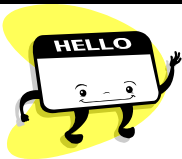


Orchid Press

AISSG-USA Orchid Newsletter
October 2008,
Volume 5, No. 2.

- *This issue includes poetry, a letter of thanksgiving from a parent, ‘first-timer’ recollections, and many more stories of courage and love.*
- *Look for another Newsletter in December with important information on new board elections, 2009 conference, and much, much more, including a father’s first time to our conference.*



The **2008 AISSG-USA Annual Conference** was held in the City of Chicago during the month of July at the Four Points Sheraton. There were affected adults, teens, parents, family members, friends, and medical professionals present. Everyone was well represented and had a wonderful time. There were several first time attendees present as well. We all had lots of questions and hopefully we all found the answers we were looking for. For me, the annual conference is like a reunion of friends and family.

*When I was lost, you found me
When I was sad, you drew me near
When I was confused, you cleared the rain
When I was mad, you stood by me
When I was alone, you loved me*

*When you are lost, let me lead you
When you are sad, let me hold you near
When you are confused, let me clear the fog
When you are mad, I will lend you an ear
You will never be alone because I will always be there for you.
You are my friends. You are my family. You are my forever. You are me.*

➔ Tryla Brown, Conference ‘08 Coordinator

Five Words that Changed My Life...



Enlightening, Encouraging, Engaging, Empowering ...but most importantly, Embracing 46 XY would be the five words that I find to be most definitive about my very first International AISSG Conference.

Within one week of being introduced to sweet Jeanne Nollman by email, I was excitedly in route to meet her in person in Chicago as well to meet others like myself for the very first time. We had no spare money for me to go (especially at the last minute), but all I knew was that I had to go, and my husband really wanted me to! This was one of those “all hell couldn’t hold me back” moments!!

Suffering a lifetime of trying to understand the frustrating dynamics of my own body, I was now on the yellow brick road to self discovery.

Like the zany trio characters of the Wizard of Oz I was no longer satisfied with the imprisonment of my shame. I was now pressing into the hope of getting a new heart, a new brain...to get courage! I wanted to “come home” to that which I belonged. I didn’t know why my ruby red slippers captivated the interests of so many...in the end, the wicked witch of medical professionals weren’t so wicked after all, even all her imps of shame who were trying to keep me from my destiny didn’t prevail in the end. Little did I know I was about to embark on the most *exciting* journey of learning my new identity as an “*Intersexual*.” With a capital “I”. Though I held the truth in my medical records, all along I lacked understanding of my diagnoses. So for years I was held in captivity from a *lack of knowledge*. [I have always said, “A lack of knowledge is a dangerous thing.” How true that statement!]

As it turned out The great Wizard of Oz was not the all knowing, all wise, untouchable, unseen entity....of my diagnosis. I was not defined by my condition, but rather by the love of a tribe I belonged to. A tribe of compassionate people with real bodies, real personalities like my own, also seeking answers.

Walking into the lounge of the hotel was unnerving. It was as though I was to meet my birthmother for the very first time!! Would they like me? Want me?? I was honestly curious what others *like me* looked like. Each part making a whole, my new Orchid Sisters hugged and celebrated me with such love. Our affections were immediate, linked together by fate. Each brought a legacy of their own to share with me; a desire for normal. To hear someone else tell my story through their own tears was an interesting moment I cannot fully express. Having walked that

long mile of heartache all alone had been difficult enough by myself...but to hear each woman's story so much like my mine, made me aware of the *spirit of shame* each of us has lived painfully and many times in great secret with the fear of rejection.

Each had been robbed of self worth, many feeling insecure by the standards of the outside world, having believed vile lies whispered in our ears, with some belief that we are less than human, as though a freak of nature. It's like looking into a mirror seeing oneself through the eyes of an anorexic; unable to see the truth. What I learned for myself was that each one's story of discovery of being an original design was something to be celebrated. Because that's exactly what we did; we celebrated the worth of each woman, beholding their beauty, their value to the rest of us, celebrating their strength, their talents, their dreams. We became each other's cheerleader! It's interesting how down on ourselves we can be, isolating from the world, or even angry to have this 46 XY consequence to contend with.... Yet coming together, was like a family reunion. Being a newbie at my first conference, there was no measure of qualification. I was hugged, loved on, encouraged, listened to, and most importantly strengthened by my new tribe. We celebrated each one's worth to "our family" as a tribe.

Despite the hand we were dealt at birth, as human beings we were not intended to live above or beneath the suffering of so many others in the world. Being a curiosity should not be confused as being untouchable.

The fact is we are all are curious of what seems peculiar!! The most captivating *thought* came to me as I heard the stories of my celebrated 46 XY chromosome sisters in the share time of Saturday morning...

"That I will no longer live my life under a shadow of shame. I am not defined by a syndrome or a diagnosis. I was born to live life large and beautiful, to impact an imperfect world just being myself".

For years I felt I was crawling one leg at a time in the smallness of my limitations. But I made a personal decision at this conference that *this caterpillar may have traveled long and even hard but, from here on out, I was meant to fly in all my array of colors and to soar high.* I came to the conference as a big fat juicy caterpillar, but in four days I changed into the butterfly I was intended to become. I already knew who I was as a person, as a spiritual being...but I needed confirmation of knowing *who I was as a woman...*to understand the needs of my body, to be healthy and to live life with wisdom. To know that Yes, indeed I am a sexual person, who has nothing in the least to be ashamed of. These beautiful

brehtaking intelligent, ambitious, powerful women possessed a 'property stake' of their own: *to love and be loved.* Each having contractual rights to love their bodies fully with territorial domain: born to be celebrated as *created breathing beings* full of life; to live life in the complete fullness of their purposes with no prejudice. To be happy people.

As I was driving home, I realized that the one thing I had always desperately wanted to possess was *the very thing I already had all along.* I arrived to the conference as a woman, and I "came home" a much better woman!! "Dorothy was no longer lost in a strange, foreign land!!" I no longer felt like an alien.

I can now pronounce Swyers properly, and I'm a proud new member of the "Snappin' Swyers Sisters!!" Being intersexed now means something different to me as my fears of being half man/half woman have been extinguished. I'm so thankful for the conference speakers that brought light into the shadows of darkness. For the first time I was able to totally *embrace* myself as a woman, and gaining much knowledge to help my caregivers better understand my medical needs that have been so misunderstood for so many years.

Since the conference, I am now a *Woman with a Mission ...to live Life Large!* Having the instant bond of affection, admiration and adoration of many other women like me, *of all ages,* is life-changing. (It's right up there with marrying the love of my life, and even becoming a mommy after years of prayer!!)

Coming into this Circle of Orchid Sisters has been a beautiful ceremony of connecting hearts with compassion, encouragement and unconditional love for one another.

From tears to laughter we celebrated each other as unique, feminine, as an once-in-a-lifetime creation. Looking into the faces and hearts of each one there has me home sick for next year's conference. When I think of the beautiful women in this group, I feel the heart of Jesus, going out searching for the one who is lost and dying in a hurting world. To bring healing and refreshment to those who need a haven of refuge.

"Click your heels, Dorothy and say 'there's no place like home'."

We are in the company of Sisters; I just love my new friends!!

Ann of Michigan



Catching up with the ‘Prez’....

It has been almost three months since we gathered in Chicago. I feel nostalgic just thinking back on our weekend together. I realize that it passes so quickly and that we all crave more. The newsletter is one of many resources that we have available to help us keep in contact. Thank you to Nancy and to all who have contributed.

Any one of us who has attended one of our annual conferences realizes that it takes a tribe to create a meeting. I want to give a special thanks to Tryla who truly went above and beyond to make this year’s conference a success. I also want to thank our exiting board and current board for the many hours dedicated to our gathering. I think you will all agree that our meetings are priceless and it is because of these women that things went off as well as they did. My deep gratitude goes out to each of you.

I think we all can agree that the biggest impact of the weekend was our time to share our stories. One of the biggest pieces of feedback that I wanted to share from the weekend was from one of our parents. This parent thought it would be a great idea that we have an opportunity to hear sharing from an affected adult, an affected teen, and a parent on the impact of AIS and other related conditions on all of our lives. This is an experience that we have not had at a conference to date. I thought this was a great idea and I look forward to it next year.

In closing, I want to share that although the miles may keep us apart, each of you holds a special place in my heart and each others. I always look forward to our email contact, a phone call, a newsletter, etc. We will be organizing regional meetings in late winter/early spring and it looks like our annual meeting for 2009 will be held in Texas. I hope this newsletter finds you well and look for another edition in December.

Cheers, Marissa Jaye
President, Board of Directors, AISSG-USA

Our Teens & Young Adults



This year was, for many reasons, a very special conference. But perhaps one of the most exciting parts of the experience was the expanded Teen and Young Adult Orchids program. This year, we had 10 teens and young adults, ranging in age from 12 to 23. We all had a blast this year—we went to the movies (although we were split between “Mama Mia!” and “Batman”), had impromptu pool and dance parties, and stayed up late laughing and eating way too much junk food. And we pretty much carried the talent show.

We also learned a lot about ourselves and each other through some of the special, Teens-Only programming we had. Dr. Nadine Haddad, an endocrinologist out of Bloomington, hosted a Q&A session about AIS where we could ask any questions we wanted in a small, private setting. The teen coordinators, Katie, Miriam, and board member Aimee, also hosted an “Our Stories” session, where we grew even closer through our special bond.

All in all, it was a truly amazing experience. We laughed, we cried, and we made (and strengthened) life-long friendships. Even though we’ve scattered back to our homes and schools in Chicago, Boston, New York, California, Pennsylvania, and Spain, we’ve stayed connected to each other through a private group on Facebook, where we continue to share thoughts, concerns and questions. I know I speak for all of us when I say that we are truly blessed to have found such beautiful young sisters at this meeting, and I know we’re all looking forward to being reunited next year.

--Katie Baratz, Teen and
Young Adult Coordinator

(For more information about the teen program or our facebook group, please contact Katie at katie DOT baratz AT gmail DOT com)



Parents’ Corner

Travelling from places as far away as British Columbia, an unprecedented 34 parents of children affected by DSDs attended the 2008 AISSG meeting. Our children range in age from infancy to adulthood. While story-telling was deeply emotional, it provided an unprecedented opportunity to share successful strategies for issues ranging from disclosure to dating to dealing with physicians. The expertise of Anne Tamar-Mattis, director of Advocates for

Informed Choice (www.aiclegal.org), enriched our discussions about informed consent and shared medical decision-making. Pediatric urologist Dr. Martin Kaefer gave a talk and answered endless questions afterward, nearly missing his return flight to Indianapolis.

In 2008, we renamed ourselves the "AIS/DSD Parents' Support Group." Parents of boys and girls affected by any DSD are welcome to join us. For more information, please send inquiries to:

AIS-DSDParents@yahoo.com

Arlene Baratz, MD

A Parent's Letter of Thanksgiving.



My husband, my daughter, and I wish to thank everyone for the warm welcome that we have received into the group. When we first took our daughter to the

doctor in February, we had no clue that what lay ahead for us with the many, many, and many more doctor visits. All we knew was that she was living a normal teen life at home, at school and at church. But we then found out from a simple blood test that she was an XY female. Now, to my horror, I did not have any idea as to what that meant at all. All I knew was that I heard the doctor say she wasn't going to be able to have children biologically. My heart was shattered into a million pieces. We had spent 15 and a half years believing, dreaming, wishing and counting on the fact that our daughter was just like everybody else!

So everything that we were going through at the time, my beautiful and caring sister went online to Google~!!!! For which I have to say is the Google queen!! Anyway, she found this amazing group of people that were just like my girl. She knew I was feeling all alone and had no one to talk to about any of these medical problems, for which I knew nothing about. I then spoke with someone on the phone and wham; I am online with other mothers of these beautiful girls.

I have to say that I truly thank Doc Quigley and Arlene for being the best listeners in the world while I was having my nervous breakdown!! If not for them, taking my million phone calls at all hours and giving me advice to be strong, who knows?

The group managed to get us to the Chicago meeting, where we met some of the most wonderful, outreaching, caring, beautiful, lovable and kind people. The meeting was very enlightening. It was also the best thing I and my husband could have done for our daughter. She has begged to go to the meetings every year, I did, however, tell her she had to start

selling the rest of her organs to get there, ha ha, but truthfully it was wonderful. I felt such love in the room! There has never been a more caring group of people that I have ever met before. Since the meeting everyone has kept in contact with us and has called and emailed us to make sure my baby is okay. The funny thing is someone usually calls when I am feeling a bit down and out which is kind of weird but great timing!!

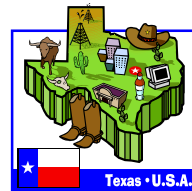
Our daughter however, has stayed in touch with the group of teens that were there and is currently trying to help another girl like herself be strong for her surgery. She is truly an angel! She has said recently that she wants to help with the group in any way that the group will let her. She has said she now wants to take genetics in college and maybe go on and help other girls like herself and the girls maybe in the group. She really has had a positive outlook on her life and others since we met everyone in Chicago!

So the next time you are thinking that this is terrible or there is no end in sight for a solution on AIS or SWYERS or any of the other syndromes, learn from my mistake in thinking that the world has ended - - It has only just begun!!! Because we are continuing to learn new things and as long as our girls and guys are positive (like they are), there will always be someone out there trying to make our lives better for us as parents and for our babies!

Thank you to the board for allowing us to be a part of something so meaningful.

Yours Truly,
Lisa C.

(mother of a 16 year old Swyers girl)

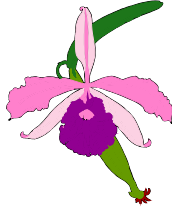


Texas – 2009 AISSG-USA Conference (tentative!)

Somewhere in the big state of Texas, we will hold our 2009 Conference. Our favorite person, Susie Denard is working on details.

In our Newsletter due out in December, more details will hopefully be available. Please mark your calendars (tentatively!) for July 23-25, 2009! Break in those cowgirl boots and get ready for a super meeting!

"A DAY ALONE"



We waited and waited,
for her sentence to ever end,
But obviously her ovaries WOULD NOT BEND!

So we called up the family doc,
they sent us to another.
But he's just as dumb,
as his other doctor brother!

2nd doc took some blood, and told us to wait.
After sticking her so many times,
she felt like fishing bait!

He calls us up, says he needs to see us.
Had no idea, we were hopping on the worry bus!

To make a story short, he says she's XY.
Really didn't know what that meant,
but now, golly geez, oh my!

3rd doc says, surgery is up next.
Thank God for doc 1,
cause now I got Xanex!

4th doc says, he put her appendix at bay.
He removed her testicles,
and sent her on her way!

5th doc said, her chromosomes were screwed.
Said something about genes,
in the womb they were just brewed!

Can't tell her there's more tests, cause she's done with
the pushing cause she smiles, laughs
and is fine, but feeling like a pin cushion!

So we found a group of people,
'cause someone threw us a bone.
Feeling a lot better with them, and we
NEVER SPEND A DAY ALONE!!!!

Lisa C., September 20, 2008, 12:23am

Northern California regional and more.....

On April 26th, 2008, we gathered in Castro Valley for a Regional Meeting. Present were: Renee, Eliza, Lori (from Canada), myself, and Sheila and Meg with their two lovely daughters who have DSD's. While the girls were in the pool being entertained by my daughter, we relaxed on a warm day next to a huge waterfall wall. We swapped stories, talked about world events, and answered all kinds of questions Meg and Sheila had regarding their intersex daughters. Later, we watched some videos. It was a great day, and I look forward to the next regional.



by

Coming up:

Calling all intersex women to celebrate intersex awareness day on October 26, 2008!

The very first person I met in the circle was Lori from Canada. We met in San Francisco on the 2nd Intersex Awareness Day. Wow I was nervous! Last year, a group of us got together and celebrated Intersex Awareness Day and this year will mark the 2nd annual get together. I will attempt to gather women who are in the circle and those that are not. This year, October 26th falls on a Sunday. We will be meeting somewhere in San Francisco (maybe the beach) in the afternoon. So mark your calendar and send me an email confirming your attendance. Please contact me at: jeanne333@sbcglobal.net.

Lastly, I must say that the conference in Chicago was life changing. Each year I eagerly look forward to our conference. Each year I discover something new about myself and renew my commitment to educating the public about DSD's. You all inspire me to be a better me. Every year I try to get to reconnect with old friends from the group and get to know the newbies. Of course, there is never enough time. Thank goodness we have our email circle, a lifeline for us all.

Fondly, with hugs, kisses, and happy thoughts,
**One of the Snappin' Swyers Gals,
Jeanne Nollman**

Just received email from AISSG Canada (West):

Hi ladies,

I just wanted to share our report from our Fall meeting here in Vancouver. Jane (Goto) was up too, and shared information about the initial plans for the

2009 USAISSG meeting. It's wonderful to have made some great connections. We're even talking about the possibilities of hosting the US meeting here in Vancouver, but I need more people to commit to help out with this before we can be serious about this...our little team of three people who organize and host the west coast meetings cannot do everything for a national meeting,... but there is interest so we'll continue to work on it.

I'm forwarding this report to you so that maybe you can post it in your next newsletters and/or on the website. Please let me know if you need any further information.

Coleen Bohlen
Parent Representative
AISSG Canada (West)



Empowerment Through Advocacy

While AISSG retains its important role as a support group for women and families affected by AIS and related conditions, some other activities are focused on making a difference in our lives.

The NIH Rare Diseases Clinical Research Network (NIH RDCRN) has a government mandate to conduct research that will have a meaningful impact on the lives of affected people. Part of the RDCRN mandate is that patient groups have a voice in the direction of this research. Dr. Arlene Baratz is the AISSG representative to the official NIH Coalition of Patient Advocacy Groups that provides input on RDCRN projects. Drs. Charmian Quigley and Arlene Baratz are currently both involved in applications for funding of AIS- and DSD-related RDCRN projects.

Accord Alliance (www.accordalliance.org) is a new organization, established in March 2008 to promote comprehensive and integrated approaches to care that enhance the health and well-being of people and families affected by disorders of sex development. Accord Alliance does this by fostering collaboration among all stakeholders. In other words, Accord Alliance is setting the stage for face to face communication in which everyone involved - members of our community, physicians, nurses, social workers, psychologists and psychiatrists, foundations, government, researchers, insurance companies, professional societies, and more - can talk directly about how to make OUR lives better. It is time to translate talk into action! Two hospitals with new DSD teams are already engaged with Accord Alliance, Children's Hospital of Orange County and University of Michigan Mott's Children's Hospital. Introductory events for Accord Alliance are scheduled for October

24th in Ann Arbor, Michigan, and in San Francisco on November 7th. Arlene Baratz is a member of the advisory board of Accord Alliance.

All donations are greatly appreciated, are tax-deductible. Again, check with our wonderful treasurer, Susie Denard @ caisusie@aol.com. She will gladly work with you on your donation.
- Nancy Evans

We are a self-help group providing information, contact, and support to AIS women and to parents of AIS girls.

AISSG-USA GOALS

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

Board Members and Directors of AISSG-USA

President: Marissa Jaye, **Secretary:** Tryla Brown
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2008 Board Members: Arlene Baratz, Diana Esparza, Aimee Owens, Cynthia Johnson, Carolina Johnson, and Jeanne Nollman

Web Mistress, AISSG-USA Web Site: Cindy Stone.

This document is published by the AISSG-USA Board of Directors. Nancy Evans is editor for this issue. Questions or comments should be addressed to the AISSG-USA at aissgusaAThotmailDOTcom or mailed to:

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