored in from New York, Indiana and parts in between. We numbered around 75 adults and teens with AIS and related conditions, husbands and partners, mothers and fathers, and teenagers at the Holiday Inn/Brownstone, Raleigh, NC.

Also on hand were our wonderfully dedicated doctors: Dr. Charmian Quigley (Dr. Q), Dr. Brinda Kalro – her first meeting, Stephanie Sanders, Ph.D. and Dr. Sue Stred. Dr. Arlene Baratz did triple duty as mother, leader and physician. Oh, yes ... spouse of Dr. Mark Baratz, too. Dr. Mark did a great job making husbands and dads feel comfortable and included.

For those who arrived early, Thursday night supper at a local burger & brew place was within walking distance. As it turned out, our hotel shuttle graciously took many of us there (owing to the high temps).

For All  
Your  
Hard Work!



A big thank you goes to all the board members who worked very hard in getting speakers, organizing workshops, and helping with the many details of such a conference. We salute Rebecca Baughman Kerns (president), Cher Thorpe (secretary), Susan Denard (treasurer), and directors Arlene Baratz, Tryla Brown, Diana Esparza, Nancy Evans, Marissa Jaye, and Jeanne Nollman.

**Friday, July 20, 2007**



Our morning session started off with some lively get-awake-and-moving activities with Jeanne Nollman and Marissa Jaye. Excellent and informative talks by Dr. Q on AIS & related conditions, Dr. Kalro on gynecology, and a

crowd favorite, Sexuality by Stephanie Sanders. We had a bit of free time for Q&A then had lunch.

The afternoon session was broken into groups: Rebecca Dnistran, MA, held a workshop on SEX 101, Drs. Baratz & Quigley led a Parents' Social, and Stephanie Sanders and Dr. Kalro met with the teens in their own space to share their own questions and concerns. The teens had their own area the whole weekend and shared meals and free time there.

Dinner was open – many walked down to Irregardless (Raleigh's first vegetarian restaurant), others went to Cameron Village and



some ventured around the city. The teens met in the hotel's restaurant for pizza and conversation with folks who were leading the Carolina Shag Dance later on for everyone in

the fellowship hall of Pullen Memorial Baptist Church. I think a few really got into it and would make a great Carolina Gal! Our Hospitality Suite was open each night and people gathered to meet old friends and make new ones.

**Saturday, July 21, 2007**

After a great breakfast, which included hot grits, Jeanne and Marissa got us going again with some get-awake-and-moving exercises. Then the adult women with AIS & related conditions, parents and teens went their own ways to share and hear others tell their stories. Sharing time has to be the best and hardest part of the weekend. You find out how most everyone has gone thru many of the same sort of childhood to adulthood experiences.



While we were sharing, Dr. Arlene Baratz hosted the parents' group, where similar stories

were explored and appreciated. So many things are learned at these sessions – particularly that you are not alone!

The teens were on their own – perhaps to the pool, checking out a movie in their room, or like most of us, just hanging out sharing their own discoveries. Our new prez, Marissa Jaye and Katie Baratz facilitated this group.

A light lunch of soup and salad preceded a marathon of mini-talks on topics such as Your



Authentic Self by Suzanne Luper; Domestic Adoptions by Rebecca Baughman Kerns; DSD 101 lead by Cheryl Chase; Disclosure was lead by Jane Goto and

Jeanne Nollman. Room 802 was the site for PAIS 101 lead by our Orchid Lady, Cynthia Johnson. A BIG THANK YOU goes to her for supplying our conference with more orchids than I have ever seen. We donated many of them after our conference to the hotel, who very much appreciated it. They had jumped in at the last moment to supply flower vases.

More discussions took place with all the doctors (Baratz, Quigley, Stred and Kalro) and our good friend Cheryl Chase. They worked with parents in Exploring AIS for Parents.

The final hour consisted of Journaling from the Inside Out lead by local Raleigh author, Alice Osborn, to Dilation – Traditional and Novel Approaches led by various doctors, and the final session was two groups: Moms & Daughters Together led by Dr. Arlene Baratz, Jeanne Nollman and Susie Denard, and Dr. Mark Baratz had some Guy Time for the men.

To round out the afternoon before dinner, we were treated to a special viewing of One in 2000, a documentary film by Ajae Clearway.

All in all we had a very busy Saturday. After a break, we gathered once again for a traditional North Carolina Down East Buffet where we sampled pork barbeque, steaks, corn on the cob and all the usual trimmings for a pig picking.

After gathering back in our main meeting space, our silent auction coordinators, Cindy Stone and Cynthia Johnson reported on the auction results. At one point, a real-life auction took place with people shouting out bids. Our own Dr. Q was quite the bidder



and won a beautiful orchid shawl. Thanks to everyone in bidding on items donated. We raised approximately \$1,500 for the Scholarship Fund. Our evening program was the now famous **Talent Show**, headed by the Baratz theatrical and musical team of Mark and Katie. Many people joined in with songs and Ms. Cynthia wowed the crowd with her own rendition of a popular song (which we dare not print), to the shocked amusement of all.



**Sunday, July 22, 2007**

The sun came up too early for most of us (particularly those who went dancing!), but we all met for a big breakfast for the road home.

Activities scheduled were Making Your Own Journal by local artist, Laura Drewry, to a last chance for a tarot reading by Betty Whyte, mom to Jane Goto. A very traditional southern activity ended our morning session with designing your own quilt square for our 1<sup>st</sup> AISSG-USA quilt. Cherie Thorpe explained how this was to work, and some 75 squares were completed. We hope to have this quilt with us at a future national meeting.



As people took those last pictures, exchanging emails and phone numbers and organizing rides to the airport, 2007 Sweet Tea & Grits came to a close in the state capital of North Carolina, Raleigh.



Some gals went on to Shell Island Beach Resort at Wrightsville Beach for several days of sun, sand, and seafood.

The ocean was just outstanding and many of us just sat like lumps in our chairs or blankets. Each evening we explored a new seafood restaurant in or around Wrightsville Beach and Wilmington, NC.

As coordinator of this event, one of my goals was for you to find out about North Carolina and all that she has to offer. I believe I accomplished that goal. I know that I thoroughly enjoyed every minute.



I strongly urge you to attend our 2008 Conference in Chicago, where many activities are being planned for everyone – an affected adult, a parent, grandparent (Our Fighting Grannies) and our great teenagers, who grow more confident and beautiful each year! Thanks, you 'all.

- **Nancy Kay Evans**



Lately it seems that our money is flying away @ \$4.00+/gal for gas, \$15 for that 1<sup>st</sup> suitcase (not additional ones) when we fly on some airlines, and don't even get me

started on groceries – even at Wal-Mart! So, if you feel you need a little help to attend the 2008 Conference in Chicago, please let us. We have scholarships for plane, hotel, and food needs. Just email Susie Denard, our treasurer, at [caisusieATAOLDOTCOM](mailto:caisusieATAOLDOTCOM) and she'll walk you thru the process. Please join us – it will change your life!

Donations are greatly appreciated – do you have any extra "Prez George money" you would like to donate? All are tax-deductible. Again, check with our wonderful treasurer, Susie Denard at [caisusieATAOLDOTCOM](mailto:caisusieATAOLDOTCOM). She will gladly take your money!



- **Nancy Evans**

*We are a self-help group providing information, contact and support for women, teens and families affected by AIS and similar conditions*

**AISSG-USA GOALS**

- Reduce secrecy, stigma, and taboo surrounding AIS and other DSDs/intersex conditions, by encouraging doctors, parents and society to be more open
- Promote psychological support for young people and their parents
- Bring parents and women with AIS and other DSDs/intersex conditions together
- Increase access to information on AIS and other DSDs/intersex conditions

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