



# ARTHRITIS INTROSPECTIVE

UNITING PEOPLE WITH ARTHRITIS DURING THE PRIME OF LIFE

*The Gathering*



2010 Issue 1 Vol. 4

## *El Festival de Amistad*

The time is near. The 2010 Gathering is almost here. Are you ready? April 9<sup>th</sup>, Arthritis Introspective members from all over the country will come together in Tempe, AZ for a weekend of education, sharing and laughter. Over the past six months, AI has grown tremendously and each day new members are joining us on Facebook and through the official AI site. So what's next? The Gathering, that's what. The one time of year we can all come together reuniting with old friends, making new ones, sharing challenges and celebrating triumphs.

We all know that there's nothing better than having someone say, "I know how you feel" and actually really KNOW how you are feeling; to see someone with hands like yours or a walk like your own. In fact, AI was born from a group of friends brought together through an arthritis conference many years ago.

This year's sessions are geared towards empowering and encouraging ourselves and those who love us, along with leaving plenty of time for socializing and new adventures!

The 2010 Gathering El Festival de Amistad -The Festival of Friendship will take place April 9-12<sup>th</sup> at the Courtyard Tempe Downtown.

### Schedule of Events:

Friday: 4-6 pm Registration.

6-9 Opening Ceremonies, Barbecue & Live Music

Saturday: 9-10:30 am Registration & Continental Breakfast in hotel lobby.



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10:30 – 11:45 am Attitudinal Barriers – Attitude can affect our disease.

12 – 1:30 pm Lunch on your own.

1:45 – 3:00 Break Out Sessions

- Art Therapy—Mandala
- Alternative Therapies

3:15 - 5 Break Out Sessions

- Spirituality
- Coping with Depression

6:00 NIGHT ON THE TOWN

Sunday: 10:30-11:45 am Pharmaceutical Advancements.

12-1:30 pm Lunch on your own.

1:45-3 Breakout Session

- Relationships/Dating
- Sex

3:15-5 Roundtable Discussions

- Men w/ arthritis
- Women w/ arthritis
- Spouses/significant others

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Sunday Con't...

5:30 – 8 Closing Ceremonies

8:00 pm A NIGHT ON THE TOWN TAKE 2

Outside Excursions:

- Road Trip & Glider Ride  
(Monday, April 12)
- Accessible, Adaptive Sailing on Tempe  
Town Lake
- Pueblo Grand Museum & Indian Ruins
- Heard Museum

See AI website or contact [pjfischer@hotmail.com](mailto:pjfischer@hotmail.com)  
for more information.

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### *Taking Take of the One Taking Care of You*



We've heard it before; arthritis doesn't just affect the person diagnosed, but the entire family. Yet little attention gets paid to the emotional well-being of the able-bodied partner. We know that the pain, the uncertainty and the loss of ability from arthritis (aka Arthur), along with pharmaceutical side effects, lead to depression and that depression, stress and anxiety, aggravate Arthur, creating a vicious cycle. However, how often do you and your partner/spouse have an open dialog about his/her feelings about the disease and the impact it has on your life both as individuals and as a unit?

Did you realize that his mood can affect your disease? Recent studies have found that, "When spouses are depressed, they may be less likely to provide the necessary quality support needed by the partner with rheumatoid arthritis (RA). Spousal support given to the partner with RA enhances

coping mechanisms, therefore reducing pain; support also reduces catastrophizing-which can become an irritant to those sharing the environment with chronic pain patients. Spousal depression, and the criticism and hostility depression often engenders, can result in a RA patient having maladaptive coping behaviors, and therefore poor psychological adjustment, not to mention more pain. (Arthritis Care and Research, 2009)."

It cannot be easy to watch the person you love hurt. In fact, it is heartbreaking. It is also frustrating as you both mourn the loss of activities that you used to share and struggle to accept and learn to celebrate the new life you must cultivate...replacing old dreams with new ones. There is guilt on both sides. The sick spouse feels guilty for "holding him back." Meanwhile the able-bodied spouse may feel guilt over his continued activity or more so, guilt over his own feelings of resentment, mistaking resentment for the disease as resentment toward his spouse.

The hardest part of loving a person with Arthur is "Constantly seeing someone you love in pain and the frustration of watching them not able to live the life you know they would like," says Don, whose wife of 22 years, Annette, was diagnosed with very aggressive RA shortly after they married. Don also admits to the frustration he sometimes feels at the limitations placed on the couple's activities. "I don't do as much because I know she cannot." However, the couple does their best to adapt, finding new activities to do together; and allowing Don to still participate in many of the physical activities he enjoys without feeling guilty for "leaving her behind." The key is communication. "And patience," says Don. "Patience on both sides. Don't get mad at the person; get mad at the disease. My wife taught me that. Since there are good days and bad, don't waste the good ones. Take advantage of the time when the disease lets you enjoy life a little more."

In order to assure that you, your partner and your relationship remain as emotionally healthy as possible, we've compiled some tips for you to share with your partner. It can be difficult to bring up those feelings of fear, loss, resentment and guilt, but

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they exist and if acknowledged, can be worked through. We hope that the following tips will help begin a dialog with your partner and give you new ideas to help him/her cope with life with Arthur, both alleviating a lot of the burden he/she may feel and help you feel empowered by taking care of the one who takes care of you.

### TIPS FOR THE CAREGIVING PARTNER

- Educate yourself about your partner's condition.
- Talk to your partner and develop safe ways to express feelings of frustration, anger and loss—recognizing and accepting that these feelings are towards the disease not the person diagnosed.
- Remember that you too, have been diagnosed with this disease and though you are not the one in physical pain, your emotional pain is just as valid.
- Learn the Kubler-Ross Grief Cycle: denial, anger, bargaining, depression, acceptance. Understand that the cycle applies to those dealing with chronic illness and that when dealing with Arthur, we will often re-visit the stages as new challenges arise.
- Watch for signs of depression, and don't delay in getting professional help when you need it.
- Remember that it's still okay to be active even if your partner can't be. Don't give up your favorite sport, work out or physical activity. You may need to cut down the frequency, but do not give it up. This can only lead to resentment and guilt on both sides.
- When possible look for creative ways your partner can still participate, even if it's merely cheering you at the finish line or steering the boat.

- Keep a journal. Write down your thoughts and feelings. This helps provide perspective on your situation and serves as an important release for your emotions.
- Watching helpless as your loved hurts is heartbreaking. Seek support from other caregivers. There is great strength in knowing you are not alone. Keep an eye open for the new AI Partner Program.
- Caregiving is exhausting. When your partner is flaring, make sure to give yourself breaks as well. When people offer to help, accept the offer and suggest specific things that they can do.
- There's a difference between caring and doing. Be open to technologies and ideas that promote your partner's independence, empowering them and alleviating some of your responsibilities.
- Grieve for your losses, and then allow yourself to dream new dreams.
- Trust your instincts. Most of the time they'll lead you in the right direction.
- When all else fails, buy yourself a Nerf baseball bat beat the hell out of something sturdy!

Survey Says...multiple regression analysis revealed spouse depressive symptoms at initial assessment to be predictive of follow-up PWRA (patient with rheumatoid arthritis) disability and disease activity, even after controlling for initial levels of PWRA depression, disability, disease activity, age, number of years married, education, disease duration, and employment. Specifically, higher levels of spouse depression predicted worse disease course over a 1-year period for PWRA, as indicated by higher reports of subsequent PWRA disability and disease activity.

*Help us continue to continue our mission by donating today.  
Arthritis Introspective is a volunteer-run organization relying solely  
donations from the greater community to fund our events, programs and  
services. Every dollar makes a difference.*

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## *Expression Session*

### Hands

I notice the hands of the women around me  
The fingers that knit and tie shoelaces  
Write letters  
And rub backs  
Trail up thighs  
Entwine with other long, straight, fine fingers

And fold together to pray

Upon first glance, our hands are not the same  
These knuckles dip  
Sink where they should extend  
Growing large and red  
Thumbs drift as if attached backwards

Some find these hands ugly  
Those to whom they don't  
Belong  
Often find them  
Wrong

Yet we still care for these gnarled knuckles  
These deformed digits  
Meticulously moisturizing, manicuring and  
maintaining

These hands that  
Too  
Knit and tie shoelaces  
Write letters  
And rub backs  
Trail up thighs  
Entwine with long, straight, fine fingers

And fold together  
To pray.

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## **Each day, our community grows. Form a Support System in Your Area! What IS an AI Support System?**

- A place to find information about arthritis, providing information, resources and emotional support.
- A social network, providing fun, affordable and informative events to its members.
- An empowering community of people living with arthritis, dedicated to providing a safe, confidential place to share your feelings while sharing positive coping strategies and finding the best way to navigate life with arthritis.

### What does a Facilitator do?

- Facilitate meetings ensuring a positive, respectful and comfortable atmosphere to those attending.
- Coordinate fun and engaging events, from pot luck dinners to group outings.
- Lead the group discussions, prompting and allowing honest and confidential discussion on both the trials and triumphs of living with arthritis.
- Communicate with other AI members to ensure that all members are getting the support and positive experience intended.

### **Local Chapters:**

Phoenix & Tucson, AZ  
Dayton, OH  
Milwaukee, WI  
Illinois Valley Area, IL  
Idaho-Southwest Area  
Metro Richmond Area, VA  
Northern Vermont  
Louisville, KY

\*For information on beginning a Chapter in your area, contact [Kevin@arthritisintrospective.org](mailto:Kevin@arthritisintrospective.org).

Arthritis Introspective and *The Gathering*, is a member-driven organization. We want your input and feedback and are looking for writers to contribute to both the newsletter and the website. Visit [arthritisintrospective.org](http://arthritisintrospective.org) to join the discussion forums; share stories, poems, essays or general rants.

**Visit our new Facebook Friends  
Together we will change the world of arthritis!  
The Gimp Club  
RA Warrior  
Changed by Rheumatoid Arthritis-Young (CRY)**

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