

# TalkBack

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### Aims of CSA

Promote growth of membership in Canada

-To be a voice for advocacy for Spondyloarthritis patients across Canada, nationally and provincially

-To support and advocate for research into Spondyloarthritis in Canada

-To provide a national resource centre for information relevant to the Spondyloarthritis community

#### Disclaimer

The information contained in this newsletter is not medical advice. The Canadian Spondylitis Association offers evidence-based information and support to help you better understand your form of Spondyloarthropathy, as well as, to help you talk to your own rheumatologist and family physician about your symptoms and general health. Always seek the expert advice of your rheumatologist or other health care professional before making changes or additions to your treatment plan.

## "What have you done for YOU lately?"

In 1986 a young pop icon named Janet Jackson had unprecedented success when she sang out the lyrics "What have you done for me lately?". I'm sure it is no surprise to you to find out that this famous eighties hit has nothing to do arthritis, but is, instead, a song about a woman simply wanting a more attentive boyfriend. I am also sure that right about now you are all wondering why I am even bothering to bring it up. I was thinking about this line a few weeks ago and realized this is the attitude I tend to take sometimes when dealing with my Ankylosing Spondylitis. I start thinking that my doctors could be doing more, my family could be more understanding or my employer could cut me some slack, I mean don't they realize what I am going through? It's not uncommon for me to feel like other people are not doing enough to help me out in battling my disease. However, it doesn't take long to realize that this attitude is neither helpful nor encouraging, so I decided I needed to modify "What have YOU done for ME lately", to "What have YOU done for YOU lately" ?

The purpose of Talkback is to be a tool of education and information for you. We try our hardest to bring you information that will help to keep you up-to-date with what is happening in the world of Arthritis and we hope by providing information it may be one more way for you to help yourself stay healthy. In this issue we are featuring some information about a 12 month National Arthritis Awareness Program called "Arthritis is Cured (if you want it)". This new initiative was started by the Arthritis Society and the Arthritis Consumer Experts to "debunk myths and change Canadians' perceptions of the effects arthritis has on our communities, our families, and our lives". This initiative is a great example of how you can take ownership of the disease and start helping find a cure. Why leave it up to everyone else? Let's start making things happen!

I think that it is time to put the "Janet Jackson mentality" to rest and instead of asking others what they have done for us lately, we can start asking ourselves what are we doing to take control of our disease and take care of ourselves.. Maybe this means cutting out one activity a week and letting your body rest. Or maybe it means adding one activity a week to get your body moving. For someone else it could mean getting involved in Arthritis is Cured (if you want it) and for another it could mean educating those around you, so they can understand you and AS a little better. Don't get me wrong, we always need each other and it is always ok to ask for help, but let's not depend on others to cure us, let's make sure we are helping ourselves!

It is so important to be in charge of your health, so as we head into another wild Canadian winter, let's start singing a new song and take good care of ourselves!

Until next time,  
Christy

Christy MacPhail  
Co-editor Talkback



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## CSA National Secretary Honoured

Anne Riddick, the CSA's National Secretary received the highest honour that The Arthritis Society can bestow on an individual at a recent event in Vancouver. Anne received the Arthritis Society BC and Yukon Division's 2009 Circle of Honour Award at the Annual Roundtable on Arthritis Research event. Anne was honoured for her more than 25 years of unparalleled volunteer contribution, not only to people living with Spondylitis, but all forms of arthritis. In outlining Anne's contribution, TAS representative Quincey Kirschner highlighted not only how much Anne contributes to numerous committees, but her more important contribution in teaching volunteers and in passing on her infectious belief in making life better for all of us who struggle with living day to day with our disease. Those close to Anne were smugly satisfied with themselves for managing to keep the award a secret from her, and in the deceptions used to ensure she was in attendance and that a family lunch date covered for everyone being in the room. Anne's surprised reaction at the honour was consistent with her underestimating her contribution. Congratulations to a "one of a kind lady".



Pictured: Anne Riddick

## CSA – Provincial Reports

### **Alberta:**

The Edmonton chapter will continue with information, education, and their support group. We are hoping to have Dr. Alexander Yan come and speak this fall. For more information please contact Christy MacPhail

### **Maritimes:**

We are actively looking for another Maritime member for our board and are trying to get the word out to Maritimers about the CSA

### **British Columbia Chapter:**

#### ***Infusion Clinics:***

CSA members from the Vancouver area attending the fall meeting received a very informative presentation on Infusion Clinics. Christine Fitzsimmons R.N, the manager of the infusion clinic at Mary Pack Arthritis Centre provided a rundown on the numerous options offered by the ever expanding number of biologic drugs now on the market for Spondylitis patients. Chris went over each drug outlining its background, clinical delivery and the side effects she and her colleagues watch for during infusions. The questions from those in attendance started early and carried on for one of the longer meetings we have held in some time. It is clear these drug therapies are on people's minds. The BC Chapter is grateful to Chris for taking the time away from a very busy clinic to prepare her presentation and stay after work to provide it to us.

#### ***Electronic Delivery:***

The BC Chapter prints, stuffs and distributes by mail over 170 copies of the CSA newsletter in hard copy. We continue to encourage all members to accept their newsletter electronically but for those who can't we're still going to offer hard copies. One area of expanded hard copy will now be to the infusion clinics in BC. This gives new and existing AS patients something to read (and an organization to join) while they get their infusions.

#### ***Outreach Forums:***

The BC Chapter continues to offer outreach forums to those AS consumers who do not live in the Vancouver region. We are currently working on going to the Queen Charlotte Islands in November (who picked winter?) and are looking at the cities in the valley east of Vancouver for a forum in late spring 2010 after the Olympics settle down. These forums are usually well attended. We typically offer presentations from a Rheumatologist, a Physiotherapist, and a patient consumer.

#### ***TAS BC & Yukon Bluebird Gala:***

The 2009 TAS BC & Yukon Division Bluebird Gala was held in Vancouver on October 1st. Another spectacular and successful evening of fund raising, dining and dancing. The CSA BC Chapter Executive and spouses were the guests of Amgen Canada who purchased a table for the event. Jim Favaro and his wife Karen and Maureen Roberts and her husband Kenny were our Amgen hosts. All CSA members huddled to confirm that bidding on silent auction items was OK, but during the formal auction we were to sit on our hands and remain quite still while the "big boys and girls" stepped up with bids on the really high end stuff. Fortunately none of our small group ended up with anything worth 4 or 5 figures. Our thanks to our Amgen hosts for a wonderful evening.

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### Ontario:

The Ontario Spondylitis Association, held in conjunction with The Arthritis Society, Ontario Division, and AARC, the Arthritis and Autoimmune Research Centre Foundation, a public forum on Thursday, October 1, 2009 at Toronto Western Hospital. Presenting on the latest research into SpA and the need for early diagnosis will be Dr. Robert Inman and Dr. Barry O'Shea, followed by exercise sessions led by physiotherapists Mary Aisen and Laura Passalent.

Mary Aisen, who is also a board member of the OSA, led a two-session education programme called "Heads Up, After the Diagnosis" September 21 and October 5th in Markham. Mary has developed a complete programme that can be led by physiotherapists in many regions of Ontario. If you would like to approach a physiotherapist in your community to conduct the programme, please contact us at [info@on.spondylitis.ca](mailto:info@on.spondylitis.ca)

The OSA has been approached by the Canadian Working Group on HIV and Rehabilitation, which has recently been granted funding by the Ontario Trillium Foundation to set up a provincial episodic disability resource centre, and an Ontario Episodic Disabilities Network (OEDN) to identify and respond to issues and needs from a cross-disability perspective. This may be of interest to our membership where, for example, one has to stop working for a period because of an inflammatory flare-up. The OEDN will provide resources on health-insurance, rehabilitation, care, etc. As we learn more about the progress of the OEDN we will keep you up-dated.

Ontario memberships are due annually in September. There is no longer a membership fee, but please complete and return your membership form so that we have your current contact information.

### Manitoba:

At their fall support group meeting held Wednesday, October 21, in the second floor conference room at Nelson McIntyre Collegiate, Winnipeg, members of the Manitoba Ankylosing Spondylitis Association learned that they had been approved as a Chapter of the Canadian Spondylitis Association.

The meeting, chaired by Donna Fedon, President, approved a new slate of officers for the coming year. The highlight of the meeting, attended by persons with A.S., family members and friends was the multi-media presentation by Michael Bayer titled "The Healing Power of Laughter". Persons present found it informative, entertaining and inspirational. To stay healthy one has to look on the bright side of all situations and maintain a positive, optimistic position.

The presenter, Michael Bayer, President of Custom Learning Systems Group, based in Winnipeg is an internationally recognized keynote speaker, humourist, facilitator, author and magician, who travels in excess of 100,000 miles a year, bringing his message to audiences in Canada, the U.S., Central and South America.

## Some varieties of basil may help ease arthritis, research suggests.

The Daily Mail (9/26, Stephens) reported that, according to research presented at the British Pharmaceutical Conference, "several varieties of basil...have been shown to be as strong as anti-inflammatory medication when it comes to easing the swelling and pain of arthritis." Specifically, researchers from India's Poona College of Pharmacy "found that, when taken orally, concentrated extracts from two types of basil -- *Ocimum americanum* and *Ocimum tenuiflorum* -- reduced joint swelling by up to 73 percent within just 24 hours." The investigators theorized that "eugenol, the oil that gives basil its distinctive aroma," may be "the active molecule responsible for the anti-inflammatory effect."

## Yoga may ease back pain and depression

People with chronic low back pain may benefit from doing yoga, scientists have found.

A study by researchers at West Virginia University revealed that people who did yoga tended to be better at overcoming pain and depression than those who received conventional back pain treatment.

The team recruited 90 people, all of whom were experiencing mild to moderate functional disability as a result of chronic low back pain.

Some participants were asked to take part in 90-minute yoga classes twice a week for 24 weeks, while others received conventional medical treatment.

After six months had passed, patients who had taken yoga classes typically reported enhanced mood, less pain and improved function compared with those who had received standard treatment.

Dr Kimberly Williams, research assistant professor in West Virginia University's department of community medicine, confirmed: "The yoga group had less pain, less functional disability and less depression compared with the control group. These were statistically significant and clinically important changes that were maintained six months after the intervention."

Dr Williams noted that not everyone is convinced by the reported benefits of yoga for reducing back pain - a problem that affects around one in three UK adults each year.

However, she pointed out that the latest study in the journal *Spine* is a "much bigger, much more rigorous evaluation than had been done before".

Link: <http://www.arc.org.uk/news/article/19345098>

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## National Arthritis Awareness Program: Arthritis is cured! (if you want it)

October 2009 – September 2010.

Arthritis Consumer Experts and The Arthritis Society, with advice and support of Canada's arthritis community, launched a National Arthritis Awareness Program across Canada in October, starting on October 20 in Montreal and Toronto.

During the **Arthritis is cured! (if you want it)** program, the arthritis community is "hitting the street" to debunk myths and change Canadians' perceptions of the effects arthritis has on our communities, our families and our lives.

Arthritis is a vastly misunderstood disease. Among the top three chronic diseases in Canada, arthritis is actually a group of more than 100 diseases affecting people of all ages. One in six Canadian has arthritis – that nearly 4.5 million people – costing the economy billions of dollars per year. The most serious inflammatory forms of the disease can be fatal as well as devastating and debilitating.

TODAY Arthritis disables more people than any other disease including cancer, heart disease, asthma, or spinal cord trauma. It also is among the most common chronic diseases in children.

TODAY There is no cure for arthritis. Arthritis research receives less funding than other chronic diseases.

TODAY Sixty per cent of the nearly 4.5 million Canadians with arthritis are under age 65. One in 1,000 children in Canada also has arthritis.

TODAY Arthritis is the leading cause of work disability and a significant burden to the Canadian economy.

Launched in October, 2009 and running through to September 2010, this 12 month national program is designed to talk to Canadians about arthritis. The national program will offer resources, workshops and information. During the campaign we will be reaching out to the general public, community leaders, media, people living with arthritis, healthcare professions...and you.

The national program has been divided strategically into two phases: Phase One – a national and regional public/consumer outreach program from October 2009 to January 2010; and Phase Two – a national and regional healthcare professional outreach program from February 2010 to September 2010.

Stakeholder support is essential. Your participation in the National Program legitimizes our efforts and validates the key themes and messages we intend to communicate to consumers and the general public. Our first priority throughout the 12 month program is to communicate news about **Arthritis is cured! (if you want it)** to you directly so that stakeholders can understand the goals, messaging and progress of the program.

We hope you will join us for this exciting and unique program for arthritis awareness in Canada. The nearly 4.5 million Canadians with arthritis deserve our efforts and support.

Please email your interest in becoming involved or to receive more information about the program to [info@arthritisCured.org](mailto:info@arthritisCured.org)

Cheryl Koehn, Arthritis Consumer Experts [www.jointhehealth.com](http://www.jointhehealth.com)  
Lynn Moore, The Arthritis Society [www.arthritis.ca](http://www.arthritis.ca)

## A "ROAR" Heard in Vancouver

The 2009 edition of the Roundtable of Arthritis Research (ROAR) was held in Vancouver on September 25th at the Executive Plaza Hotel and Conference Centre in suburban Coquitlam, BC. The event is sponsored by the Arthritis Research Centre of Canada and is hosted by the Centre's Consumer Advisory Board. The delegates were treated to presentations on "Obesity and Osteoarthritis"; "Self-Helping"; "Internet Innovations in Diagnosis"; "Team Approaches in Improving Care"; "Hip and Knee Replacement Surgery"; and a poster presentation featuring the paintings of "Mother's Living with Arthritis". The CAB provided volunteer facilitators at each table to guide discussions and coordinate questions for the presenters who participated in an "Ask the Presenters" Q & A. Another successful ROAR.

## Robots expected to eventually be used in all surgical procedures.

BBC News (9/9, Elliott) reported, "Within ten years some doctors and scientists are predicting that all surgery could be scarless," as, according to them, "by using the natural orifices of the body and the body's own natural scar the belly-button (or umbilicus), it will be possible to insert robots into the body which can help perform every surgical procedure." Although "it sounds fantastical...prototypes are already in existence that can crawl and swim inside the body taking pictures of difficult to access areas." BBC cited ARES (Assembling Reconfigurable Endoluminal Surgical System), which was "developed by Scuola Superiore Sant'Anna, Italy, with the support of the European Commission." The robot is designed to "self assemble inside the body, after the patient has swallowed up to 15 separate parts, and then aid the surgeon to carry out procedures." The article also described other robots, such as FreeHand, which is "a robotic camera controller for minimally invasive surgery," or the Da Vinci robot, which "offers surgeons great precision."

## Research has shown that daily injections of PTH can help to slow down bone loss and increase bone mass.

Now, a new drug delivery system that allows PTH to be administered via a skin patch has been tested in a three month-long phase IIA clinical trial.

Pharmaceutical company TransPharma Medical tested the ViaDerm drug delivery system in postmenopausal women with severe osteoporosis and achieved promising results.

Chief executive officer Dr Daphna Heffetz revealed: "We are very pleased with the results of this trial, which demonstrate remarkable progress in the use of the ViaDerm system in clinical trials.

We are looking forward to the phase 2B trial and hope that, in the future, we will be able to improve therapy for people suffering from osteoporosis by offering an alternative to daily injection of PTH."

The delivery system consists of a handheld electronic device which creates microscopic channels through the outer layer of the skin.

The osteoporosis drug can then be administered by placing a patch on the skin and allowing the treatment to pass through the skin and into the bloodstream.

Link: <http://www.arc.org.uk/news/article/19345107>

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This newsletter is distributed in Ontario through the generosity of The Arthritis Society, Ontario Division, of which The Ontario Spondylitis Association is a Specific Disease Chapter.

## Modern technology should be harnessed to bring back house calls.

In an op-ed in the San Jose Mercury News (4/27) Dr. Kaveh Safavi, vice president and global lead for the Cisco Internet Business Solutions Group Healthcare Practice, argued for a return to the era of house calls by doctors, using 21st Century information technology. Safavi writes, "We need to modernize our healthcare system by embracing a different model -- a transformational healthcare environment. ... virtually through two-way, real-time video."

Medtronic director says the time for telemedicine is now.

In a Washington Post (9/24) op-ed, Dr. David Steinhaus, Medical Director of Medtronic Cardiac Rhythm Disease Management, champions telemedicine, which "saves money by lowering the number of visits to doctors and emergency rooms...and some associated costs, such as transportation. But the greatest benefits are to the quality-of-care. Imagine if patients and physicians could see the first signs of worsening disease, providing them an opportunity to intervene quickly." Likewise, "more points-of-access make the right-minded goal of universal coverage...more realistic, with telemedicine-enabled virtual clinics a great complement to the traditional office model." Still, notwithstanding "government assistance," telemedicine is "no longer 'a year away,' but, rather, a key platform for a healthcare marketplace desperately in need of solutions now."

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## Muscular inflammation linked to increased heart risk

Scientists have discovered that two serious autoimmune disorders that affect the muscles are associated with an increased risk of cardiovascular disease, such as heart disease and stroke.

Inflammation is now known to increase the risk of heart disease, but this is thought to be the first study to find a link between muscular inflammation and cardiovascular risk.

Scientists at the McGill University Health Centre in Montreal focused on two autoimmune disorders - polymyositis and dermatomyositis.

These are rare autoimmune diseases that are characterised by inflammation of the muscles.

Multiple muscles are affected in polymyositis, while muscular inflammation is accompanied by a skin rash in dermatomyositis.

Researchers at McGill have recently observed that patients who suffer from either of these two disorders are more likely to develop cardiovascular disease than healthy people.

Dr Sasha Bernatsky, one of the authors of the study in the Journal of Rheumatology, revealed: "Our results indicate that the risk of heart attack is twice as high in these people as in the general population.

Each year, one out of every 200 people with muscle inflammation, or myositis, succumbs to a stroke and one out of 75 to a heart attack."

The researchers also revealed that immunosuppressive therapies which are used to treat polymyositis and dermatomyositis appear to have a protective effect against arterial diseases.

Dr Bernatsky noted: "Sometimes patients do not want to undergo immunosuppressive treatment, which can last for years.

"Knowing that it has additional preventive effects may help some people decide to opt for the treatment."

Link: <http://www.arc.org.uk/news/article/19345085>

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## Pregnant Women With Inflammatory Arthritis and Anti-TNF Therapy

Although some pregnant women with inflammatory arthritis may experience an improvement in disease activity during their pregnancy, others may need to continue therapy throughout pregnancy and during lactation as well. The information on the safety of these drugs during pregnancy is limited.

Anti-TNF drugs have demonstrated efficacy in reducing disease activity and joint destruction and improving health-related quality of life in patients with Ankylosing Spondylitis and other inflammatory diseases such as rheumatoid arthritis, psoriatic arthritis, and juvenile idiopathic arthritis. Those anti-TNF agents commonly used include infliximab, adalimumab, and etanercept. These three drugs fall into the United States FDA category B concerning fetal risk, indicating that while animal studies have not shown a risk to the fetus, adequate studies of pregnant women have not been conducted. Consequently, and probably for legal reasons, drug manufacturers have recommended that these agents be avoided during pregnancy and lactation.

A survey of rheumatologists in the USA showed that fewer than half of those questioned agreed that anti-TNF drugs should be avoided in pregnancy. Almost half stated that they were uncertain about their safety during pregnancy. The respondents generally agreed that recommending effective birth control for women taking these drugs was important.

It is interesting that women of reproductive age suffering from inflammatory arthritis and who are being treated with anti-TNF therapy may increase their chances of reproduction and pregnancy outcome. It is still controversial if anti-TNF agents have a positive impact on fertility but it has been noted that pregnancy rates have increased in women with the rheumatic diseases during the last few years.

While most pregnant women with rheumatoid arthritis experience an improvement in disease activity, the picture is different for most of those women with AS. Ankylosing Spondylitis tends to demonstrate persistent disease activity during pregnancy that decreases only late in pregnancy. Disease activity in pregnant women with AS tends to equally either be unchanged, improved or worsened. A post-partum flare of disease activity is experienced by 60-90% of AS patients, generally within 6 months of delivery. Most often, the post partum flare is experienced by those who had active disease at conception.

It is considered important to explore the safety of anti-TNF therapy exposure in those women who experience worsening of their disease either during or after pregnancy.

Current data do not seem to support a large excess risk of adverse pregnancy and/or fetal outcomes in women exposed to anti-TNF therapy at some point during pregnancy. Evidence is limited by the small number of published case studies and by differences in the type and amount of anti-TNF agents, possible use of other drugs and the timing of exposure during pregnancy. Most of the data relate to exposure in the first trimester and few patients have been exposed during the entire pregnancy or during the second or third trimester. No long term follow-up studies are yet available on the possible effects of exposure to the offspring. Some effects of in utero drug exposure may not be observed for decades.

To date anti-TNF agents have been shown to be transferred via the placenta to the unborn child. The agents can be found in breast milk but are probably digested in the gastrointestinal tract of the child. No large excess risks of fetal or maternal adverse outcomes have been reported following exposure to anti-TNF therapy during pregnancy compared with the general population. Sporadic cases of congenital malformation have been reported, but do not seem to be in excess of what is expected in the general population.

More data is expected over the next five years which will allow for assessment of the post in utero exposure to anti-TNF drugs.

Source: Excerpts from "Anti TNF Therapy and Pregnancy Outcomes in Women With Inflammatory Arthritis"  
Authours: Evelyne Vinet, MD; Christian Pineau, MD; Caroline Gordon, MD; Ann E. Calrke, MD, MSc; Sasha Bernatsky, MD, PhD

Published: 02/04/2009  
Medscape.com

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## More Evidence on the Harmful Effects of NSAIDs

Further evidence of the harmful effects of NSAIDs on heart failure patients has recently come to light. The new study was published in the Archives of Internal Medicine and shows dose-related increases in the risk of death and rehospitalization for heart failure or myocardial infraction with all COX-2 inhibitors and other NSAIDs.

The lead authour of the study was Dr. Gunmar Gislason of Denmark who commented that, "Our results suggest that all NSAIDs have harmful effects in heart-failure patients, even naproxen at high doses. Naproxen is probably the best of the bunch, but it still increases fluid retention, which is bad news for heart-failure patients." In his opinion, Dr. Gislason believes all NSAIDs should be prescription only as anyone can buy them without the advice of a doctor. The fact that they are available in non-pharmacy settings, does give the impression that they are harmless. Certainly, many heart patients are not aware that they should not take these drugs.

If it is considered necessary that heart patients take NSAIDs, the authours suggest that they should take an anti-inflammatory drug which is COX-1 selective, in as low a dose as possible and for as short a time as possible.

Source: Medscape Medical News, February 4, 2009

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### CSA Membership Form

Become a member of the Canadian Spondylitis Association. Membership is Free.

Name.....

Address.....

City..... Province.....Postal Code.....

Email address.....

Donation Amount \$..... (We are unable to issue charitable receipts.)

Mail Membership form to:  
Canadian Spondylitis Association, 18 Long Crescent, Toronto, On. M4E 1N6

