



## Keeping Secrets

*“The man who can keep a secret may be wise, but he is not half as wise as the man with no secrets to keep.”*

Edgar Watson Howe (1853-1937)

Mr. Howe most assuredly didn't have the AIS woman in mind when he wrote the above quote. Perhaps he would have modified it somewhat if he knew of the secrets kept by us all at some point in our lives. Many of us grew up with family members that never spoke of AIS, treating it like a gorilla in the corner. We know it's there, but we're not going to talk about it.

Keeping the AIS secret for years through adolescence and early adulthood can cause feelings that you're "not normal" or a "freak," especially if no one in your family tells you otherwise or takes the time to explain what AIS is all about. And, for many of us, our doctors kept us in the dark as well, withholding the truth or shying away from explaining the medical aspects of AIS; thus, another layer of secrecy. In some instances, this was further compounded by doctors and parents advising us that we should never disclose this information to anyone.

As adults, we yearn to share our "secret" with friends and become torn when it's time to tell our significant other/suitor. We ask ourselves, is now the right time to tell him/her? Will they reject me? Will they freak out? What if they ask questions I can't answer? What if...? Our imaginations work overtime, conjuring up scenarios that involve melodramatic outcomes, increasing our anxiety and confusion.

The following are just a few stories of fellow AIS-ers who have "spilled the beans" to their friends/boyfriends/girlfriends. Perhaps through their experiences you will see that sometimes disclosure isn't such a painful thing.

*For a few years, I worked with a group of women at a law firm and through the stresses and tribulations of day-to-day work became pretty close friends with them. Gradually, we all left the firm but still kept in touch and got together for happy hours, movies, etc. Over time, they shared their life stories with me, and I kind of danced on the edge of divulging my AIS status. I thought I could trust them, but just wasn't sure. One night, we were sitting around the table at happy hour, and I thought "what the heck. I'm going to tell!" I then launched into the story of*

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*how I had recently found the AIS support group, and told them my life story. Not once did my friends cringe or express feelings of horror (my worst nightmare); quite the opposite. They were very curious about AIS, and I did my best to explain it to them. One of my friends had heard of AIS, which helped a great deal. If anything, my divulging AIS to my friends has strengthened my friendships and now I don't feel like I have this deep dark secret looming overhead. If there's any advice I can give fellow Orchids who may be going through the issue of disclosure, it would be to go with your instincts. Are there certain friends who have broken your trust with secrets in the past? They will most likely not be the best friends to confide in. Choose friends who are true, and have shown that they can be trusted. I'm so glad I opened up with my friends, and I hope you find a trusted confidante or two to help you overcome your fear of disclosure. –Joyce H.*

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*Following decades of denial and shame about my diagnosis (revealed to me at the age of 24 when I was already a married woman), I took stock and re-evaluated as I neared my 50<sup>th</sup> birthday. I sought out the support group and became involved in intersex activism and education, including speaking frequently at two local medical schools and acting as the primary contact for the Intersex Society of North America. All this activism raised an interesting situation ... will it just be a matter of time before friends, colleagues and family stumble across some reference to me in the media or on the internet? Facing this eventuality and, more importantly, not wanting to perpetuate the white lies and evasiveness of the past, I have begun to selectively tell my story. My readiness for this change was bolstered by my husband when he told me "Please don't hide who you are in an attempt to spare me from embarrassment. Be who you are!" And so, to my great joy, the people I have chosen to tell my story have been wonderfully accepting and understanding. I once feared the earth would open up and swallow me if anyone discovered "the truth." Now I start each day relieved to be free of*

*the burden of secrecy that once hobbled my spirit. .  
–Jane G.*

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## Regional Meeting Wrap Up

One of the most satisfying events an AIS woman experiences is a meeting with other AIS women. Regional meetings were held across the country from January to April of this year. A summary of the meetings follows.

### Midwest

The Midwest regional meeting was a success! The meeting was held at Teresa's home in the St. Louis, Missouri area. The actual meeting was attended by two affected individuals and one interested individual. Many people were planning on attending the meeting, but due to health issues and family matters were unable to attend. The people that did attend the meeting were treated to great conversation, a wonderful lunch, lots of chocolate and feelings that can only be felt by meeting with other AIS individuals!

*Submitted by Teresa, St. Louis, Missouri*

### Southern California

During a brief break in the rainy season in Los Angeles in January, Kathryn hosted a regional meeting at her house. It was low key and informal, but as always, extremely informative. This meeting was a chance to meet newcomers and catch up with old friends. Newcomers this year consisted mainly of parents of young children, which was a very gratifying experience. It's always good to give young parents who may be scared or worried about doing the right thing the benefit of our adult AIS

experiences. This is exactly what happened that day and we all could have spent hours more discussing everything, but as it was, we spent nearly four hours together and there were many heartfelt goodbyes after it was over.

*Submitted by Kathryn, Los Angeles, California*

### Northern California

The Northern California regional meeting of the AIS Support Group was held March 19 and was a huge success. The morning started off dark and rainy, but the weather broke at around noon and we were treated to brilliant sunshine.

We did not have a set agenda so that people could take as much time as they needed to tell their story. This is always a wonderful part of the meeting, hearing about the incredible journeys we've taken to get to where we are today.

Some of the things we discussed in the afternoon were:

- If a carrier mother produces two affected AIS daughters, and the older daughter is diagnosed with PAIS, does this guarantee that the younger daughter will also be PAIS? Can there be PAIS and CAIS forms in the same offspring of one mother?
- What is the current belief on leaving the gonads in on an adult woman, as opposed to removing them?
- (For parents) At what point do you tell your AIS daughter about all of the details of her condition?
- AIS women adopting children and the difficulties they might experience in relating to a daughter when she goes through puberty.
- Any consistency in the theory that there is a prevalence of 'latent' bisexuality in AIS women? We've heard about the research on homosexuality in AIS, but several of the



attendees commented that they had 'thoughts and urges' throughout their life that they did not act upon, that could only be explained as suppressed or latent bisexuality.

And the overwhelmingly popular topic:

- The PSYCHOLOGICAL issues relating to AIS - Interpersonal relationships, how we perceive others and interpret their comments and behavior, and the psychology of dealing with the secrecy and shame resulting from the diagnosis.

We also discussed the August Annual Meeting and planned a couple of meetings to work out some of the small details and to assign tasks.

*Submitted by Jan, Portola Valley, California*

### **Pacific Northwest**

On a beautiful spring day in Seattle, a dozen women from Washington and Oregon got together to share their stories and a wonderful potluck lunch. Finding the hospital conference rooms of past meetings a little off-putting, we opted for a home setting this year; enjoying being able to sprawl about the sofas and wander out to the deck occasionally for a breath of fresh air or, conversely, a cigarette or two.

Coming in a close second in popularity to Carolyn's amazing cinnamon buns, was our annual Hormone Replacement Therapy show-and-tell. Fanny regaled us with her story of frustrated attempts to use an estrogen ring until we all dissolved in laughter.

It was great to see old friends and marvel at their progress from secrecy and shame to burgeoning self-confidence. It was also wonderful to finally get to know support group alumni Janice who was able to make the meeting this year.

*Submitted by Jane, Seattle, Washington*

### **Oklahoma**

The First Annual Oklahoma Regional Meeting was held on Saturday, April 9th. It drew members from Oklahoma, Texas and Kansas and included parents and adult women with AIS. The meeting was spent with time for getting to know one another, telling our stories, asking questions, sharing ideas and offering support to each other. Within a few minutes of everyone's arrival, we felt like old friends and soon we were laughing and having a wonderful time. As one of the meeting planners, I was thrilled that it all went so smoothly. There is talk about including the young girls of the attending parents at our next meeting. I hope that we will continue to grow and be able to reach many of the others in our area.

*Submitted by Connie, Edmond, OK*

### **New England**

For some girls, this was their first face-to-face meeting with AIS individuals. There were six of us in attendance: one mother of affected daughter and five AIS women. I have to say the Wake Robin Inn couldn't have been more professional and courteous setting up our rooms and especially the meeting room. When I stepped into it Saturday morning, there was sodas, ice, glasses, water, yellow legal pads and pencils on the table. They gave me a frame for my 'Women's Support Group' picture that hubby made for me. We had the sunroom and views of peaceful wooded surroundings. Just beyond our large table there was a small, intimate sitting area with antique furniture.

We began by introducing ourselves and giving brief bios - all very moving histories. We discussed all issues dealing with AIS from gonadectomies, doctors, HRT, bone density, adoption, harvesting sperm from intact gonads (maybe a dream but addressing our inner need to bear our own kids in a way), breastfeeding and having personal resolve to monitor our health. During one of our breaks we walked the path down to the lake, let off some steam by skipping rocks, basking in the warm sun



and talking about life in general. I think we've formed a bond. We also decided to make next year's meeting a little more accessible to the mid-Atlantic region by changing the venue to Pennsylvania or maybe even New Jersey. New Jersey?

We had lunch on the sundeck under an umbrella. The Inn provided wraps, salad, drinks and best of all - brownies dusted with powdered sugar. We also had a supply of peanut M&Ms at our meeting table. Nothing takes away the anxieties like chocolate. When will pharmaceutical companies get wise?

I was very impressed with the strength and resolve of the attendees to address their personal medical and life's requirements. These are not naive little women as I was way back when, but informed and smart, beautiful and accomplished.

We ended the day with hugs and best wishes and then went our separate ways. We'll see each other again at the annual meeting in Palo Alto. I miss you girls so much.

*Submitted by Barb, New Jersey*

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## **One to Grow On...**

**A parting thought to help inspire you**

*[The secret of] how to live without resentment or embarrassment in a world in which I was different from everyone else.... was to be indifferent to that difference.*

-Al Capp, "My Well-Balanced Life on a Wooden Leg"

*A wonderful fact to reflect upon, that every human creature is constituted to be that profound secret and mystery to every other.*

-Charles Dickens, A Tale of Two Cities

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