



Orchid Press

Vol. 4 No. 2

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Fall 2006

Blooming in Bloomington

On a warm summer weekend, nearly 100 of us rare orchids -- adults, dozens of parents and teens -- gathered in Indiana to give and gain support from each other. We laughed at funny talents, hugged new friends, ate good Hoosier cookin' and cried our way through many boxes of Kleenex. Most of us spent some four days or more on the IU campus with equal times inside and outside the classroom learning more about ourselves and each other. The evaluations would later say it was a magical weekend ... "a weekend we would remember all our lives."

For the board and planning committee, the weeks leading up to the 10th anniversary 2006 AISSG-USA National Meeting in Bloomington, were filled with anticipation. Would enough folks come for three full days of presentations? Would parents and teens enjoy their new programming? Our anxiety was for naught because the meeting came off just great, and the orchids were blooming in Bloomington's sunshine!

Thanks to my four members of the program committee (Arlene Baratz, Charmian Quigley, Jane Goto, & Becky Baughman) all the countless hours of hard work made all the difference. In addition, a big round of applause to the rest of the board, they made sure a wonderful table was set for all of us to gather and care for ourselves in new ways.

On Friday, August 4th, we had a full day of sessions (*See separate article in Session Notes for a list of speakers & topics*). In the afternoon, there were museum tours, campus walking tours, teen-swim time, plus the Kinsey art tour. A board meeting ended the day with some evening dinners and late night hospitality suite visits for chatting, noshing and laughter.

On Saturday, August 5th, we spent part of the day on HRT regimens and sharing our stories in the all afternoon story-telling session. Participants tell us this affects them the most when they can tell their personal journey in a totally safe and supportive place -- one of the few times they may have told their story to anyone out loud! That evening, we had an outdoor cookout at sunset in a nearby meadow and then came back in for Katie's fabulous talent show -- which knocked everyone's socks off!

Dr. Charmian Quigley is shown here in the center as Cindy Stone and Arlene Baratz present her with a certificate of appreciation as she learned of the new "Annual Quigley



Scholarship Program" to be given every year from now on in her honor. The scholarship was created by a generous longtime member, who wanted to anonymously recognize our beloved Charmian, and how she has

attended every AISSG-USA meeting, given much of her time, energies and dollars to help our meeting grow from such tender

beginnings. First timer, Maggie from Detroit, was the inaugural Quigley Scholarship recipient and Maggie thanked us so movingly with a gift of her dancing prowess in our talent show that she opened up to all to join her on stage.

On our last day, Sunday August 6th, we learned about ways to care for ourselves and Charmian gave her advanced 501 talk. As we walked into town for lunch that Sunday afternoon, we knew that something rare and wonderful was coming to an end -- and it was time for the orchids to start their journey back home.

Now, summer has faded, and as it slips away into herstory, I want to thank all those who worked on this year's annual meeting, and to say what a privilege it was to host all of you who made it to Bloomington. I am truly grateful to Charmian Quigley for helping us locate our many speakers and giving so freely of her own wisdom and counsel; for Arlene Baratz for working with the parents' group to develop a needs assessment for parents and teens; for Tryla Brown for gathering so many silent auction gifts of art and orchid memorabilia and seeing to that we raised some \$1,300+ for scholarships and our year-round work; for Jeanne Nollman for presenting her own sessions and for providing leadership for all the teen sessions; for Anne J. and Lynette P. for keeping the hospitality suite stocked; for Mark Baratz' amazing photos, slide show and emceeing our talent show; for Katie B. for finding and corralling women to join the talent show and so much more; for our Prez Becky Baughman for giving her all, and for my fellow board members Marissa Jaye, Connie Brooks, Cher Thorpe, Susie Denard and Nancy Evans for supporting our speakers and presenters in a myriad of ways; for Vicki B. giving local support to teens and adults; and last but not least to Jane Goto for doing everything from folder-stuffing to applying orchid tattoos on special orchid bodies to facilitating story-telling so compassionately.

In closing, your board was honored to welcome and be of service to nearly 100 women with AIS and a wide variety of similar diagnoses. Further, we were delighted to welcome women from all over North America (we want to make special note of the Canadians who were there). Lastly, we were thrilled to be joined by women from the UK and the Netherlands -- who came because our expanded meeting making it worth their while to travel from Europe to the states for the first time.

The meeting evaluations tell us this event went well -- some said it "changed their lives" and another said "I will remember this weekend for as long as I live..." Such praise, yet it's really for all of you for not being frightened to give of yourselves as you did. We believe your collective efforts did indeed change some lives and will provide seeds that will germinate and bloom in new-found support and healing for all of us.

On a personal note, I can't thank you all enough for showering me with gifts of a blues rap song by "Mark & the Board," a 50th birthday cake and a gift certificate for a day at the spa! I feel quite grateful to all of you. Chairing this annual meeting is the best volunteer thing I've ever done and I hope those of you who made it, feel real growth and healing in your lives. If you didn't join us this year, you definitely need to be in North Carolina next July for the 2007 annual meeting "Sweet Tea & Grits." Our 2007 Chair, Nancy Evans, is ready to roll out her own inimitable style of southern orchid charm! You won't want to miss it!

Cindy Stone



AIS Talent Show One of the many highlights this year was our Talent Show, featuring parents, adults and teens. It was

masterfully emceed by Dr. Mark Baratz & Ms. Katie B. There was some shyness and hesitation ahead of time, but thanks to Katie's persuasive talents, the show came together wonderfully that Saturday evening. With the bright lights, good mics, a nice professional stage and a talented series of accompanists, it was a terrific event. The performers in order of appearance were:

- * Warm-up sing-along with Lynette from Houston
 - * Merkin Comedy Act with Tryla from St. Louis
 - * Reflections of a 1st-Time Orchid by Cynthia of San Diego
 - * John Lennon's Imagine sung by Cindy of Bloomington
 - * I Enjoy Being a Girl, sung by Katie from Pittsburgh
 - * Piano Impressions by Sarah
 - * My Heart Will Go On parody sung by Sarah and Bethany
 - * Monologue from The Rose by Pam from Los Angeles
 - * Let it Be sung in harmony by teens Evelyn & Miriam
 - * Only Hope sung by Miriam
- * African Dancing, led by Maggie from Detroit, and joined on stage by many orchids & families
- * A Harmonica Blues Piece for Cindy Stone, written & performed by Mark Baratz & Board Members
- * I Am Woman Hear Me Roar performed by the AISSG Board



Feedback from Parents about this year's special breakout program for parents and teens was excellent. There was special appreciation for the support and sharing provided by the adult women to parents and girls. Six fabulous girls attended and formed such a special bond that they requested a pajama party room for next year. (Moms and dads- prepare yourselves!)

The girls had an opportunity to ask questions on their own during sessions with doctors and with Stephanie Sanders, a Kinsey sexuality expert. Their joyful performances in the talent show reflected self-confidence and pride. Parents took advantage of the ever-available Charmian Quigley and her endless fund of knowledge. Stories were shared, and important issues were explored regarding the emotional and medical aspects of raising AIS girls. Many copies of the new DSD Handbooks for Parents and Clinical Guidelines went home with families. Some parents have already given them to their physicians. Cheryl Chase and Alice Dreger provided some different perspectives for AIS parents. There was a sense of relief regarding the changes outlined in the Chicago Consensus paper on DSDs. Parents were accepting of the DSD medical terminology, finding it less stressful for families with children. Thanks to the adult women on the planning committee for expanding the program for families.

Arlene Baratz

Session Notes At the AISSG-USA 2006 Annual Meeting in Bloomington, one of the UK leaders, Margaret, attended many of the adult and plenary sessions and took meticulous notes. Margaret shared them with us and gave her blessing to share them within our parent and adult AIS circles.

Space won't permit us to reprint them all here, but if you write ais AT Indiana DOT edu, we'll send you any of the topics you've missed via e-mail so you can recap.

We are most grateful to Margaret and the UK group for their support and willingness to share. The sessions we have typed up notes for are:

- Androgen Insensitivity Syndrome, Intersex 101 - The AIS Basics – Dr. Charmian Quigley, Eli Lilly
- Right to Good Healthcare & Seeing AIS without Shame – Alice Dreger, Ph.D., Northwestern University
- For Parents: Your Daughter & Her Growing Sexuality – Dr. Stephanie Sanders, IU Bloomington
- For Parents: Getting the Best Medical Care for Your Daughter – Alice Dreger, Ph.D.
- Working Through the Emotional Issues of AIS – Dr. Carol Hostetter, IU Bloomington
- Taking Care of 'dem Bones: Managing the Risk of Osteoporosis – Dr. Robert Marcus, Eli Lilly
- Women's Health Initiative: The Good & Bad in the Report – Dr. Leo Plouffe, Eli Lilly
- Disclosing AIS to your Daughter – Drs. Quigley & Baratz
- The Effects of Hormones & Sex Chromosomes on the Brain & Behavior –Sheri Berenbaum, Ph.D., Penn State
- Just for Teens: Relationships, Marriage, Sexuality & AIS – Dr. Stephanie Sanders
- Gonadectomy & HRT for you or your Daughter – Drs. Quigley & Baratz



HRT Panel Answers More Questions

Editor's Note: For those of you who attended the annual meeting in Indiana, the most popular topic was hormone replacement therapy. We had an expert panel of three researchers, and you know who they were. Your AISSG-USA Board asked these experts to anonymously summarize more of the questions and answers for this newsletter they weren't able to cover at the annual meeting.

Q: Is hormone replacement for AIS women for life, or can it be stopped at some point? [This question was asked by many people in varying forms.]

A: Estrogen is important for bones (prevention of osteoporosis), and probably for overall wellbeing during the years between about the mid-teens and 40s - 50s. After 50 or so, estrogen supplementation may be needed by some women to prevent symptoms such as severe hot flashes. Most physicians these days would recommend using the lowest effective dose that keeps symptoms at bay, for the shortest period of time. Estrogen-only preparations should be used, as there is no benefit (and possibly some harm) in using a preparation containing a progestin.

Q: Women with AIS are not the same as postmenopausal 46, XX women. Please explain how all of the information about HRT applies to us specifically.

A: This is a difficult area. There are clearly significant differences in physiology between 46,XX women and those with AIS. The majority of "regular" women have a cyclic pattern of rising and falling estrogen and progesterone levels

every month for about 30 - 40 years. In addition, their bodies are able to respond to the (relatively weak) androgens produced by the adrenal glands and ovaries. So the body is exposed to varying concentrations of a mixture of estrogens, progesterone and androgens over many years. In contrast, women with AIS produce no progesterone and are partially or completely unable to respond to androgens, so the effect of estrogens in their bodies (whether produced by their own testes, or provided through medication) is unopposed by any other hormone effects. Nevertheless, based on the information available from various sources, treatment with estrogen alone during the period between the teens and 40s-50s remains the overall best approach.

Q: What's the effect of HRT on the heart?

A: The effects seem to be mixed. There is good evidence that estrogen improves the lipid profile, by lowering the total cholesterol and LDL ("bad" cholesterol) levels, while increasing the HDL ("good" cholesterol) levels. However, there may also be an increase in triglyceride levels and in levels of an inflammatory marker called C-reactive protein. So overall, the effect on the parameters related to cardiovascular health seems to be neutral. In addition, the Women's Health Initiative study has not found any beneficial effect of estrogen on risk of heart attack (however, we also know that this is a study of 46,XX women, so may not directly apply to AIS). Estratest (combination of estrogen and testosterone) causes a worse profile of lipid changes than estrogen alone.

Q: What's the effect of HRT on insulin levels?

A: Estrogen appears to improve insulin sensitivity. So, women with diabetes who take estrogen may need to use less insulin.

Q: What are the effects of oral vs. transdermal estrogen?

A: Oral estrogens have to be absorbed through the gastrointestinal tract which means that they reach the liver in high concentrations, so they tend to affect the production of the clotting proteins by the liver. This effect may result in an increase in the risk of venous thromboembolism (blood clots). Transdermal estrogens avoid this problem by being absorbed directly into the circulation.

Q: How do I know what dose of estrogen to take?

A: There is no "one size fits all" in estrogen treatment. This is because the effects of hormones (or other treatments for that matter) depend not only on the dose, but on the specific individual's responsiveness to the treatment. And two people may respond quite differently to the same dose of a medication. The best approach is to aim for the lowest dose that prevents or controls symptoms (such as hot flashes, moodiness, etc.). This has to be worked out between you and your physician on a personal basis.

Q: What is the risk of breast cancer for a woman with AIS taking long-term estrogen?

A: The risk of breast cancer from estrogen-only treatment in the Women's Health Initiative (WHI) study was not elevated. However, as we have discussed, women with AIS have different physiology from the women in the WHI study, so the results may or may not be relevant. That said, we are not aware of any evidence of an increased risk of breast cancer in women with AIS who take estrogen. However, data have not been collected in any kind of systematic fashion in AIS, so there is no real evidence either way.

Q: How do I get rid of brown patches on my face caused by my HRT?

A: The brown patches are called "chloasma" (sometimes referred to as "melasma") and are quite often seen in pregnant women as a result of their very high estrogen levels. A reduction in the

estrogen dosage may help, as may change from an oral formulation to an estrogen patch. Advice from a dermatologist with expertise in the dermatology of pregnancy may be helpful to provide specific guidance on treatments that can be applied to the skin itself.

Membership Dues Update



Increased postal rates and other expenses have made it necessary for us to require our first increase in membership fees in several years. Memberships received before December 31, 2006 will be honored at the US\$20 rate. Effective January 1, 2007, annual dues are US\$25. Dues are now payable on a calendar year basis with the membership year now running from January 1st to December 31st. For your convenience, PayPal available at our site: www.aissgusa.org

YES! Canadian and overseas memberships welcome!

“Sweet Tea & Grits”

AISSG-USA Conference

North Carolina

July 20-21-22, 2007

We'll have a wonderful hotel – one that has worked with my employer for many years, They are very anxious to have us there and will to work with us in many ways. Just a sample of room rates: \$79.99 for a single and \$99 for a double (can share also). More details coming your way soon. Save those dates!

You can email me with conference questions/comments at: wakectygal@yahoo.com -- Thanks,

Nancy Evans
2007 Conference Chair

From our Prez First, I want to thank everyone who made the trip to Indiana this year. What a wonderful and invigorating time we had! The presence of so many first time visitors was a sight to behold.

While in Indiana, the board of directors of the Androgen Insensitivity Support Group – USA held our annual general meeting, both as a board meeting and a public hearing for those interested in participating.

The decision was made to hold next year's meeting in North Carolina (July 20-22, 2007), spearheaded by our dear Nancy Evans. The meeting was dubbed "Sweet Tea & Grits," and promises to be an exciting time. The decision was made to continue with the three day format, a great way to make certain that we had an adequate amount of time to stuff a year's worth of fun into three days! I am looking forward to a brilliant time and hope you are as well.

The Board also voted on the inclusion of the terminology of "disorders of sex development" in our brochures and on our website. This is very exciting as it keeps AISSG-USA in line with the thinking of physicians who see the new cases of AIS and other related disorders and will allow us to remain in the forefront of physicians minds as they recommend treatment and help families align themselves with others.

Finally, the Board decided that it was time to raise dues a bit; we are going to raise annual membership fees from \$20 annually to US\$25.

I am so excited to be the president of such an amazing and interesting group of women. Every time I receive a telephone call or email from the group I am ecstatic to hear the voices of other dynamic women with AIS and similar conditions. Please, feel free to contact me at any time with questions or comments. You can reach me at rebeccakbaughman AT yahoo DOT com or at (314)324-8834.

Rebecca Baughman

Call for Nominations!

Board & Officer Replacements Needed

AISSG-USA election time is approaching. Your current Board, Officers and Medical Advisors are:

President: Rebecca Baughman

Secretary: Cher Thorpe

Treasurer: Susan Denard

Directors: Connie Adams Brooks, Tryla Brown, Nancy Evans, Jane Goto, Marissa Jaye, Cindy Stone

Medical Advisory Panel:

Arlene Baratz, MD; Sue Stred, MD; Charmian Quigley, MBBS

Rebecca, Cher, Tryla, Nancy and Marissa have another year in their terms of office. Connie, Jane and Cindy have completed their current board terms and are eager to step aside should some fresh faces and fresh talent step forward. Susie has completed her current term as Treasurer but has graciously agreed to carry-on to provide continuity. Cindy would like to continue on with the mammoth task of maintaining the AISSG-USA website at www.aissgusa.org

So there you have it – three positions open. Voting materials will be going out in the mail shortly to paid-up members. If your dues are not paid up, you will not receive a ballot.

Here's where we stand at press time regarding nominations:

- We are thrilled to announce that long-time circle member, Diana E. of Arizona, has agreed to run for a seat on the board.

- Following coordination of a highly successful Teen Program in Bloomington, Jeanne Nollman from California has agreed to "throw her hat in the ring."
- We're also grateful that Medical Advisory Panel member, Arlene Baratz of Pennsylvania, has stepped forward and accepted a nomination to run for a board seat.

We sincerely need new members to step up to the plate and volunteer for a position, or accept a nomination. We would be particularly interested in securing Canadian representation on the Board of Directors.

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 with questions. Thanks for considering our call for help.

Rebecca Baughman

Our Fall 2006 Newsletter ends with a very special poem from one of our new adult email circle members – Cynthia J.



Reflections of a First-Time Orchid

Spread our legs, Put us in pink?
Draw our blood. And we'll make you think!
Why do we meet? The necessity to link.
But what do we gain? To put it all "in sync."
And how do we love? Both traditional, gay ,
And some kink.
As for bad docs and oppressors? Just call 'em a fink.
When we're down and feeling low?
Take a stride 'round the rink.
As for our fine hairless skin, Ahh, as smooth as a mink.
When will we see each other again? Not more than a wink.
How long before we should love ourselves unconditionally?
No more than a blink!

I love you, sister orchids, keep Bloomington!

Note: Email addresses throughout have been altered to inhibit spammers. Please replace the AT with an @ and the DOT with punctuation.

Published by the AISSG-USA Board of Directors. Guest Editor is Nancy Evans. Questions or comments should be addressed to the AISSG-USA at [aissgusa AT hotmail DOT com](mailto:aissgusa@hotmail.com)
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U.S. Website: www.aissgusa.org
Int'l. Website: www.medhelp.org/www/ais/



AISSG - USA

Membership Form & Questionnaire - 2007

Mail to: AISSG-USA
P.O. Box 2148
Duncan, OK 73534-2148
Email us: aissgusa AT hotmail DOT com

1. Your Name: _____
2. Mailing Address: (If your address has not changed, please attach the address label from this mailing)

3. Contact Information (*not mandatory*): Home Phone: _____
Cellular Phone: _____ E-Mail or Other: _____
4. Membership Category:
 AIS (or related condition) Adult Parent of an AIS Adult Other Professional
 AIS Teen (under 18) Other Relative or Close Friend Organization
 Parent of an AIS Child Physician Other: _____
5. Would you like to be contacted by someone from the support group in your local area?
 Yes Yes, but check with me first No
Comments: _____
6. Would you like to receive a supply of support group brochures? Yes Quantity: _____
7. Should we send support group brochures to anyone you know? Yes
Please list names and addresses below or include on separate sheet.

8. Are there any topics you would like to see addressed in the newsletter? If so, please list below:

9. AISSG-USA is an all-volunteer organization. Would you like to volunteer to help the support group operate? Yes
What would you most like to do? _____
10. Help us track the success of our out-reach efforts by telling us how you found out about us:
 A documentary on TV A family member/friend An on-line chat group
 My doctor/therapist My local PFLAG, LGBT center Other: _____
 Found you on the web At a conference (please specify) _____
11. We welcome your comments and suggestions on how we might improve services to our members;

dues increase to US\$25 effective January 1, 2007

Save \$5 and renew now! Rate of US\$20 accepted until December 31, 2006

If you have not already paid your 2007 dues, please mail your check and completed questionnaire today to:

AISSG-USA, P.O. Box 2148, Duncan, OK 73534-2148. NEW! Visit www.aissgusa.org to pay by PayPal

- I paid my 2007 dues via PayPal and will mail my questionnaire. Please waive my dues due to financial difficulties.
Donations are tax deductible and greatly appreciated. AISSG-USA is a registered non-profit corporation. FEIN 37-1407648

Dues: \$ _____ Donation: \$ _____ Total amount enclosed: \$ _____