



ARTHRITIS INTROSPECTIVE

UNITING PEOPLE WITH ARTHRITIS
DURING THE PRIME OF LIFE

The Gathering—A Newsletter

The 6th Annual National Gathering Conference A 'rockin' good time!

WE ROCKED IT!! Yes, we did it, together; the 2013 Annual National Arthritis Introspective Gathering-G6, May 17-20, Scottsdale, AZ, was the biggest and best conference yet! When the Gathering began, six years ago, we had 15 people attend. How things have changed, for the founding members of AI, reaching the 100 participants mark is a truly inspiring milestone.

While the Gathering is always a great reunion for veteran members, we were very excited to see that nearly 50% of our participants were first time attendees and by the end of the weekend, many new friendships were made.

Our keynote speaker, Laurie Ann Miller gave an amazing and inspiring talk. Diagnosed at 12-years-old, she spoke about her struggles with coming to terms with her illness, of the pain of hiding the disease while pursuing her dream of becoming an actor and how excruciatingly lonely it is when the disease isn't visible and you don't look sick.

"It's such a silent disease," Laurie explained. "You smile through the pain, especially when you don't look sick." This is something every single one of us can understand. However, Laurie's message was one of challenge to triumph. After Laurie's first trip to our nation's



capital as an arthritis advocate, she says she heard a voice that said, "This is where you are supposed to be." Though there is pain, though there is loss, Laurie has found her place and her passion through her disease and that is why we believe she ROCKS!

Along with Laurie's moving keynote talk, the weekend was filled with amazing and informative speakers and even more inspirational stories. That is truly what the Gathering is all about, our stories. Every person wants to be heard and acknowledged. Women and men who rarely speak of their disease, open up and their feelings pour out into a sea of understanding that only others living with arthritis can sail.

We would like to thank our collaborators, Rheumatoid Patient Foundation, Arthritis Foundation-Pacific Region, Virginia G. Piper Sports & Fitness Center for Persons with Disabilities-Spofit, Spooner Physical Therapy, Crescendo Bioscience and Abbvie Pharmaceuticals. A special thank you also to our dedicated committee and event volunteers! You made this a record-breaking event!



Volunteers are the foundation for our organization

Did you know that Arthritis Introspective is the only national non-profit dedicated to providing local, volunteer-led Support Systems specifically designed to assist those living with arthritis and its related autoimmune diseases in the Prime of Life, those “too young to have arthritis”?

It takes a village of passionate, committed volunteers to help us run this crucial non-profit organization. Because the most vital advice and support comes from others who have “been there”, we believe that the best way we can grow and prosper is by asking our members, those who have experience in non-profit, volunteer and/or business management, fundraising, marketing and/or event planning to contribute their skills and talents to help build and lead Arthritis Introspective. So very many of us have had to take very early retirement, but that does not mean that your skills need to be retired as well. We all have something to contribute, and by volunteering, you are not only helping AI, volunteering also helps build your self-esteem and confidence, fights depression and helps keep you physically active. So please do something good for yourself and for AI. Volunteer for Arthritis Introspective today.

Be part of making AI Shine

Are you interested in joining the AI national leadership team? Do you want to help AI grown? Currently, we have several open key volunteer positions including:

- Board of Directors – Directors at Large
- Fundraising / Grant Writing
- Marketing & Communications
- Membership
- Board Development
- The Gathering 2014
- Outreach Relations Specialists

Please help us help others know they are not alone. Submit an online application by clicking below:

<http://www.arthritisintrospective.org/Volunteer.html>

To start an **Arthritis Introspective Support System** in your area, please visit:

www.arthritisintrospective.org/ORSApplication.html



To Tell or Not to Tell: Love in the age of the internet

In this new millennium where we virtually live online, it's become a given that if you are single, you've tried at least one online dating site. In fact, it's estimated that over 40 million singles in the U.S. alone, are online dating (ansonalex.com). We see the success stories on the TV ads, but more often, we hear horror stories about people lying about everything from looks to gender.

For many of us living with arthritis and/or a related condition, rather than subtracting a few pounds or adding a couple zeros to our incomes, it becomes a question of "Do I mention my disease and if so, how?"

Personally, I've been playing the online dating game for a decade (obviously not very well) and this question has always perplexed me. I was diagnosed with Rheumatoid Arthritis (RA) as a child, therefore my hands are crooked, I have a limp, and my body bears many scars. But you don't see this in a profile picture. What you see is my smile and the laughter in my eyes. However, the question remains, do I mention my RA in the "About Me" section?

Through trial and error, I've decided that my disease is worth mentioning, as a lot of men seem to want sporty partners. I mention it casually, for example, "I've had arthritis since I was a kid, so I don't play sports but I'm a great cheerleader." I've also found that if I choose not to declare my diagnosis but mention the work I do with AI and other organizations, can lead to a natural conversation about why I became involved with the arthritis community. However, I'm only one person and I'm still single, so I decided to ask a few other ladies who have had success with online dating, "Did you disclose and if so, how?" Here's their advice.

Rocio, who met her husband online says that while she didn't actually list her RA on her profile, she was sure to casually mention it in conversation soon after the first contact. "I'd say something like, 'Man my bones hurt, they aren't the typical 30s cause of my arthritis.' Then mention something else and go back to it, little by little." Rocio says that because she doesn't make arthritis the center of her world, she didn't want Jaime (her now husband) to make it the center of their romance. "I would slowly add

information, but nothing that would overwhelm him. Men scare easy," she laughs. By the time they met in person, Jaime knew Rocio had limitations but they didn't appear until they had already been on several dates. "You have to reel them in first," she advises. "I've dated several guys from online and the thing that got them all smitten was my confidence, not my looks."

Research agrees, as I scour the Internet for "what men find attractive," Confidence continues to show up in the Top 10. Yet for each of us, the older we get, the more confident we become with who we are, and the easier it becomes to own the disease without turning it into anything more than a fact of life.

Kelly, who was also diagnosed as a child and has used a wheelchair since grade school has also learned that it's best to be open right away. "Years ago, I hid it at first--wanting guys to like me for me," Kelly explains. "I soon realized it is better to be up front about it. I usually let guys approach me and plenty did! That way I knew they could accept it." Kelly's current boyfriend was one of those guys. "Matt realized from my profile and by meeting me that I did more than most women who don't have a disability. To this day, he says it never really stood out to him." That is Confidence.

Of course, these are stories of women who've lived with the disease a long time, and have obvious physical differences caused by the disease progression. So what about those who are newly diagnosed, those who "don't look sick." The decision to disclose seems to be the same. Emily was diagnosed with RA two years ago, in her early 30s. The year leading up to her diagnosis was very painful and limiting. She had problems doing her hair, walking short distances and even being sexual. Now that she is on a biologic and the disease is controlled, she does mention her diagnosis, not in her profile but once she feels the relationship may go somewhere. "I think it's only fair," she says. "If I flare, I want that person to be able to be there for me, or at least know what is happening. I don't think it's something I should have to keep a secret."

It seems that honesty is still the policy. Of course, age, weight and income are another story.

Announcing New AI Support Systems!



One of the key initiatives of AI is our **AI Support System program**. Our trained Outreach Relations Specialists (ORS) coordinate regular educational and social events, serving as a resource of information, and understanding right in your community. We are pleased to announce five new ORS have completed the training program and we have added four new AISS. We look forward to connecting with you. To join please visit:

www.arthritisintrospective.org/supportsystems.htm

[Marilyn Swallow](#)



[Catherine Riley](#)



[Stephanie Manus](#)



[Mary Harrold](#)



And [Denise Hribar](#) joins Orange County CA as co ORS



*Planning for the Future!
The Arthritis Introspective National
Conference in
Your city here*

Many members have suggested their city as the location for future AI national events and we're listening. The National Conference is a labor of love and hard work. In order to conduct a successful national event the first step is to recruit a strong, knowledgeable committee and to have the time necessary to oversee such an involved and important event. We would like to give everyone the opportunity to become a host city for a future AI event and the first step is to complete the AI Conference Chairperson/Host City Interest Form. If you have the necessary resources, you will be invited to submit a formal event proposal. Please visit

<http://www.arthritisintrospective.org/future.html>

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