



Orchid Press



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Fall 2005

California, there we were

For many of us, the weeks leading up to the Tenth Annual AISSG-USA National Meeting in beautiful Palo Alto were filled with anticipation. I found myself humming the old chestnut:

*California here I come, right back where I started from.
Where bowers of flowers bloom in the sun... etc.*

So open up them golden gates, California here I come.

Well, we orchids did bloom in that sunshine from August 19-21, 2005 at the Sheraton Resort in northern California thanks to the incredible work of Jan Johnson.

Jan had set the table very well for all of us to gather, share, learn, laugh and care for ourselves and each other. The enormous amount of "woman-power" Jan personally gave to this organization is extraordinary. We all owe her our gratitude for making the "10th annual meeting" such a huge success. Thank you Jan!

The meeting was attended by some 50 AIS adults, along with a few parents, teens and physicians. A welcome reception held poolside got us started, and the 60-70's August weather was perfect for dining under the stars at the MacArthur Park Restaurant (no, they didn't leave the cake out in the rain), a nearby historic restaurant that hosted some 30 of us fellow orchids. It was the first opportunity for several of the attendees to get to know each other, eat some good food and of course drink some excellent California wines!

Saturday was a full day of informative speakers and storytelling. The day began with introductions and greetings from the board. Soon after, Dr. Charmian Quigley, Senior Clinical Research Physician for Lilly Research Laboratories, gave a presentation on "The ABCs of AIS." Dr. Quigley relayed the history of AIS which included the discovery of DNA in 1953 and



molecular defects in AIS in the 1990s. Then, in detail, she spoke of the medical aspects of AIS including the definition and clinical features of AIS. Dr. Quigley's presentation was most informative to "newbies," giving them much needed background on the intricacies and nuances of AIS. We thank Dr. Quigley for taking the time to travel to the west coast and shed light on AIS and give wonderful information to all.

After Dr. Quigley's presentation, our host Jan Johnson, surprised the group with a gift basket for each of us filled with gifts, candies, information, and treats! For months Jan had worked with businesses to secure donations for all attendees – and she surprised us all!

The afternoon event on the Saturday schedule was storytelling. Adults and parents split into two separate groups and took turns telling their AIS stories. It was a very emotional exercise for many. Our personal experiences with secrecy, mis-information and feelings of isolation came to the surface. However, it was very therapeutic and bonding experience. *(The photo above was taken after the story-telling and sharing session.)*

Attendees asked that evening activities be opened up for people to make their own plans. Many participants went into the center of Palo Alto, others made the trek into San Francisco. The day wrapped with enjoyable late night chats between AIS adults and parents rounding out the evening.



Sunday started with a breakfast and a presentation by Dr. Richard Auchus, Assistant Professor, Endocrinology at UT Southwestern Medical Center in Dallas. Dr. Auchus gave information about the Rare Genetic Steroid Disorders Consortium and explored the clinical aspects of AIS. Many attendees had questions about HRT and the consortium (along with other topics), so Dr. Auchus's information proved most useful.

After a lunch, attendees had much pampering and fun activities before people started splitting off to head back home. There were many tearful goodbyes. In all, it was a weekend of soaking up much needed information on AIS, bonding with fellow AIS-ers and parents, and making friendships that will last a lifetime.

By Cindy Stone

The President's letter

Dear Members!

We are heading into the home stretch of 2005, and there are some things I'd like to touch base with you all on.

Some of you have sent me private e-mails saying, "you've been quiet." I have been. I've been quiet as a circle member and even quieter as President. I guess the truth of the matter is, I am suddenly busier than I've ever been in my life (the new boyfriend is still around, believe it or not) with my shows and my job and just life in general. Suddenly, AIS is only a small part of who I am. I also think I'm suffering from burnout – me? Seems inconceivable but there you are.

I was unable to attend Palo Alto at literally the last minute. So much the last minute that I even got charged for one night of a hotel room! My little dog got very sick – he's s-l-o-w-l-y getting better but my God, it's slow. Poor Mom was devastated at the last minute change of plans. I know we would have both loved the meeting, and I'd like to publicly thank Jan Johnson for putting on what I heard was a spectacular show! Thanks Jan! Instead of sipping cocktails by the pool and smelling my beautiful fresh orchid, I was on my hands and knees scrubbing my carpet – it was ugly.

At any rate – the other real purpose of this e-mail is to catch you up a little bit on some AISSG-USA business.

Annual Meeting in 2006

This will take place in Bloomington, Indiana and Cindy Stone will be the coordinatrix. She volunteered and we voted yes! I think it'll be outstanding – there are so many sisters in that part of the country.

Regional Meetings for 2006

We pretty much have the old standbys in place – there is usually a Northeast one, a Southwest one, a Northwest one and a Midwest one. If anyone else wants to have one, contact me at causavon@yahoo.com. The more the merrier! It's a great way to meet new members, who otherwise might not be able to meet anyone, due to geographical limitations of the annual meeting.

Attending the annual meeting for the first time

Alone Together – a poem

I was alone for years.
Alone so long I believed that it would never change.
Alone I endured the poking and prodding, the half truths & lies.
Alone I learned to lie about myself for fear of being cast out.
Alone I came to loathe what I was or what I thought others might think I was if they knew.
Alone I was when all my friends went through the rite of passage from girls to women.
Alone I cried for the babies I would never carry.
Alone I struggled with intimacy.
Alone I smiled while my heart was breaking when friends would share their happy news of marriage and children.
Alone I came to search for who I really was.
Alone I learned that I had been lied to by the very people I should have been able to trust the most.
Alone I came to my first meeting, face to face with the tribe I never knew existed.

Together we cried.
Together we listened to the stories and nodded our heads in silent understanding.
Together we shared our heartbreaks and triumphs.
Together we battled the medical profession...and got some to listen.
Together we learned more about our bodies than most of the doctors knew.
Together we healed ourselves and stood proud.
Together we reached out to other people like us and brought them home.
Together we took baby steps toward true self-acceptance.
Together we educated medical professionals on the importance of the truth.
Together we learned what it means to be a woman.

By Eden Atwood

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Board & Officer replacements needed

Your current Board and Officers are:

Melody Bowen - Secretary
Connie Adams Brooks - Board Member
Tryla Brown - Board Member
Susie Denard - Treasurer
Kathryn Gallagher - President
Jane Goto - Board Member
Joyce Henning - Board Member
Cindy Stone - Board Member

Eden has decided to step down – her term does not expire until the end of this year, but she is unable to continue on as Board Member now. She will, however, continue on as liaison to the parent's circle – she is a member of their circle and I'm sure it's a great comfort to them to have her in their midst. Marissa has been volunteering already, and has expressed interest in replacing Eden, and the membership will need to vote her in, if they choose, at the next election.

In addition, we need your help for these replacements:
- Joyce Henning's term expires in December. She has decided not to renew her term as Board Member. This leaves us with an open position for Board Member.

- Melody Bowen has decided not to continue on as Secretary as the end of this year. This leaves us with an open position for Secretary

- President: I am not going to continue on as President in 2006. This leaves us with need of a President as well.

So there you have it – three positions open. Susie has decided to stay on as Treasurer, as have all the other Board members, whose terms don't expire until December 2006.

We sincerely need new members to step up to the plate and volunteer for a position, or accept a nomination.

We are a group who meets by phone or e-mail, which means no monthly meetings or travels during the year. Yet, there are other projects the board has on a back burner which should be revived if you can help with them as a board member or a new volunteer. Again, contact me (causavon@yahoo.com) or Jane Goto (ayameservices@yahoo.com) with questions.

Thanks for considering our call for help. – Kathryn

More California, feedback

I left my heart in San Francisco



San Francisco is such a beautiful city. Sightseeing was a blast! The 2005 annual AISSG meeting was above and beyond all my expectations. Jan did a superb job of organizing the event and making sure that everyone's needs were met (*see photo below of host Jan with assistant Jane at the registration*

table with one of Jan's many orchids). The hotel was gorgeous and the food delicious and bountiful. It was so good to see so many familiar and new faces. There were a total of ten first-timers attending the meeting.

One of the main reasons I attend these meeting is for the socializing. Being around, hanging out, or just socializing with other AIS women is very therapeutic for me. It is also very fulfilling for me to be there for others who are just finding out about their AIS. Story sharing time is always a particularly emotional portion of the meeting for me. I could hear an AIS story many times over and still be moved each time. This year was no exception. Some of the stories shared this year were very moving. The tissue-box was definitely put to good use.

The speakers at the meeting were excellent, as always. Dr. Quigley is a plethora of useful AIS information. If Dr. Quigley wrote a book about AIS I would definitely buy a copy for myself and everyone in my family. I can't wait to see everyone again next year. *by Tryla Brown*





One orchid's poem

The Child Inside

I grew up with guilt, but not knowing why;
A naive child living a lie.
They didn't tell me, but everyone knew,
My mind was so frazzled, I hadn't a clue.
I wanted to run, I was filled with self hate,
There was nowhere to go, there was no escape.
A child of GOD, a sister of fate,
I wanted to grow up, oh, I couldn't wait.
I became a woman at the age of fourteen,
A whole lot to learn, the world seemed so mean.
I thought I knew what I would become,
It ended up, I was still on the run.
I'm much older now, I can see clear,
I feel it inside, the truth is so near.
I know what I am, I can't hide the pain,
But the child inside should feel no shame.
Come home to me child, I'll take care of you.
Come home to me child, I've been there too.
Come home to me child, let me feel through you.
I promise I will come through, I promise I will come through.
by Tryla Brown

Shine your light, for others

As many of you know, the AISSG-USA group has a new web-site. Generously donated web space was provided by Indiana University to host the necessary files. Cindy Stone has designed the pages and Tryla Brown has obtained the domain names of aissgusa.com and aissgusa.org so that only our organization can use them!

We tell everyone to use www.aissgusa.org as we are a non-profit organization and proud of it! When you type that URL in, you will see the site automatically jump to the Indiana URL, but that's behind the scenes. You won't need to remember the longer IU address. Just always use: www.aissgusa.org.

In an effort to make our site useful to AIS women and parents just learning of their condition, it would truly help us to have a series of "profiles" – anonymously of course – that can share some of your experiences with those just discovering their status.

Won't you please share a brief version of your AIS story as the UK web-site has done for years. You can make up a first name or use your own first name (no last names published). We ask that you set a limit of 300 words. If you wish to use the sample questions below instead of writing something on your own, that's fine. Here are the questions to help you get started:

- Tell us how you first learned about your AIS status?
- Tell us how you've dealt with it?
- What do you wish your parents or doctors had told you as a young teen?
- What's the hardest part of having AIS?
- Are there any positives about having AIS?
- If you had a niece just discovering she had AIS what would you tell her?

Send your brief story OR your answer to these questions in an e-mail to: ais@indiana.edu with the name you wish us to use with your story. Send it in by October 25th and we'll put up your words anonymously on our new site for AIS women to learn from each of you.

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

This issue of the *Orchid Press* has been published by the Board of the AISSG-USA, and has been edited and designed by Board Members Cindy Stone of Indiana & Tryla Brown of Missouri.

AISSG-USA
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Our new web-site: www.aissgusa.org

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