



TalkBack

Canadian Spondylitis Association Newsletter

Aims of CSA

- ❖ Promote growth of membership in Canada
- ❖ Be a voice of advocacy for Spondyloarthritis patients across Canada
- ❖ Support and advocate for research into Spondyloarthritis in Canada
- ❖ Provide a national resource centre for the Spondyloarthritis community

The Annual General Meeting will be held on Wednesday, April 13, 2011.
Please see www.spondylitis.ca for details

World Ankylosing Spondylitis Day Events

by Ken Mulholland, CSA Treasurer, ASIF Secretary

The first Saturday after the 1st of May each year has been designated World Ankylosing Spondylitis Day by the Ankylosing Spondylitis International Federation (ASIF). This provides the international AS community the opportunity to stand up and be heard. The following countries organized events that raised the awareness of Ankylosing Spondylitis and related Spondyloarthropathies in various forums and formats.

Canada

The Canadian Spondylitis Association (CSA) held a patient forum in Toronto, Ontario on April 10th, 2010. This day was chosen as it was the most convenient date for the guests and speakers that were invited to help us raise the awareness of AS. The event was attended by close to 200 patients and guests. To see a summary of the event visit our website under Latest Events on our home page or click on news and read about it in our last issue of TalkBack.



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.



We Make You
Look Good on Paper.™

The Canadian Spondylitis Association would like to acknowledge the generous support of The Printing House Limited for the printing of our Newsletter.



Advertising Disclaimer: The CSA does not endorse any products in this newsletter. Its mention is strictly for informational Purposes.



United Kingdom

The National Ankylosing Spondylitis Society (NASS) marked World AS Day by hosting a sponsored walk in Richmond Park on Sunday 9 May. 160 people turned up to the event ranging in age from 9 months to 90 years and chose to walk either 5km or 10km. It was a wonderful day. There was a great spirit of friendship and fun. As well as raising money for NASS, it also helped to raise awareness of AS. As participants

walked, people wearing the orange NASS T-shirts were stopped and asked about AS. People also came up to the start tent and asked about AS and why we were there.

The event has so far raised around £23,000 for NASS. They have put the date of 8 May in the diary for 2011 and also hope to roll out the walk to other venues in the UK next year.

Portugal - May 8, 2010

The Portuguese AS Patient Association (ANEA) joined ASIF in commemoration of the first AS World Day, with several events held on 8 May 2010. Communications were identified as being very important to advertise this event. They included communication in various media including appearances on television, radio, references in various written journals and reviews.

ANEA promoted various events at their AS Day, including:

- Participation in the AS International Congress, which was held in Salamanca, Spain, between May 7 and May 9. Mr. Pedro Nobre represented ANEA at this Congress.
- Tournament held in the swimming pool facilities of ANEA on May 8 in the afternoon, followed by lunch and socializing activities.
- Forum for discussion of various topics for patients with Ankylosing Spondylitis, an event held at HOTEL ESTORIL EDEN, on May 8, 2010, afternoon. Dr. Fatima Godinho presented a paper on 'THERAPEUTIC OPTIONS ON PREGNANCY' and Dr. Fernando Pimentel presented a paper on the subject of 'HEREDITARIAN FACTORS IN AS'. Mrs. Rita Fernandes and Mrs. Alexandra Cardoso, Dieticians in Portuguese Institute of Rheumatology, presented a communication on the topic: 'DIET: WHICH EVIDENCES ON THE IMPACT OF DIET REGIMES IN AS'. The Forum was attended by about 50 participants, patients and their families. They noted that the participation of members from regions beyond Lisbon, and in particular young patients, was lower than expectations.
- Swimming pool tournament was attended by about 40 users, mainly built around two groups: (i) Patients of EA treatment classes and (ii) participants of the 'seniors on the move' classes.

ANEA delegates will also participate in the AS International Congress, which is organized in Salamanca by our friends of the AS Spanish Associations.

Hungary - May 8, 2010

The AS society in Hungary also celebrated their first AS Day, May 8th, at a half day meeting in a hotel in Budapest. Presentations:

- Sándor MAJTÉNYI: V. Bechterew, ASIF and his experience with the treatment of AS during the last 40 years.
- Judit ORTUTAY (President of the Hungarian Patients' Organizations with Rheumatism): Why it is important to have a strong patient society.
- Krisztina FAFULA: My experience with my disease
- Sándor SZÁNTÓ, MD: The treatment of AS
- Gábor PAPP: How I became an Olympic game participant in Beijing despite my disease
- Pál GÉHER MD: Problems in AS and how to prevent and treat them (complications of the disease and its treatment)

A one hour heavy discussion followed the presentations with the 300 participants from all over Hungary who were invited. A short exercise was also included, directed by a physiotherapist. A book presentation, "Questions and answers about AS", closed the meeting, which was followed by a reception.

A new website was also inaugurated: www.bechterewes.hu

The whole program was free of charge due to the sponsors (Abbott, MSD, Novartis, Pfizer, and Richter).

Turkey - May 2010

The Ankylosing Spondylitis society in Turkey (ASHAD) had Dr. Tuncay Druöz talk on Turkey's famous TV channel (TRT1: Turkey Radio Television) for 30 min about World AS day 2010. He also gave some information about AS: the importance of early diagnosis, its clinical and functional assessment and the new modalities in treatment.

The Canadian Cochrane Centre And The Cochrane Library

By Marilyn Walsh

Have you ever been to the doctor and been confronted with a treatment you knew nothing about and an explanation that left you just as confused?

How do you decide which treatment is best for you? What are a treatment's harms, benefits, and objectives? Making informed health-related decisions can be difficult. The abundance of health-related information these days, whether it is from the internet or from medical, scientific or health-related journals, can be overwhelming for consumers (patients), healthcare providers and policy-makers alike.

Some patients assume all doctors, who have many years of education and training in their fields, must be experts in all things medical. But the reality is that due to personal time restraints and ongoing world-wide research, it is a challenge for any healthcare provider to stay constantly up-to-date. New scientific studies are published daily in a myriad of sources. To compound the problem, the results

of one study may be different from or even contradictory to the results of another making it difficult to draw accurate conclusions. Another problem is that the research findings can be published in a language different from that of the person doing the searching. This is where the work of the Cochrane Collaboration can be of great help to both healthcare provider and consumer.

What is the Cochrane Collaboration?

The Canadian Cochrane Centre (CCC), formerly known as the Canadian Cochrane Network and Centre, is one of 14 independent not-for-profit Cochrane Centres worldwide. Collectively, these centres are known as the Cochrane Collaboration, which is based in the UK. The main objective of the Cochrane Collaboration is to help people make well-informed healthcare decisions by producing, maintaining and promoting systematic reviews which provide up-to-date information about healthcare interventions.

To fulfill its purpose, the Cochrane Collaboration is made up of groups that are based on a particular disease or health problem. An example is the Musculoskeletal Group which encompasses the spondyloarthropathies and other types of arthritis and soft tissue disorders. Most people involved in contributing to the reviews, whether they be healthcare provider, researcher or consumer, do so voluntarily because they are committed to the outcome.

What is a Systematic Review?

A systematic review begins by addressing a clearly formulated question such as, “Is sulphasalazine helpful in eliminating the symptoms of AS?” The results of many studies or trials are then rigorously assessed using scientific guidelines set out by the Cochrane Collaboration in the Cochrane Handbook. A systematic review is the detailed summary of these results and provides the answer to the initial question. Is the intervention helpful, harmful or are the results inconclusive indicating that more high quality research is necessary? Cochrane systematic reviews take the guess-work out of making well informed decisions about healthcare by providing people with a reliable source of evidence about an intervention. Due to the fact that Cochrane systematic reviews use such high scientific standards to determine which health therapies work and which ones don't, they are less biased and more comprehensive than traditional reviews. They are, in fact, the “gold standard” in Evidence-Based health care.

What is the Cochrane Library?

The Cochrane Library is a collection of nearly 4,000 health treatment reviews which are published on the internet and updated quarterly to ensure they contain the most current data. The Library covers hundreds of medical conditions as well as a variety of topics such as injury prevention and alternative remedies.

If someone is trying to obtain information regarding a treatment for one of the spondyloarthropathies, for example, the easiest way to access the Cochrane Library would be to:

1. Go to www.thecochranelibrary.com
2. Browse the “Cochrane Database of Systematic Reviews” to the left side of the page
3. Click expand option
4. Click on Rheumatology
5. Click on Spondyloarthropathy
6. Choose a review topic

If you don't find the topic you're looking for immediately, do an advanced search using keywords or by all means browse other rheumatology topics such as rheumatoid arthritis which may contain reviews on similar treatments. Of course, don't forget to check out associated disorders like psoriasis or

inflammatory bowel disease if they are relevant.

Unfortunately, not everyone will have free access to full Cochrane reviews in Canada. They are unavailable in most Canadian provinces without a subscription; however, consumers can access the full library free of charge at most good medical libraries. It may also be available in some public libraries, so ask your local librarian.

The good news is that **ALL** Canadians can download **FREE** abstracts and plain language summaries of reviews. Abstracts are shortened versions of reviews which still contain a certain amount of medical terminology and technical information on how the review was conducted. Plain language summaries, on the other hand, are exactly what you would expect. The review is briefly summarized in easily comprehensible language which includes the findings on benefits and harms of the intervention in question as well as any limitations of the review and studies it includes. The plain language summary is perfect for the layman and generally follows the abstract in a review.

You can also browse plain language summaries of reviews of the Cochrane Musculoskeletal Group prepared for the Arthritis Society. The link is available at www.ccnc.cochrane.org.

For anyone interested, the publisher (Wiley) is offering a free 6 month trial of the full Cochrane Library, including full reviews, until the end of 2010. Details are available on the CCC website above. The Canadian Libraries Association and the Canadian Cochrane Centre staff are presently working together to try and secure a national license which would give all Canadians free access to the full Cochrane Library on the internet.

If we're honest, many of us are intimidated by physicians and are hesitant to question treatments. Perhaps there have even been times when you consented to a treatment you silently questioned because you didn't feel you had other options. How many times have you realized shortly after leaving a doctor's office that you had many questions that should have been asked - but weren't - either because you were too nervous, overwhelmed or there simply wasn't time? By broadening your knowledge base with the evidence-based information Cochrane systematic reviews can provide, you might feel better prepared to face that next doctor's appointment and have the confidence to ask questions and work with your doctor in shared decision making. Who knows? You might even be able to mention treatment options not thought of previously.

Remember that knowledge is power and you have a right to have a voice in your own health care. The Cochrane Collaboration is always interested in the opinions and involvement of consumers. If you are interested in becoming involved, please contact the Cochrane Consumer Network at www.cochrane.org/consumers for details regarding all the ways that consumers can contribute. You can also contact them directly via e-mail at ccnet-contact@cochrane.de with contact information and any enquiry. Being involved with the Cochrane Collaboration is a satisfying way of contributing to potential improvements in the quality of health care.

The information for this article is adapted from links found at www.cochrane.org/consumers and www.ccnc.cochrane.org, as well as from promotional material distributed through the Canadian Cochrane Centre.

BC Chapter Report

First, some good news from British Columbia: our long term Executive Member, Anne Riddick, who has had to step back from her volunteer duties of late, is doing better. She is on a biologic and it is having some positive results.

On November 23rd, BC Chapter members attended a presentation on clinical trials provided by Nancy Ellis, RN from the Arthritis Research Centre of Canada. Nancy treated those in attendance to an excellent overview of how clinical trials are conducted and why trials are necessary, which included:

1. *What is a clinical trial?*

A trial is a scientific study that tests the safety and effectiveness of a medical treatment for a specific condition. Each trial attempts to answer one or more research questions. In other words the trial is not wide open. The drug is designed to address a specific ailment in a certain way and the trial tests if it works as designed.

2. *Risks/Benefits:*

Research trials are not completely devoid of risks. Most drug therapies have side effects. The Pharmaceutical Companies who develop new drugs can predict some potential side effects, and provide all participants with a list of them, but one reason to conduct trials is to confirm that side effects are manageable or acceptable given the benefits of the drug. One thing is certain, participants get excellent care and it's all free. And if at any time you feel you can't continue, you can leave.

3. *Why Participate?*

Volunteers are critical to the success of any research study. Clinical trial participation is dropping in Canada where although the quality of the studies is superior, trial rules are very strict and costs associated with conducting a trial are high. Also, media's fascination with buzz words has led to the use of "guinea pigs" to describe participants when in Nancy's view, and ours, heroes is more accurate. All great therapies have been verified by human clinical trials and many inefficient drugs have been withdrawn when they failed to deliver.

4. *If you participate:*

Clinical trials require commitment. The amount of time participants put in and the need to follow instructions requires dedication. You must attend all appointments and might also need to participate in extra testing. In addition not all participants initially receive the actual drug or combination of drugs. And not all volunteers are accepted. Eligibility may include disease severity, age, and the absence of some other specific medical conditions.

Conclusion: We all hope that someone will invent a treatment that fixes our condition. Those of us with chronic ailments like Spondylitis are realistic, a fix is more likely an improvement than it is a cure, but new therapies have made living with arthritis much easier. Human clinical trials are a fundamental component of those developments. A TAS researcher put it well. "There is only so much you can learn from a mouse."

For additional information, contact Nancy at nellis@arthritisresearch.ca or go to www.clinicaltrials.gov.

2011 At Home Interview Project, Faculty of Medicine at UBC

The UBC Faculty of Medicine in Vancouver is looking for individuals, and family members of individuals, with disabilities and chronic conditions who are willing to be interviewed in their home or community by first-year medical students.

By providing students with experiences of this type early in their careers, we hope they will have greater insight into the effects of health conditions on the lives of individuals and families when they see them as patients.

The interviews will take place in the Vancouver/Lower Mainland (British Columbia) area during January and February 2011. Each interview will cover such topics as: an individual's experience of their condition and their experiences with healthcare professionals. For further information, or to sign up to participate, please contact the Program Assistant for the "Doctor, Patient and Society 410" course at:

At Home Interview Project 2011
MD Undergraduate Education
Faculty of Medicine, UBC
Life Sciences Centre/ 1536C - 2350 Health Sciences Mall, Vancouver BC, V6T 1Z3
Phone: 604-827-5958 / Fax: 604-822-8720 / E-mail: dpas.410@ubc.ca
www.med.ubc.ca

Ontario Chapter Report

Up-coming events include a free Patient Forum to be held in Ottawa on Thursday, March 3, 2011 at 7:00 pm at the RA Centre. Dr. Doug Smith, an Ottawa rheumatologist, will be the keynote speaker. Please see www.spondylitis.ca or www.arthritis.ca for further particulars including registration details.

At the last public forum in Ottawa there was some interest in forming a local support group. Unfortunately, a lack of resources and someone to head the initiative meant that it never happened. However, there have been recent expressions of interest from several Ottawa residents in founding a group, so the upcoming patient forum is an ideal opportunity to attend and express your interest in becoming involved.

The Arthritis Society's Walk to Fight Arthritis will be held on Sunday, May 15, 2011. Walk locations in Ontario are Collingwood, Durham, Burlington, Kingston, Kitchener, London, Mississauga, Ottawa, Sudbury, Thunder Bay and Toronto, as well as a Virtual Walk for those unable to participate in any of the walks. Once again there will be a Spondys Team in Toronto. Why not form a Spondys Team in your community? Full details of the walks and registration/sponsorship can be found at www.arthritis.ca.

If you share your story of dealing with and fighting Spondyloarthritis after you have registered for the Walk to Fight Arthritis, Tylenol will donate \$10 to your fundraising campaign. It's a great way to get started!

We are pleased to welcome Marilyn Walsh as a local contact in Hamilton/Burlington. There's an article by Marilyn on the Cochrane Collaboration in this issue of TalkBack and in the next edition, Marilyn will share her experiences with Patient Partners. Please email us at info@spondylitis.ca if you would like to contact Marilyn.

Manitoba Report

The November 2010 meeting of the Manitoba Chapter of the CSA held in Winnipeg attracted both urban and rural persons to share concerns and hear Dr. Glen Thomson address the topic "Why Ankylosing and why Spondylitis?"

Dr. Thomson stated the disorder dates back 10,000 years. It is believed that 10% of the persons on the street carry the HLA B27 but only 1% develop Spondylitis. It is still not known what triggers the reaction. Eighty to ninety percent of those patients have problems with their bowels.

The frequency of the HLA B27 marker increases as one approaches the geographical poles. There is no Spondylitis at the equator.

At the conclusion of his presentation, Dr. Thomson fielded a variety of questions from the audience. He mentioned that the family doctor is the quarterback in the medical team looking after the patient.

Contact Lorne Ferley, at 204-256-5320, for details on the Spring 2011 meeting.

Hotel Comfort Survey for AS Patients

The Ankylosing Spondylitis International Federation (ASIF) is conducting an international survey designed specifically to help advocate for improved hotel comfort for AS patients. The CSA supports this effort and request that our members please participate by completing the survey.

This survey has been developed by a collaboration of ASIF and patient organizations in Holland, Belgium, Australia and Denmark to assess the scope of the problems involved for AS patients when staying in hotels. It will take 5-10 minutes to complete the survey.

The survey is confidential. You will not be asked to submit any information that may identify you. Your answers will be handled in accordance with best practice as recommended by the relevant protection data.

Follow this link to the survey - <https://asif.any-survey.com>

Become a CSA Member. Go to www.spondylitis.ca

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.