

NEWSLETTER

FALL 2003 VOLUME 1 ISSUE 1

Healthy Bones and
Healthy Joints...Keep
Canada Moving



It's Your "Move"...

It's Your "Choice"





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Healthy Bones and Healthy Joints...Keep Canada Moving

Volume 1 Issue 1
Fall 2003

"Bone and Joint Decade - How It All Began"

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"A World Health Perspective"

On January 13, 2000, the Bone and Joint Decade was formally launched at the headquarters of the World Health Organization in Geneva Switzerland. This came on the heels of the November 30, 1999 endorsement by the United Nations. UN Secretary General, Kofi Annan said, "There are effective ways to prevent and treat these disabling disorders, but we must act now. Joint diseases, back complaints, osteoporosis and limb trauma resulting from accidents have an enormous impact on individuals and societies, and on healthcare services and economies."

The goal of the Bone and Joint Decade is to improve the health-related quality of life for people with musculoskeletal disorders throughout the world. These disorders are the most notorious and common causes of severe, long-term pain and physical disability, affecting hundreds of millions of people around the world. The Decade aims to raise awareness and promote positive actions to combat the suffering and costs to society associated with musculoskeletal disorders such as joint disease,

osteoporosis, spinal disorders, severe trauma to extremities and crippling diseases and deformities in children.

The goals will be achieved by:

- Raising awareness of the growing burden of musculoskeletal disorders on society
- Empowering patients to participate in their own care
- Promoting cost-effective prevention and treatment
- Advancing understanding of musculoskeletal disorders through research to improve prevention and treatment.

No one single organization can accomplish the desired benefits for the patient or his or her family. The Decade is a multidisciplinary global campaign that will be developed in partnership with appropriate patient, professional and scientific organizations, companies, healthcare providers, governments and non-government organizations in consultation with global and regional stakeholders.

The Bone and Joint Decade began with an inaugural consensus meeting in Lund, Sweden in April 1998 at which time the goal and objectives were agreed upon. An International

Steering Committee of fifteen experts from various geographical regions and disciplines guide the Bone and Joint Decade. The diversity of the ISC and its staff includes rheumatologists, researchers, orthopaedic surgeons, patient advocates, trauma, rehabilitation, and emergency medicine specialists.

The Bone and Joint Decade is headquartered in Lund, Sweden under the leadership of the ISC Chairman, Professor Lars Lidgren, MD, who is chairman of the Department of Orthopaedics at the University of Lund.

The initial outreach calls for a three-part strategy: 1) the endorsement of the Bone and Joint Decade by patient and health professional organizations around the world; 2) the call for coordinators to step forward to coalesce the endorsing organizations within nation borders into National Action Networks to leverage their national priorities within the framework of the Bone and Joint Decade umbrella and mission; and 3) the call for broad dissemination about the Decade through health professional journals around the world.



www.boneandjointdecade.org

" A MESSAGE FROM THE COORDINATOR "

Bone and Joint Decade in Canada

I am delighted to be able to communicate with everyone interested in the Bone and Joint Decade by means of our brand new newsletter! As many of you know the Bone & Joint Decade officially began in the year 2000; the National Action Network of the Bone and Joint Decade in Canada was established that same year and has worked hard to advance the awareness of musculoskeletal health in Canada.

We have had some success in that the Decade has been recognized by a proclamation issued by the Federal Minister of Health in October 2002; in January 2003 we were able to meet with many of the constituent organizations that make up the bulk of both patient advocacy and patient treatment groups in this country.

Our short-term goals for the Bone and Joint Decade in Canada relate to increasing awareness. They are relatively modest but are also tremendously important to the continued success of this initiative in Canada. Firstly, and perhaps most importantly, we want to get all of our constituent members to use the Bone and Joint Decade logo on their correspondence and - even

better - to have a statement on their letterhead stating something similar to "a proud sponsor of the Bone and Joint Decade". Secondly, we also want to share the Bone and Joint Decade (BJD) Canada Newsletter with the membership of our constituent organizations. Wide dissemination of the BJD Newsletter can be achieved in a variety of ways:

- 1) Member organizations can include the newsletter in their mailings to their members;
- 2) They can supply us with their mailing lists (primarily email lists) so that we can email it to their members;
- 3) They can provide a link on their websites to the newsletter on the BJD site.

Our intermediate goal relates to engaging the various stakeholders. We aim to host a Bone and

Joint Decade Conference in Canada in the year 2005. The International National Action Committees of the Bone and Joint Decade have agreed to hold their meeting in Canada. We would like to combine this with a general conference that would bring together a number of our constituents; including consumer advocates, clinicians, researchers, government representatives and policy makers.

I am delighted that **Hazel Wood** (representing Eastern Canada) and **Dot Brown** (representing Western Canada and who is generously being funded through CIHR's Institute of Musculoskeletal Health and Arthritis - IMHA) are supporting the National Action Network to help move the Bone and Joint Decade agenda forward.

It is with great enthusiasm that I look forward to continuing developments in the Bone and Joint Decade.

James P. Waddell, MD,
FRCS
Coordinator, Canadian
National Action Network
for the Bone and Joint
Decade



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Research - Education - Access to Care

Hope through Education, Support and Solutions

THE ARTHRITIS SOCIETY

Over the past six years, The Arthritis Society has been actively involved in bringing together various stakeholders in the Arthritis Community. All of these initiatives sit proudly under the banner of the Bone and Joint Decade!

The Arthritis Community, led by The Arthritis Society, has been gradually zeroing in on the target *to rid the world of arthritis*. The work began with a conference in 1997 called **Arthritis 2000**. For the first time in Canadian history, this conference brought together the varied arthritis stakeholders to develop a mandate for action. Paul Martin and Pat Carney gave inspirational presentations, and this was where Pat Carney came up with our vision slogan, "A World Without Arthritis."

Arthritis 2000 listed information and education as top priorities. The Arthritis Society recruited 170 professional and lay volunteers to help build one of the most reputable health care web sites www.arthritis.ca. Through the Internet, we reach more people each day with information about arthritis than we ever dreamed possible, and we have made it possible for them to reach out to each other as well.

Arthritis 2000 also listed reliable health information

as a priority. The **Cochrane Collaboration** is an international effort to conduct systematic literature reviews which, when shared with health professionals and consumers, will improve the lives of people living with serious and debilitating diseases like arthritis. Canada was given responsibility for the Arthritis Musculoskeletal area. The Arthritis Society financially supported the Cochrane MSK Group and requested that the medical reviews be in lay language and that patients be "at the table" in a decision-making role.

Arthritis 2000 listed research as a priority. Arthritis has the first disease specific network - the **Canadian Arthritis Network/Network Centre of Excellence**. Network Centres of Excellence are the most prestigious research awards a group can have. They are reviewed by an international panel and granted by the Federal government. CAN/NCE added \$14.5 million to the arthritis pot over three years. As a condition for the establishment of CAN/NCE, The Arthritis Society insisted that an arthritis patient consumer advocacy be struck. This laid the foundation for consumer influence of the arthritis research agenda.

Arthritis 2002 noted the major issue of hip and knee replacements and surgery wait times. The Arthritis Society and the Canadian

Orthopaedic Foundation supported The Canadian Joint Replacement Registry (CJRR), which is now funded by the Canadian Institutes of Health Information (CIHI) and Health Canada. **Canada in Motion** - a joint project/partnership of the Canadian Orthopaedic Association and The Arthritis Society paved the way for meetings with every Health Minister in the country, and has put orthopaedics on the health care agenda.

The Medical Research Council (MRC) of Canada was the largest medical research funding agency in Canada. When MRC existed, there wasn't even an Arthritis Panel to review arthritis-specific grant applications. Through the Health Charities Council of Canada, The Arthritis Society was involved in lobbying for the establishment of the Canadian Institutes of Health Research (CIHR) to replace MRC. The result was the announcement of the **Institute of Musculoskeletal Health and Arthritis (IMHA)**, one of 13 virtual research institutes established by CIHR. The next goal was to organize the arthritis stakeholder community to ensure the establishment of an institute to serve the needs of people with arthritis.

The Arthritis Society's National Strategic Directions Report (November 2001) stated that The Arthritis
Continued on page 5

The Arthritis Community, led by The Arthritis Society, has been gradually zeroing in on the target *to rid the world of arthritis*.

Continued from page 4

Society and people with arthritis would be the driving force for the arthritis community. In August 2001, the voluntary organization of the **Canadian Arthritis Patient Alliance (CAPA)** was created. This is a self-governing virtual entity of and for Canadians with arthritis - located at www.arthritis.ca/capa. To date, there are more than 300 members of CAPA. They have representation across Canada and have become a strong advocacy force within Canada.

In order to address the changing situation of health care in Canada and in preparation for the various commissions and committees, such as the Fyke Commission, Mazenkowski Commission, Kirby Senate Committee and the Romanow Commission, we developed the **Canadian Arthritis Bill of Rights and Responsibilities**. Dr. Marvin Fritzer, an eminent rheumatologist, chaired the committee. Members of the Canadian Arthritis Patient Alliance (CAPA) played a significant role in its development and helped to launch the Bill on Parliament Hill, meeting with various MP's. The Bill had special mention in the House of Commons and the Quebec Legislative Assembly. The Bill provides a basis for advocacy and policy work.

The **Osteoarthritis Consensus Conference** was the first of its kind. One hundred and fifty scientists, clinicians, epidemiologists, rheumatologists, orthopaedic surgeons, patients, and allied

health professionals were in attendance. We determined the Four Pillars of CIHR research (Basic Research, Clinical Research, Health Services/Policy Research, and Population Health Research), the six OA priorities, and we developed four New Emerging Teams grant - \$5.5 million in new money for CIHR, IMHA and CAN. One full day was devoted to patients "Speaking for Ourselves" to ensure active participation of arthritis advocates. Patient groups emphasized the importance of research into 'pain' and 'fatigue.'

Following the OA Consensus Conference, we took advantage of key stakeholders in attendance to discuss moving our efforts to the next step. The key stakeholders were interested in taking advantage of recent success with CAN, IMHA, the Bill of Rights and the OA Conference to move the arthritis agenda forward. The Arthritis Society was asked to chair the Steering Committee and the Executive Committee. It was an honour for TAS to take on this responsibility and to have the confidence of these key opinion leaders in the arthritis field.

In 2002, The **Alliance for a Canadian Arthritis Plan (ACAP)** selected three key areas of focus: Access to Care, Research, and Education, all of which were identified at Arthritis 2000. The areas of Advocacy, Fundraising and Infrastructure would form part of all three areas.

Medication is a major therapy

for people with arthritis and a major issue - access being one on one! In 2002, the provinces (First Ministers) and the federal government agreed to a **Common Drug Review (CDR)** system. In order to influence the process as much as possible, The Arthritis Society agreed to Co-Chair (with Dr. Kathy Kovacs Burns from the Canadian Diabetes Association) the Best Medicine Coalition (BMC) to further TAS's objective of equitable access to medications across the country for people with arthritis.

Biologics are the major advances in medication for people with arthritis. Canadian approval times for drugs such as Enbrel and Remicade as compared to the US are lengthier. Biologics are still not listed on the formularies in a number of provinces, which means inequitable access to therapies for Canadians with arthritis. This is why coalitions and collaborations across the country are critical!

May 4-9, 2004 will be the **Frontiers in Inflammation and Joint Diseases** conference, similar to the OA Consensus Conference. We expect that this event will help to shape the priorities for research into inflammatory forms of arthritis.

Denis Morrice
President,
The Arthritis Society

OSTEOARTHRITIS CONSENSUS CONFERENCE PRIORITIES

Theme 1: What are the risk factors/causes of OA and how effective are OA treatments?

Theme 2: What are the best models, markers and tools for evaluation of OA and what are the most effective models of OA care?

Theme 3: What are the causes and treatment of pain in OA, and what is its relationship to outcomes of OA treatment.

Theme 4: What are the best prevention strategies for OA?

Theme 5: What are the new targets for OA treatment?

Theme 6: What are the best methods of knowledge transference and how effective are they?

Partnerships – The Key to Bone and Joint Health

IMHA/Canadian Space Agency support weightlessness study

Three years ago, the federal government took a major step forward in fostering health research in this country. That step involved the establishment of a new agency - The Canadian Institutes of Health Research (CIHR) - and 13 Institutes dedicated to helping CIHR become the best health research agency in the world. The Institute of Musculoskeletal Health and Arthritis (IMHA) is one of the 13 institutes established to help CIHR achieve its goal. Unlike most Institutes, IMHA is comprised of six equally important focus areas - Arthritis, Bone, Skin, Muscle, Rehabilitation and Oral Health - each committed to working together to "eradicate pain, suffering and disability and to enhance the quality of life for people affected by arthritis, musculoskeletal, dental and skin conditions".

IMHA's research and knowledge translation mandate is truly a mammoth undertaking requiring tremendous collaboration and team work. And so, when Minister McLellan endorsed the "Bone and Joint" decade late last year, IMHA applauded her efforts. "What Minister McLellan has endorsed is a template for the future of our health care system," said Dr. Cy Frank, IMHA's scientific director. "This template stresses the importance of forming equal partnerships with government and non-

government agencies alike and is fully in line with IMHA's partnership philosophy."

Even before the formal endorsement of the Bone and Joint Decade, IMHA recognized that partnerships were the key to bone and joint health. In 2002, for example, IMHA partnered with The Arthritis Society (TAS) and the Canadian Arthritis Network (CAN) to launch the very successful Osteoarthritis Consensus Conference. On the heels of that conference, IMHA joined once again with TAS and CAN along with the Cochrane Collaboration (Musculoskeletal Review and Back Groups) and the Canadian Arthritis Patient Alliance (CAPA) to form the "ACAP" alliance - a spirited group dedicated to developing a coordinated National Arthritis Plan.

Most recently, IMHA partnered with the Canadian Space Agency to support a long-term bed rest study being organized by the European Space Agency and NASA. The muscle wasting and bone loss seen in long-term bed rest is very similar to the muscle and bone loss experienced by astronauts in the weightlessness of space. A novel research proposal from Canada will examine musculoskeletal limitations to physical activity in healthy women restricted to bed for 60-90 days. The proposal, which is just entering the peer review process, could produce some interesting results for astronauts and non-astronauts

alike.

Human beings and all life forms on earth have developed under the effect of gravity and have adapted to it. In the absence of gravity, the human body loses muscle and bone mass. This could seriously restrict long-term spaceflight such as would be required in a mission to Mars. While studies like these are important to space travel, they can also help shed light on conditions here on terra firma. As it turns out, the negative impact on bone and muscle mass seen in astronauts during space flight, is similar to the effects experienced by aging people and those affected by certain musculoskeletal diseases and conditions.

"The OA Conference, ACAP and the Canadian Space Agency are only a few examples of the kinds of partnerships that IMHA has formed to address the growing incidence of musculoskeletal disorders," says Dr. Frank. "Now, working under the umbrella of the Bone and Joint Decade, we all have an excellent model that we can rally around to form the kinds of partnerships and collaborations that can truly make a difference to those suffering from diseases and conditions of the musculoskeletal system.

Doris Ward
Communications Manager
Institute of Musculoskeletal
Health and Arthritis

*IMHA
partnered
with the
Canadian
Space Agency
to support
a long-term
bed rest
study being
organized by
the European
Space Agency
and NASA.*

PATIENT POWER: The Canadian Arthritis Patient Alliance (CAPA)

Canadians with arthritis are increasingly speaking out and becoming a force to be reckoned with. One of the most effective patient advocacy organizations in Canada is one whose core membership is entirely composed of Canadians with arthritis, the **Canadian Arthritis Patient Alliance (CAPA)**.

CAPA was formally established in 2001 in order to better mobilize and support arthritis advocacy and improve the quality of life of all people living with arthritis. While members of CAPA speak for themselves, the organization as a whole works through its Steering Committee and subcommittees to engage in a wide range of arthritis advocacy. CAPA has more than 300 members and there are active committees on arthritis research, access to medications, access to professionals, public education and advocacy training, increasing political awareness, disability issues, pain issues, member outreach, communications and external relations.

As an advocacy organization, CAPA recognizes the importance of collaborating with others to achieve common aims and these collaborations are already showing results. For example,



through CAPA's efforts and collaborations with The Arthritis Society (TAS), the Best Medicine's Coalition and other organizations, people with arthritis have gained better access to medications in several provinces and are increasingly invited to participate in establishing arthritis research agendas. CAPA members are contributing to the arthritis information and education offered by such organizations as TAS, the Cochrane Collaboration and Patient Partners for Arthritis. They have lobbied for more research dollars and access to care and participated in the formulation of the Canadian Arthritis Bill of Rights and Responsibilities.

CAPA is one of the founding members of the Alliance for a Canadian Arthritis Program (ACAP) and is a supporter of the Bone and Joint Decade. CAPA's role is to ensure that these programs and the policies of organizations such as Health Canada are relevant to people with arthritis and that arthritis patients/consumers have a voice in their deliberations and decisions.

CAPA's principal partner is The Arthritis Society which provides CAPA with materials and staff support. The CAPA website is 'home'.

Members are recruited and connected through the Internet and communicate by email. A forthcoming newsletter, *CAPA Voices*, will make it even easier for CAPA members and other advocates to communicate about arthritis issues. Visit the CAPA website at www.arthritis.ca/capa to join CAPA and to learn more about this growing organization. CAPA's members are achieving results in opening the health care system to people with arthritis and are ready to take on new challenges in improving the lives of people with arthritis.

Ann Qualman
President, Canadian Arthritis
Patient Alliance

CAPA has more than 300 members and there are active committees on arthritis research, access to medications, access to professionals, public education and advocacy training, increasing political awareness, disability issues, pain issues, member outreach, communications and external relations.

“Story-Telling and the Teaching of Values in Rheumatology

An innovative CME workshop for family physicians on the American College of Rheumatology Guidelines for the Treatment of Rheumatoid Arthritis (RA) will seek to humanize the teaching of evidence-based medicine in rheumatology by bringing the patients’ perspective to a unique combination of Art and Science. The workshop, which will be launched this fall, was supported by an educational grant from AMGEN and Merck-Frosst.

Traditional case-based discussions on the diagnosis and treatment of R.A. will be introduced by four theatre moments describing the patients’ response and adaptation to the disease and the treatment: the patient’s story (c.f. figure 1). Both the theatre moments and the case discussions are evidence based.

The life-shaping power of stories as teaching tools has been described by various authors in medical education. Annabel Soutar from the “Porte Parole Project”, a bilingual theatre group based in Montreal, has interviewed patients to create the theatre experience after having reviewed the literature on adaptation to the disease. Patient input stresses the importance of the new active role of patients in the research, teaching and management of their condition.

Four rheumatologists, Dr. Louis Bessette, Dr. Monique Camerlain, Dr. Frédéric Morin and Dr. Angèle Turcotte authored the scientific aspect with a family physician, Dr. Pierre Raïche. The workshop is fully accredited by the Federation of Family Physicians of Quebec and it was warmly received by the Education Committee of ACAP (Alliance for a Canadian Arthritis Plan) .

A group of family physicians took part in a successful external validation of the project in June. One of the participants is quoted as saying, “I will never forget what I have learned in this workshop today.” It was interesting and very gratifying for the authors to witness how the questions and discussions were influenced by the artistic and emotional experience.

The French workshop is now being translated and we hope

that when it is presented throughout Canada, it will improve patient care by combining best practices and empathy. It will also demonstrate how patients’ contribution can improve both the teaching and practice of medicine.

References:

- American College of Rheumatology Subcommittee on Rheumatoid Arthritis Guidelines. Guidelines for the Management of Rheumatoid Arthritis: 2002 Update. *Arthritis & Rheumatism*, Feb 2002, Vol 46 (2), pp 326-348.
- Steinman, Beverly Tell me a Story: The Life Shaping Power of Our Stories. *Medscape General Medicine*, Vol 3 (4), November 27.

“I will never forget what I have learned in this workshop today.” It was interesting and very gratifying for the authors to witness how the questions and discussions were influenced by the artistic and emotional experience.

*Monique Camerlain,
M.D. F.R.C.P.C.
Consulting Member
service de rhumatologie
Centre Hospitalier
Universitaire de
Sherbrooke, Quebec*



Keeping Education on the Move in Alberta

The prevalence of many chronic Musculoskeletal (MSK) diseases and conditions will continue to increase, consuming an even greater proportion of Canada's health care resources.

The Alberta Bone and Joint Health Education program seeks to empower patients to participate in their own care, promote cost effective prevention and treatment, and to further develop the understanding of MSK disorders.

This initiative is intended to allow MSK professionals to achieve a world-class education, which derives excellence from a variety of

collaborative transdisciplinary research projects.

The Alberta Bone and Joint Health Education program will host public education forums where experts in their field will deliver talks, answer questions and provide information which will empower patients and the public with the knowledge to prevent and protect themselves against



musculoskeletal disorders.

This program wants to educate from the cradle onwards and Calgary will be internationally recognized as the Centre for supportive, dedicated and innovative education programmes, which acknowledge the distinct learning needs of MSK professionals, patients and the public. This program will support and provide a unique opportunity to integrate education, research and best clinical practices.

*Lorraine Royall
Education Coordinator,
Alberta Bone and Joint Health
Faculty of Medicine,
University of Calgary*

The Alberta Bone and Joint Health Education Program and the Alberta Provincial CIHR Training Program in Bone and Joint Health are proud to support the Bone and Joint Decade.

The Alberta Provincial CIHR Training Program in Bone and Joint Health recently celebrated its first year of operation.

The Training Program provides an opportunity for research and graduate training in bone and joint health and uses the combined strengths of the University of Calgary and University of Alberta

to provide in-depth transdisciplinary research training for health professional ((clinician)-scientists to focus on primary and secondary osteoarthritis, back disorders, and joint injuries.

The Training Program has identified the enormous and rapidly growing societal needs; demand for bone and joint health research; an established record of the University of Calgary/ University of Alberta complementary research strengths in bone and joint health; unprecedented university and provincial infrastructure development; and exceptional sustainable partnerships through the universities with Calgary Health Region, Capital Health Authority, the Alberta Heritage Foundation of Medical Research, Canadian Institutes for Health Research, Canadian and Alberta/NWT Arthritis Societies, Réseau Provincial de Recherche en Adaptation-Réadaptation, McCaig Professorship in Joint

Injury and Arthritis Research, and the Wood Professorship in Joint Injury Research.

At this time, the Alberta Provincial CIHR Training Program in Bone and Joint Health not only supports 18 PhD trainees in research and graduate training, but also provides financial awards of full stipends or top-up funding as well as travel allowances. For further information on the Training Program, please visit our website at www.boneandjoint-training.ca

*Dot Brown
Graduate Coordinator,
Alberta Provincial CIHR Training
Program in Bone and Joint Health
Faculties of Medicine, Kinesiology
and Engineering,
University of Calgary*



THE COCHRANE MUSCULOSKELETAL GROUP

Helping people make informed health decisions about arthritis

Since 1993, Cochrane Musculoskeletal Group (CMSG) researchers, health care professionals and patients have focused on helping people make informed health decisions about treatments for arthritis. It was, therefore, exciting and a natural fit for the CMSG to support the Bone and Joint Decade (BJD), particularly because the BJD is achieving its goals by advancing the understanding of musculoskeletal disorders through research to improve treatment and by empowering patients to participate in their own care.

The CMSG is one of 50 international groups of The Cochrane Collaboration. The Collaboration was established to ensure that patients, physicians, researchers and policy makers have reliable information to make decisions about treatments. The 50 groups produce, maintain and update research reports (called systematic reviews) of the effects of health care and treatments in 50 different disease related areas. The CMSG reviews the results of research for arthritis treatments, synthesizes the information from the best research and provides a best estimate of the health benefits and risks of those treatments.

Advancing understanding to improve treatment

The synthesized evidence from Cochrane systematic reviews

is contributing international data to improving treatment of musculoskeletal disorders in the BJD Monitor project (http://www.bonejointdecade.org/activities/activities_bjd_monitor.html). The activities of the CMSG support the Monitor project in identifying, collating and disseminating information about the present and future predictions of the burden of musculoskeletal disorders and about ways to prevent and treat musculoskeletal disorders to decrease that burden. Much of this information is available but needs to be pulled together and made more accessible in order to have an impact on health care. Part of the mandate of the Cochrane Collaboration, and consequently the CMSG, is to make their systematic reviews readily available. In Canada, abstracts of the Cochrane Reviews for arthritis treatments are freely available at <http://www.cochrane.org/cochrane/revabstr/MUSKELAbstractIndex.htm> and at the Arthritis Society web site as consumer summaries at http://www.arthritis.ca/look_at_research/cochranereviews [<http://www.arthritis.ca/look%20at%20research/cochrane%20reviews/default.asp?s=1>] With a subscription, the full systematic reviews can be accessed in the Cochrane Library at <http://www.cochrane.org>.

Empowering patients to participate in care

In early 2003, the Canadian Institutes of Health Research, granted funding for an innovative research project designed to empower patients with musculoskeletal disorders to participate in their own care. The project is a collaboration between the University of Queensland, Australia and the University of Ottawa, Canada with plans for an international conference to reach people worldwide.

It was felt that in order to empower patients it is necessary to first understand what skills they need to participate effectively in their own care. Therefore, the research project will answer two questions:

- What skills and attributes does an effective musculoskeletal and arthritis health consumer need to manage their disease well? and,
- How do we measure those skills and attributes?

Because this decade was endorsed the BJD, the research project chose to focus on the skills and



The Collaboration was established to ensure that patients, physicians, researchers and policy makers have reliable information to make decisions about treatments.

Continued from page 10...

osteoarthritis, osteoporosis and back pain. People with musculoskeletal diseases, and family members, health care providers and health organisation representatives of people with musculoskeletal diseases, as well as researchers studying this area, will provide input to identify the skills and attributes and how to measure them.

It is hoped that the answers to the above questions will ensure that in the future, patients are taught the skills that will be most helpful in managing their disease. It is also hoped that we will be able to determine how best to help patients develop these important skills to empower them to participate effectively in their own care.

The CMSG supports the

Bone and Joint Decade through these projects and other activities. To find out more about our activities, please read about us in future newsletters, contact Maria Judd at mjudd@uottawa.ca or Nancy Santesso at santesso@uottawa.ca or visit our web site at <http://www.cochranemsk.org>

Canadian Orthopaedic Nurses Association NATIONAL CONFERENCE

Conjoint With
Canadian Orthopaedic Association

*Celebrating the
Bone and Joint Decade
June 18-21, 2004
at
The Hyatt Regency Hotel
The Telus Convention Centre
Calgary, Alberta*

Come and Help Us Celebrate

CALL FOR ABSTRACTS:

CONA's 27th Annual National Conference Planning Committee invites you to submit abstracts for the next CONA Conference which is being held conjointly with COA Conference in Calgary on June 18-21, 2004. This is your opportunity to share knowledge, expertise and research with your colleagues. Abstracts for presentations will be accepted in the following formats:

- POSTER
- ORAL
- SYMPOSIA (a collaborative presentation with COA/CORS)
a 3-5 minutes presentation of your abstract followed by discussion.

SEND SUBMISSIONS TO:

Bill Grudecki
1616 - 8th Street NW
Calgary, Alberta T2M 3K5
CANADA
Telephone: (403) 289-3176
Fax: (403) 282-5871
Email: grudeckib@shaw.ca

Guidelines:

1. 250 words (or less) in APA format with 1 blinded copy
2. A copy of author's credentials and email address
3. Indicate if submission is for poster, oral or symposia presentation
4. Deadline for all submissions is October 15, 2003
5. All presentations will be power point format. Laptop computers will be provided.



Watch our website for more information
www.cona-nurse.org

The Canadian Rheumatology Research Consortium

Pain and fatigue are the symptoms that often signal the onset of arthritis and drive people to their physicians for diagnosis. Early diagnosis is important to limit the damage to the joints and to slow the progression of the disease. New drug therapies offer the promise of freedom from disability and restoration of a good quality of life.

Dr. Ed Keystone, a member of the Canadian Arthritis Network and a rheumatologist at Mount Sinai Hospital in Toronto, saw unrealized potential in the Canadian arthritis clinical research landscape. He believed that if rheumatologists who conduct clinical trials worked together, they could attract more clinical trials to Canada and ensure that arthritis patients have early access to novel and effective treatments.

The federally-funded Canadian Arthritis Network is dedicated to creating a world free of arthritis. It funds trans-disciplinary research and development and helps scientists bring their discoveries to market. The Network facilitated the incorporation and establishment of the consortium envisioned by Dr. Keystone to conduct clinical trials on new treatments for rheumatoid arthritis.

The Canadian Rheumatology Research Consortium (CRRCC) offers a single point of contact to reach a significant number of rheumatology trialists. All members of the Consortium have expertise in the conduct of all phases of pharmaceutical

and biotechnology industry-sponsored clinical trials and provide consulting services specific to arthritis research. They are all members of the Canadian Rheumatology Association and are certified either by the Royal College of Physicians and Surgeons of Canada or the College of Physicians of the Province of Quebec.

The CRRCC is creating a centralized database of investigator and site profile information and developing a Web-enabled clinical trials patient registry. These tools will assist trial sponsors with site selection and expedite recruitment.

In addition to funding investigator driven research, the CRRCC's fee-for-service revenue will be used to enhance the quality of the research sites by facilitating training for investigators and coordinators and improving research infrastructure. The CRRCC has future plans to develop investigative site Standard Operating Procedures. This will ensure each site conducts its research in a consistent manner that demonstrates, through process and documentation, compliance with the International Conference on Harmonization, Good Clinical Practice guidelines and Canadian and international regulatory requirements. With the recent implementation of Health Canada's Inspection Strategy for Clinical Trials, this will become increasingly important. Additionally, by establishing an orientation

and mentoring program for newer sites, the CRRCC hopes to increase the number of qualified investigative sites for arthritis clinical trials.

The Network entered into a strategic alliance with the CRRCC to create a research environment for pharmaceutical and biotechnology companies that enhances Canada's competitiveness in the global marketplace. There is intense competition among many countries for clinical trials and pharmaceutical companies invest a billion dollars a year in clinical trials in Canada. The CAN-CRRCC partnership is unprecedented and creates an opportunity for basic researchers, rheumatology trialists, consumers and sponsors to work together to advance arthritis research in Canada. The collaboration will raise the profile of bench-to bedside research capability and attract partners for large projects that would not be feasible for either organization on its own. Dr. Keystone believes that "Canada is positioned to be a global leader in the discovery and development of effective arthritis treatments. Our vision and leadership will have a positive impact on the research landscape and serve as a model for others."

For more information, please contact Linda Bennett, Executive Director, CRRCC at 416-586-5912 or lbennett@mtsina.on.ca

The Canadian Rheumatology Research Consortium (CRRCC) offers a single point of contact to reach a significant number of rheumatology trialists.

AHPA - National Organization Promotes Education and Research in Arthritis

The Arthritis Health Professions Association (AHPA) is a national organization of health professionals. AHPA seeks to improve care for people with rheumatic diseases through the promotion of health professional education and research.

The Arthritis Health Professions Association (AHPA) is a national organization that seeks to improve care for people with rheumatic diseases through the promotion of education and support of research among allied health professionals. We are affiliated with the Arthritis Society. Members include physiotherapists, occupational therapists, nurses, social workers, pharmacists, dietitians, arthritis researchers, educators and students in the allied health professions. We have representatives from all provinces/territories on our Board.

AHPA's current mandate is to improve the care of people with arthritis by:

- Promoting allied health professional research and education in the field of rheumatology;
- Stimulating interest in rheumatology among allied health professionals across Canada;
- Encouraging interdisciplinary communication;
- Acting as a resource body for allied health professionals with an interest in rheumatology;
- Promoting public awareness of the needs of people with arthritis and the role of allied health professionals in their care.

To support our education mandate, we:

- Organize an annual scientific conference. The 2002 conference was held in Toronto and attracted over 100 health professionals. Highlights included sessions on the evidence supporting rehabilitation modalities for rheumatoid arthritis and ergonomics in the workplace, and a Patient Partners (trained patient educators) training workshop on the differences between rheumatoid and osteoarthritis.

The 2003 annual conference will take place in Toronto on October 3rd. Highlights include a session on new biologics and a panel presentation on the multidisciplinary management of Osteoarthritis;

- ~Organize a joint conference with the Canadian Rheumatology Association. The first event will take place in Lake Louise, Alberta;
- Produce a quarterly newsletter;
- Maintain a website

www.ahpa.ca. The website has a members-only section with resources such as a listing of arthritis clinical practice guidelines, arthritis training programs for health providers, member listing, and chat room;

- Produce regular email updates for members on current information about arthritis.

To support our research mandate, we:

- ~Organize an annual call for abstracts for our scientific conference (scientific and special interest abstracts). Monetary awards are given out to the best scientific and special interest abstracts. One hour of our annual conference is devoted

- to the presentation of peer-reviewed research presentations and poster presentations are available throughout the day;
- Organize an annual competition for a research grant co-sponsored by The Arthritis Society, National in the amount of \$5,000. This money supports one or more peer reviewed grants that focus on pilot work, instrument development, surveys, data entry and analysis, etc. This is available to AHPA members only;
- ~Publish the research abstracts in our newsletter.

To support our mandate to promote public awareness of the needs of people with arthritis and the role of allied health professionals, we:

- Contributed to the development of the Canadian Arthritis Bill of Rights and Responsibilities.
- Contributed an article for Geriatrics and Aging on models of arthritis care;
- Represented arthritis allied health professionals on the stakeholder group for the Arthritis in Canada project;
- Represent arthritis allied health professionals on The Arthritis Society, Ontario Division, Health Professional Advisory Council; and the Alliance for the Canadian Arthritis Program;
- Are a supporter of the Bone and Joint Decade.

For more information about AHPA or to join, visit our website at www.ahpa.ca or email info@ahpa.ca.

The 2003 annual conference will take place in Toronto on October 3rd. Highlights include a session on new biologics and a panel presentation on the multidisciplinary management of Osteoarthritis.



Exceed Your Limits Evolving Roles and Relationships in Arthritis Care



Friday, October 3, 2003
Novotel Toronto Centre
Toronto, Ontario

In association with



Corbis.com

About AHPA

The Arthritis Health Professions Association of Ontario (AHPA Ontario) came into being in November 1981 as an organization of health professionals who work in or have a strong interest in rheumatology. In the year 2000, due to growing interest across Canada, the newly-named **AHPA** expanded to become national, with a broadened mandate that welcomes new members and representation from across the nation.

Our members work in a variety of clinical, academic, and administrative settings, such as hospitals, clinics, community programs and universities across Canada. They are dedicated to excellence in arthritis care through the promotion of education and support of research among its members.

Novotel Toronto Centre is conveniently located at 45 The Esplanade, Toronto, Ontario
Telephone: (416) 367-8900

When registering, quote, "**Arthritis Health Professions Conference**" to obtain a fixed rate of \$175.00/night.

- ◆ Pay Parking (approx. \$17.00/day)
- ◆ Close to Union Subway Station
- ◆ 5 minutes from downtown and 30 minutes from Lester B. Pearson Airport

Education Sharing Table

The AHPA will host an education sharing table. Please bring extra copies of patient materials or interesting clinical information to share and display on this table.

Cancellation Policy

Cancellations will be accepted before Friday, September 12, 2003 with a \$35.00 administration fee deducted. For cancellations, please call Valerie Bibb at (416) 979-7228 Ext 321

Conference Objectives

This conference provides a forum for arthritis health professionals to network, to share resources and to increase knowledge on:

1. New Biologics medications for inflammatory arthritis and the implications for allied health treatments.
2. Future trends in arthritis care and the developing roles for health care providers.
3. Initiatives in arthritis advocacy.
4. Alternative models of care designed to deliver education and treatment to people with arthritis.
5. Multidisciplinary approaches to weight management and the treatment of osteoarthritis.



393 University Ave., Ste. 1700
Toronto, Ontario
M5G 1E6

Tel: 416-979-7228 Fax: 416-979-8366
www.ahpa.ca
Email: ahpa@arthritis.ca

Visit our web site at
www.ahpa.ca for
conference
details or
telephone us at
416-979-7228
for further
information.



It's Your "Move"...

It's Your "Choice"

Contact Us:

The Bone and Joint Decade Canada Newsletter provides communication between affiliated members, organizations and patients.

If you would like to share an idea, an article or conference information, please contact us at:
Bone and Joint Decade Canada
1-403-210-8706

BONE AND JOINT DECADE CANADA

Healthy Bones and Healthy Joints ...Keep Canada Moving

3330 Hospital Drive NW
Calgary Alberta, Canada
T2N 4N1

Phone: 403-210-8706
Fax: 403-283-7742
Email: dbro@ucalgary.ca

THE BONE AND JOINT DECADE CANADA RECOGNIZES IT'S PARTNERS AND STAKEHOLDERS

Alberta Provincial CIHR Training Program in Bone and Joint Health
Arthritis Health Professions Association
Canadian Academy of Sports Medicine
Canadian Arthritis Network
Canadian Arthritis Patient Alliance
Canadian Association of Occupational Therapists
Canadian Association of Physical Medicine and Rehabilitation
Canadian Chiropractic Association
Canadian Institutes of Health Research
Canadian Institute for the Relief of Pain and Disability
Canadian Medical Association
Canadian Operational Research Association
Canadian Orthopaedic Association
Canadian Orthopaedic Foundation
Canadian Orthopaedic Nurses Association
Canadian Physiotherapy Association
Canadian Rheumatology Association
Canadian Society of Orthopaedic Technologists
Cochrane Collaboration
Institute of Musculoskeletal Health and Arthritis
Manus Canada
March of Dimes
Medical Devices Canada
MedIT, Faculty of Medicine, University of Calgary
Osteoporosis Society of Canada
The Arthritis Society

Special thanks to IMHA for production costs of the BJD's FIRST edition of this newsletter

We ask our partners to consider contributing to the production of the Winter edition. Thanks.

Our web site is under construction, so please visit BONE AND JOINT DECADE [click on Canada] at www.boneandjointdecade.org

ACTIVITIES, UPCOMING EVENTS, and UPDATES...

Coming up in the Winter Issue of the *Bone and Joint Decade Canada Newsletter* we will be featuring **Osteoporosis** health related issues. From health care providers, researchers, advocate groups and patients, we look for your comments, articles, submissions, conference notices and advertisements. **The deadline for submissions is October 15, 2003. Articles up to 650 words will be accepted.**

To our partners and stakeholders, we appreciate your contribution in making this newsletter possible and thank you for your continued support.

Please contact Dot Brown at 403-210-8706 or email at dbro@ucalgary.ca with your submissions.





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BONE AND JOINT DECADE CANADA
3330 HOSPITAL DRIVE NW
CALGARY, ALBERTA T2N 4N1
CANADA

TEL: (403) 210-8706
EMAIL: dbro@ucalgary.ca

