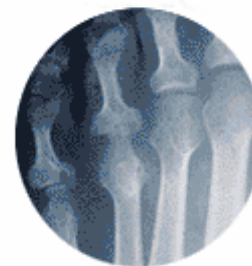


JOHNS HOPKINS arthritis center



NEWSLETTER

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A Mothers Tale: Pregnancy & Rheumatoid Arthritis

At the age of 29, Amy learned that she had rheumatoid arthritis (RA). She finally had the explanation for all the stiffness and pain in her hands and feet in the past year. Her primary care doctor suspected RA when her blood test for rheumatoid factor came back positive and she was referred her to me. I confirmed the diagnosis, on the basis of the joint examination, blood work and xrays. Fortunately for Amy, her RA was detected fairly early, increasing the likelihood of better treatment outcomes.

Amy did not have any immediate plans for a family, so we began treatment with methotrexate (and for a short time with plaquenil as well). She did very well for about two years but then her arthritis starting becoming considerably more active again, causing those all too familiar symptoms of stiffness, pain and fatigue. We added Enbrel[®] to the methotrexate, and Amy responded very well to this combination. It was also about this time that marriage and family became real possibilities.

Finding out that you have RA at a young age is very scary. For Amy, it left her with many difficult questions and concerns. "Will I be able to have children? If so, what

will I need to do? What will be the long-term impact of the medicines? I didn't know what to expect



and assumed the worse." In spite of this, Amy faced her RA and her decision to have a family with confidence and careful planning.

Given that two strong medications were required at this point to control Amy's RA, it was reasonable for her to wonder whether having children was even an option. I assured her that I would do everything I could, as her caregiver, to make it possible for her to have children and to do so with the least amount of damage to her joints.

Amy learned that she would need to stop taking the methotrexate at least 3 months before trying to get pregnant. This is because methotrexate can cause birth defects to the fetus, and a period of washout of the drug is needed. What to do with Enbrel during pregnancy is less clear. Because there are no formal clinical trials

(Continued on page 3)

New Study will Assess Effects of Physical Activity on Rheumatoid Arthritis

Researchers at the Johns Hopkins Arthritis Center are enrolling adults with RA into a new study that will evaluate the effects of a new way to increase physical activity.

In this study, RA patients will be randomly assigned to either a traditional exercise program or a new program designed to increase physical activity throughout the normal course of the day. At the start of the study, participants will complete a series of questionnaires (measures of pain, mood, physical activity), a walking test, and provide a blood sample.

All participants will be asked to attend a total of 8 group meetings spread over 4-months. During these group meetings participants receive information, support, and an exercise program.

At the end of the 4-month intervention and 6 months later, participants will return to repeat the tests they completed at the start of the study. The total length of commitment for the study is about 11 months.

To be eligible to participate in this new study, you must:

- Be between 25 to 65 years old
- Have been diagnosed with RA by a physician
- Be stable on any medications used to treat RA
- Be able to walk without assistance
- Be physically inactive (not exercising)
- Be generally healthy and willing to become more physically active

If you have RA and are interested in taking part in this study, please call (410) 550-5216 and we will ask you a few questions to see if you are eligible. If you are eligible, we will describe the study and give you a chance to ask any questions to help you decide if you want to participate. Before you are enrolled in the study, we will ask you to get clearance to participate from your doctor.

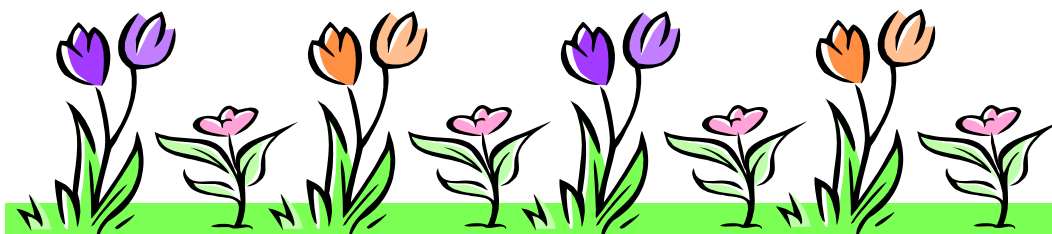
FOR MORE INFORMATION

Please call (410) 550-5216

IRB No:HBV03-10-06-01

Principal Investigator: Kevin Fontaine, Ph.D.

Happy Spring!



(Continued from page 1)

of Enbrel[®] treatment in pregnant women, we do not routinely recommend it during pregnancy. However, it is useful to note that none of the anti-TNF drugs (Enbrel[®], Remicade[®], Humira[®]) causes birth defects in pregnant animals, nor do they cause any damage to DNA in test tubes. Furthermore, there have been over 100 of women with RA or psoriatic arthritis who have conceived on Enbrel[®] without any apparent increase in the number of miscarriages or birth defects or still births compared to pregnancies in the general population. In light of this, and given the severity of Amy's RA, I suggested that she might want to consider continuing Enbrel up until pregnancy was successfully achieved, and then stop it. This would avoid a prolonged period of no treatment while she and her husband tried for a pregnancy. After all, not everyone becomes pregnant right away !!

Before making any decisions, Amy also decided to meet with an obstetrician who specialized in high risk births to discuss her condition before she became pregnant. Her obstetrician was very pro-active and also discussed pros and cons of various treatments in detail with Amy.

Amy clearly wanted children, but I could also tell how worried and fearful she was about stopping her medications. The thought of becoming sick again at a time when she most wanted to be strong and healthy (that is, during pregnancy) was very scary. Nonetheless, her courage and determination and love of children and of her husband drove her forward. When she was ready, we stopped the methotrexate for the three month washout. Indeed, she did begin to feel poorly and the dose of Enbrel had to be increased during those three long months. Once Amy learned she was pregnant, we stopped the Enbrel as well and began her on prednisone (which is safe during pregnancy).

Unfortunately, Amy ended up having a pretty rough time during pregnancy (despite what the medical literature says about RA getting better during pregnancy!!) She was followed closely by our arthritis nurse, Vicky Ruffing, RN, as well as by me and her



obstetrician. We ended up having to increase her oral daily dose of prednisone and, in addition, we had to periodically give her injections of prednisone in the muscle or in the joints (especially the knees and ankles) to keep her functional. Remarkably, she continued to work full time throughout most of her pregnancy until six weeks before her due date when her blood pressure increased. At that point, she was put to bed rest. [The high blood pressure was not a complication of the RA.]

At 12:45am on January 1, 2005, Amy delivered a beautiful, healthy baby boy named Nicholas who surprised everyone by coming 3 weeks early. I was so excited to have the privilege of meeting Nicholas and congratulating his parents the very next day !! Amy struggled with the decision of whether or not to breast feed. The decision not to breast feed was very difficult. Although she was well aware of the benefits of breast feeding, and we (her doctors) thought she could breast feed even while receiving the RA medications, she did not want to take any chances of the drugs injuring Nicholas. So, she sadly decided against it and went back on her RA medications fairly promptly after delivery. She is now feeling fairly well again, although her RA is still not completely controlled on methotrexate and Enbrel.

At the writing of this article, Nicholas is now 4 months old and his parents, Amy and CJ couldn't be happier!

When asked what words of advice she can offer to others in her position, Amy had the following to say.

- Definitely discuss your concerns and fears with your rheumatologist in advance of trying to get pregnant.
- Do the same with an obstetrician who is knowledgeable about the condition and understands the risks involved.
- Ask questions about medication risks and precautions that need to be taken.
- Planning, both mentally and physically, for what might happen is key!

I strongly concur with those recommendations. I couldn't have said it better myself !!

Written by Joan Bathon, M.D.

FAQ's — COX-2 Pain Relievers...What now?

Q Now that Bextra and Vioxx are no longer available, what can my doctor substitute for pain control?

A Controversy surrounding the COX-2 inhibitors including Vioxx[®], Bextra[®], and Celebrex[®] has been the subject of much media coverage in the past months. This has led to confusion in patients and physicians alike regarding the use of the COX-2 inhibitors and even of the entire non-steroidal anti-inflammatory drug (NSAID) class.

Several clinical trials have noted an increase in cardiovascular events. This concern and others are described in detail on our Website (see page 5). The recent decision by the FDA to remove both Vioxx[®] and Bextra[®] from the market and to add a warning to the prescribing information for Celebrex[®] has left many patients unsure of what alternatives are available for pain control.

Your doctor may switch you to one of the non-selective COX inhibitors (these are the NSAID drugs – such as ibuprofen (Motrin, Advil), naproxen (Aleve), diclofenac (Voltaren), and many more). Many of these drugs have been used for decades and, importantly, have never been shown to be inferior to the COX-2 inhibitors in ability to control pain. The main side effects, which COX-2 drugs were developed to prevent, are stomach discomfort and heart burn. Gastrointestinal (GI) bleeding can occur as well, particularly in older people and those taking higher doses of prednisone. For these reasons, all NSAIDs should be taken with food.

Your doctor may choose to prescribe another medication along with the NSAID to reduce the GI symptoms. One option is a proton-pump inhibitor (PPI) (Prilosec[®], Nexium[®],

Prevacid[®], and Aciphex[®]) which helps protect the stomach lining from damage by decreasing acid production. NSAIDs and PPIs can be safely taken together and PPIs have few known side effects or drug interactions. Cytotec[®] may also be prescribed with Arthrotec[®]. This medication also helps protect the stomach lining, but does not reduce acid in the stomach. The development of diarrhea and abdominal cramping can limit its use in some people. It absolutely cannot be taken in early pregnancy. Other options include H₂ Blockers (Pepcid, Zantac, Axio). These reduce acid in the stomach, but do not eliminate it.

Finally, your doctor may prescribe other non-NSAID analgesics, such as acetaminophen (Tylenol) or tramadol (Ultram, Ultracet). Narcotic analgesics should not be used to treat chronic symptoms unless all other options are ineffective. Some topically applied medications, such as capsaicin cream or patches containing the local anesthetic lidocaine, can provide relief for localized pain. Other analgesic methods, such as acupuncture, can provide pain relief in some people. It is important to remember that herbal remedies can be effective in some people but, unlike the NSAIDs and COX-2 inhibitors, most have received little or no testing of safety or efficacy. These options may provide pain relief, but unlike NSAIDs, do not reduce inflammation.

Decisions regarding the many options for pain control should be actively discussed between you and your doctor. It is important to let your doctor know about any over-the-counter pain medications including supplements that you take.

Written by Jon Giles, M.D.

Tips and Tricks for Daily Living

It's spring and many of us are thinking about getting our lawns gardens in shape. These tips may help prevent pain and fatigue.

- Pace yourself by allowing time for frequent breaks.
- Vary gardening tasks so you are not performing any repetitive motions for more than a few minutes at a time.
- Ask for help with heavy chores i.e. mulching and mowing. Consider making a day of heavy yard work into a family affair. You can still get the results you want if you 'direct' the work instead of 'do' the work.
- Pushing a lawn mower can mean discomfort for a few days afterward. You may want to hire someone just to do the mowing and raking or maybe a neighbor would be willing to barter mowing for a baked treat!



Written by Victoria Ruffing, RN

On The Website — Email Updates on Latest Website Additions

Every quarter, we send out an email updating our website visitors about “what’s new” on the Johns Hopkins Arthritis Website. This is an easy way for users of our website to stay informed about content additions. Signing up is easy and right on the home page. Also, opting out of future emails is just as easy and we do NOT share our mailing list!

The screenshot shows the Johns Hopkins Arthritis Center website. At the top, there is a navigation menu with links: ask the expert, case rounds, rheumatoid arthritis, osteoarthritis, arthritis other, education, disease management, message board, radiology rounds, clinical trials, links, about us, patient's corner, and search. Below the navigation is the Johns Hopkins Arthritis Center logo and a search bar with a "go" button. A "Sign Up Today!" box contains the text "Join the Johns Hopkins Arthritis Center mailing list" and an "Email:" field with a "Submit" button. To the right, there is a section titled "arthritis news" with a link to "archived news". The news section includes an update date "(updated April 10, 2005)", a disclaimer "*Arthritis news summaries and editorials are written by Jon Giles, M.D. and Joan Bathon, M.D. unless otherwise noted.", and two news items: "Does Survivin and Survivin Antibodies Play a Role in Rheumatoid Arthritis?" and "Pfizer Removes Valdecoxib From the Market".

GO TO

To join the Johns Hopkins Website mailing list, visit
<http://www.hopkins-arthritis.org>

Adults with Arthritis are Becoming a Little More Physically Active

It is clear that being physically active helps people with arthritis. It not only improves arthritis-related symptoms, it also improves overall health. Unfortunately, despite these benefits, most people with arthritis do not meet the US Surgeon General’s physical activity recommendations. Specifically, in an article published in the journal *Arthritis and Rheumatism*, Drs. Bathon and Fontaine, using data from a 2001 national survey, estimated that less than 40% of adults with arthritis meet the Surgeon General’s recommendation of accumulating at least 30 minutes of moderate-intensity physical activity on 5 or more days per week or 20 minutes of vigorous intensity physical activity on 3 or more days per week. Given the recent increased emphasis on promoting physical activity from public health and private organizations such as the Arthritis Foundation, Dr Fontaine sought to estimate whether the rates of physical activity among persons with arthritis have increased since 2001.

As reported in the February 2005 issue of the *Journal of Clinical Rheumatology*, the prevalence estimates of physical activity among persons with arthritis have changed very little since 2001. The prevalence of meeting the physical activity recommendation of the

Surgeon General increased by only 1% (38.3% to 39.2%) from 2001 to 2003 suggesting that arthritis patients are really not getting more active. However, among certain groups of people with arthritis, the prevalence did increase. That is, the prevalence increased by 6% among arthritis sufferers aged 18 to 24 and about 4% among those who never smoked. It also increased by about 3% among those who were obese and among those aged 55 to 64 years.

The estimates fall far short of the government target that at least 50% of adults with arthritis meet the Surgeon General’s physical activity recommendation. As Dr. Fontaine noted, “Needless to say, these results are discouraging. We know that getting more active can help people with arthritis, but, for some reason, we are not getting the message across to our patients. I think we are at a point where we not only need to recommend physical activity, but we need to give patients a specific prescription that they can act upon. For example, we should tell our patients to try to accumulate a half hour of activity throughout the day. Just getting them to be a little more active could go a long way toward improving the quality of their lives.”

How to Avoid the Traditional Handshake



Traditional handshake

Handshaking is a very common custom when making introductions. In the traditional handshake, both hands are in vertical position (palm facing inward) allowing a firm grip to be made. However,

the traditional method of handshaking can be quite painful for a person with arthritis. Often, joints in the hand can be swollen and painful. The last thing this person needs is to have their fingers smashed together and their hand shaken rigorously up and down. So how can this very common custom be avoided?

According to Dr. William Shiel, an Associate Clinical Professor of Medicine at University of

California, the traditional handshake can be avoided simply by changing the way that you extend your hand. Instead of holding your hand vertically, extend your hand with the palm down and the backside of your hand up. This causes the person you are greeting to grasp your hand gently, turning their palm up into yours.



Modified handshake

This hand position reduces the amount of force, avoids crushed knuckles and finger joints, and hopefully eliminates the pain!

Avoiding the handshake all together by simply holding any visible object in the right hand is another method of avoiding the painful handshake.

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WE'RE ON THE WEB!
[HTTP://WWW.HOPKINS-ARTHRITIS.ORG](http://www.hopkins-arthritis.org)

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