



*"Spring Again
Spring Again
Spring Again
Isn't it?
Buds on the branches
A breeze in the blue
And me without mittens
My sweater unbuttoned
A spring full of things
All before me to do."*

Karla Kuskin

Spring Greetings from Nancy in North Carolina. As the poem reads, we have a wonderful time ahead of us. Some of us have not had any snow but rather some very cold days and nights, while the rest still can be found underneath a shimmering white blanket of snow waiting for the warmth. Daffodils are trying to sneak up through the earth; forsythia is starting to bloom with their beautiful yellow and pink flowers. *Spring* is officially here March 20th.

Spring is a time for renewal and new beginnings where new & old come together to share the love of sun, fun and fellowship. This Spring issue of the *Orchid Press* speaks of new and old - regional meetings scheduled and exciting news from Cindy on our August 06 Meeting in Bloomington, IN. Joyce Henning shares "*Things to Help on a Path to Healing*." There is a new feature called "AIS News & Reviews" - if you have news for that, just let us know.

Best Wishes for a wonderful Spring Season.

Nancy Evans, Guest Editor



Mark Your Calendars for Indiana, August 4-6, 2006!

Well, spring is nearly here, and it's a good time to ask you to "save the date" on your calendars for the **2006 AISSG-USA Annual meeting in Bloomington, Indiana**.

This year's meeting will be held on the scenic wooded campus of Indiana University (IU). Visit www.iub.edu for a quick mini tour. IU Bloomington is nearly 200 years old, and is the flagship campus of the IU statewide system of

campuses. We have nearly 40,000 students and they'll be mostly gone in the summer months, leaving us a beautiful campus to tour and visit.

We have reserved really nice hotel rooms & quality meeting space for the dates of August 4, 5, & 6, 2006. Meetings and rooms will be in the beautiful Indiana Memorial Union Hotel, www.imu.indiana.edu on our campus.

Planning is already underway. A volunteer planning committee has been formed and has had its first meeting. It's comprised of Dr. Arlene Baratz (from the parent's group), Jane Goto (from the AISSG Board), Dr. Charmian Quigley (presenter and medical professional), plus Becky Baughman (AISSG President) and yours truly as conference chair.

Since there is never enough time to do everything we want to do at the annual meeting, your board has agreed to try a slightly longer meeting format this year - starting with "early bird speakers" on Friday August 4th - then our regular program on Saturday & Sunday. The "early bird day" is optional, but strongly encouraged. This longer meeting will permit more time for adults, parents and youth to have their own "tailored" breakout sessions and plenty of programming for all. You should consider traveling on Thursday if you are able to be off work or away from commitments at home, and enjoy all three days - Friday, Saturday and Sunday, for a full agenda packed with speakers, sessions and plenty of time for sharing, support and fun!

IU is about 50 miles south of Indianapolis, a 90 minute drive from Louisville, 2 hours from Cincinnati, and 3.5 hours from downtown Chicago by auto.

The Indiana University Memorial Union is a large complex with a traditional hotel and conference center in the Union. The IMU itself is in the heart of our beautiful college campus - with eateries, shopping, bookstores, gift shops, a bowling alley, hotel and meeting rooms all under one roof. A shuttle van runs 7 times daily between the IMU front door and the Indianapolis airport for a small fee (a little less than an hour's drive to the airport).

By popular demand, Dr. Charmian Quigley will present several sessions tailored for newcomers, youths, parents and "veterans."

Colleagues from the world-famous Indiana University Kinsey Institute for Sex, Gender & Reproduction have graciously offered their top researchers and staff as speakers if we wish, as have my own department of gender studies, and the world class IUPUI Medical Center staff -- all are truly cutting-edge resources that we will strive to gather together...

Questions? Contact ais@indiana.edu, and I'll respond. For now, simply save August 4-6, 2006 on your calendars. Cindy Stone



Things to Help on a Path to Healing by Joyce Henning

Editor's note: As women with AIS and similar conditions, we may have struggled with accepting our medical histories and learning to work through the feelings that arise. This is all normal. Many of us have experienced losses that range from medical professionals being dishonest to the fact we are not able to have our own children. If you still struggle from time to time with these issues, you might consider some of the following practical self-help tips that can lead you down a path of healing and acceptance. The information here was adapted from a number of other non-profit publications and articles.

JOURNAL: Keep a private journal, and when you feel the need to vent feelings or get a perspective on a troubling issue in your life, just begin writing and you will be able to make more sense out of whatever is troubling you. Some people find journaling things they are grateful for very therapeutic as well.

WRITE LETTERS: Write letters to people in your past who you feel harmed you. This is an excellent way to constructively deal with anger. You can burn the letter after you're done if you wish.

INVENTORY: Do a thorough inventory of your past, including the people who harmed you, how you were affected by it and how you may have retaliated. Share this inventory with someone you trust, such as a good friend, a therapist, or a priest or minister.

THERAPY: Seek additional help from a counselor or therapist. It is a good way to get new insights about yourself.

EXCHANGE PHONE NUMBERS: It is important to have people who you feel comfortable sharing with when things come up from day to day for which you need support.

AFFIRM: Self-worth affirmations can be very beneficial for your self-esteem. As you begin to declare some positive things about yourself, you may begin to believe them. (e.g., I am a beautiful person, I am honest, and I care...)

PRAY: When we pray we are talking to our creator however we define him/her. When we begin to see our prayers answered, it increases our faith and also our self-esteem, as we begin to feel worthy of our creator's blessings.

MEDITATE: Meditating is listening to our maker. It is very calming and also increases our closeness however we understand our faith. Listening to meditation tapes is also very relaxing.

NURTURE: It is very important to nurture your inner child, as for many of us our inner child was wounded when we were little and suffered much trauma. Our inner child was neglected years ago and we need to give her recognition, validation and love. Here are ways to nurture your inner child:

- ❖ Hug a teddy bear when you feel insecure.
- ❖ Tell your inner child you love her and will never abandon her.
- ❖ Take a warm bubble bath.
- ❖ Give your inner child a pet to love, such as a dog or cat.
- ❖ Go for a walk and enjoy nature.
- ❖ Be silly and laugh. Watch a funny movie or act goofy. It is a good way to lighten up and not be so serious.

WORK THROUGH EMOTIONS: As we begin to experience feelings that many times have been buried, we need to find ways that will be helpful in venting them. One of our strongest emotions is anger and many of us will have a tremendous amount of it about the unfair circumstances of our past and the people who harmed us. It is very important to work through our anger and we need to have healthy ways to do this. Working through anger can be a bridge to healing and can even lead us to the beginnings of forgiveness (e.g., make a gratitude list, punch pillows, exercise of any sort to release stress, etc.)

GRIEVE: As children we may have suffered many losses and we therefore have serious grieving issues. Grief is the process of withdrawing psychological attachments from events, persons, or objects which reality says no longer exist for us. Unresolved grief can lead to a multitude of problems, including depression and even suicidal tendencies. It is crucial that we allow ourselves to grieve because this will bring about healing.

Many of us remain stuck in the depression, but we aren't even aware that we have denial and anger. In order to begin grief work, we need to

recognize what we have lost. It could be helpful to make a list of all of your losses and then write down how you think each loss has affected you, emotionally and otherwise. Since much of our depression is repressed or suppressed anger, working through anger in constructive ways will alleviate it. Venting our anger with safe people will also be beneficial and will be validating and releasing at the same time. It is important that we express our emotions and accept the confusion that these emotions generate.

An additional place to work through grief could be a grief group or with a qualified therapist. As we work through our grief, we will begin to discover deep underlying sadness over all of the losses we suffered as children. Many unshed tears will accompany this sadness and we should allow ourselves to cry when we need to cry.

Nurture your inner child a lot when you are working through intense grief because your inner child will be especially vulnerable at such times.

* * *

Here are some additional thoughts to consider:

"I didn't plan to be this person for whom loss always hovers at the edge of my awareness ... I've carried the remote ache of longing with me long enough to understand it is a part of me now. Loss is our legacy. Insight is our gift. Memory is our guide." Hope Edelman

"When you come to the edge of all the light you know, and are about to step off into the darkness of the unknown, faith is knowing one of two things will happen:
There will be something solid to stand on, or you will be taught how to fly." Barbara J. Winter



Do You Sometimes Feel Ashamed?

Ways to let go of unhealthy feelings About your AIS status

Editor's note: This is a companion piece to the first article on healing – it contains suggestions that can lead you to more acceptance of our diagnosis. This article was adapted from several other non-profit sources.

As women with AIS and similar conditions, there have probably been times when we have felt flawed, unworthy, inadequate, or somehow defective, and that we keep saying over and over again "what is wrong with me." If you're like me, after initial diagnosis, you may have had feelings

of shame and/or remorse about your worth as a woman.

Experts say shame often leads us to low self-esteem and it plays a major role in stifling "our best self." Shame is both a feeling or emotion, and an experience that happens to the total self.

We all experience some shame. But the years and years of carrying around shame from your diagnosis or anything else is harmful and can affect your emotional well-being. If we do not work through these feelings and work to let go of them, shame can accumulate and weigh us down, until we feel even more of a victim. A good counselor or therapist can help work through this shame and help us realize that we are really women; **we just took a different biological path to becoming one.** Further, that having this diagnosis is not a death sentence nor is it our fault – it might be useful to think of it as a "genetic trait" or "a characteristic that just runs in your family" and it was never intended to destroy your happiness your whole life long! Bottom line: feeling shame no longer means you have to live so sadly.

We can learn to "just say no" to the negative messages, negative thoughts, old beliefs of what is/isn't a real woman. We often say things to ourselves so mean and hurtful – things that we would never say to another person. Maybe we heard them too often in childhood, or perhaps we just feel them so strongly because we see ourselves as flawed to a prospective mate because of our diagnosis. Then, when we have disclosed the truth to loved one, if any of these people on whom we were so vulnerable have hurt us, then we could start to believe they are somehow right.

Think about this: studies have shown that if just one person says "I really don't like your new haircut" – that it will take at least SEVEN more people saying "I love your new do" before we will discount the first person's criticism. Since you may not have shared your medical status with high numbers of people to get this 1:7 feedback, then we need to "eliminate the negative" much faster.

With 1 in 1,500 babies born every day with something other than the standard male or female anatomy, we AISSG members are not alone. We don't need to be ashamed of our bodies any more. Shame uses the emotion that attacks us by making us believe we are somehow defective or unlovable. This crippling emotion destroys self-confidence and prevents one from reaching our joy in life or love. Shame was a learned emotional reaction to an actual or perceived attack on the worth of an individual.

So let's agree in 2006 to dealing with any lingering shame by:

- ❖ Recognizing that we may still be ashamed because of our diagnosis or medical history.
- ❖ Figuring out rationally and logically if there is any validity to telling ourselves negative messages, comments or beliefs about our bodies.
- ❖ Recognizing the effect of having this condition has been harder, but it's not impossible to accept.
- ❖ Feeling the anger, sadness, hurt and pain that we may have been shortchanged in life, but it's okay now as we're becoming older & wiser.
- ❖ Learn to understand, accept and let go of all our past negative feelings and beliefs about your diagnosis and medical history.
- ❖ Take steps to write our new positive thoughts in a journal, to read more self-help books, to learn all we can about your condition, to offer support to others and if necessary work through our feelings with a counselor in therapy.

The Dali Lama has said "if you are feeling sad, think of others; and if you are joyful, think of others."

Offering up support to others whether AIS or not can be a good step to not just thinking about ourselves and focusing solely on our own problems. Yes, work through your feelings, but when you've done the work, reach out to others, too.

I believe that overcoming the paralyzing effects of shame that has kept us limited starts with developing an awareness of how and what we believe about ourselves. Let's question and explore more from now on and vow that we can learn to live as proudly as women with AIS and similar conditions, without any more shame.

adapted by Cindy Stone



2006 Regional Meetings

The following is a list of dates of the meetings and the organizers you can contact for additional information.

Couldn't make the meeting or missed the date? Please contact us to learn about other opportunities to connect with others in your area.

Email us at aissgusa@hotmail.com



Northern California
Saturday, April 8, 2006
10 am to 4 pm
Ladera Rec. Dist. Community Room
Portola Valley, CA
RSVP to Jan at (650)704-8469
or e-mail picabo58@earthlink.net



Southwest Regional
Saturday, April 8, 2006
11 am to 4 pm
Kathryn's home
3922 Tivoli Avenue (rear), Los Angeles
RSVP to causavon@yahoo.com
or call 310-463-9137



New England/Mid-Atlantic
Saturday, April 8, 2006
Wake Robin Inn, Lakeview, CT
106 Sharon Rd (Rte. 41)
9:30 am to 5 pm (wakerobinn.com)
RSVP to caisie28@comcast.net
or call Barb at (732)892-2174



Pacific Northwest
Saturday, April 1, 2006
10 am to 4 pm
Seattle Children's Hospital &
Regional Medical Center
RSVP to (206)271-1513 or e-mail
aissguseattle@earthlink.net



St. Louis Region
Saturday, March 18, 2006
12 pm to 6 pm
8 Bay Hill Drive, O'Fallon, MO
RSVP to Tryla Brown at (314)910-2286
or e-mail tryla@hotmail.com



The Carolinas/Mid-Atlantic Region
Anyone interested in gathering in
the Raleigh, NC area to
share stories in a safe place?
Call Nancy Evans at 919-557-9538
or wakectygal@yahoo.com



Oklahoma/Texas Regions
If you are interested in meeting with
Susie and others in your area,
please contact her at caisusie@aol.com

A note from Cher . . .

I've been updating our member list. If you have moved or changed e-mail addresses, please let me know at aissgusasec@yahoo.com. I'm trying to get the list as current as possible, and would appreciate your help. Or, if you prefer, feel free to use the Membership Form in this newsletter to record any changes in your contact info. If you haven't had a chance to pay your 2006 dues yet, now's time to do so and ensure future mailings reach your mailbox.

Thank you

2006 - AISSG-USA BOARD OF DIRECTORS AND MEDICAL ADVISORY PANEL

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

AISSG-USA, PO Box 2148

Duncan, OK 73534-2148

Email: aissgusa@hotmail.com

U.S. Website: www.aissgusa.org

Int'l. Website: www.medhelp.org/www/ais/

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.



HOUSE series on Fox receives an "F" in bedside manner

Most times, the sensationalism of using AIS or a similar condition as a plot device on TV does not bother me. I have a sense of humor and can take a joke just as well as the next person and I have no problem laughing

at myself. Yes, I know that Dr. House was just being his obnoxious self. I simply don't buy it. His demeanor with his 15 year old patient with CAIS was tacky, cruel, cold and ugly. Rather than feeling embarrassed or ashamed, it just plain and simple made me angry.

Tryla Brown



Dutch study takes a fresh look at gonadectomy

As documented in a recently published Dutch study suggests the risk of germ cell malignancy in various forms of DSDs (Disorders of Sex Development) is different. For patients with confirmed CAIS, the risk is about 2%. However, it's difficult to rule out malignancy in infants via biopsy, because there are immature cells in the gonad. These cells diminish in number with age. Statistics show that a biopsy taken at age 14 gives a much better picture of risk. The new recommendations are to biopsy at age 14, then leave the gonads in place (unless the patient wants them out). The pubertal biopsy should allow investigation of at least 30 seminiferous tubules, preferably diagnosis based on OCT3/4 immunohistochemistry. Keep in mind that this advice holds only if the diagnosis of CAIS is reliable. The risk for PAIS intra-abdominal gonads is 50%, and a gonadectomy is definitely called for.

Jane Goto

(<http://www.medhelp.org/www/ais/PDFs/Cools-et-al-2005.pdf>)



The Board of the AISSG-USA has published this issue of the Orchid Press. Guest Editor is Nancy Evans with editing/comments by all members of the Board. Any questions/comments should be addressed to aissgusa@hotmail.org

We end our Spring 2006 Newsletter with a special treat from adult email circle member, Aimee – lyrics from a song that resonates with her as a CAIS woman. Written by Natalie Merchant, the song is "Wonder" from the Tigerlily album. Enjoy.

*"Doctors have come from distant cities, just to see me.
Stand over my bed, disbelieving what they're seeing.
They say I must be one of the wonders
of God's own creation.
And as far as they see, they can offer no explanation.*

*Newspapers ask intimate questions, want confessions.
They reach into my head to steal the glory of my story.*

*People see me I'm a challenge to your balance.
I'm over your heads.
How I confound you and astound you.
To know I must be one of the wonders"*