



The Bone and Joint Decade 2000-2010

INFOLETTER 46

April/May 2006

Dear Bone and Joint Decade supporting organisation and friend,

On behalf of the BJD Steering Committee I am pleased to report to you of the latest achievements in regard to the initiative.

Lars Lidgren, Chairman of the Steering Committee

The BJD 2006 WORLD NETWORK CONFERENCE in SOUTH AFRICA

This year's global Network Conference will be held from 2-4 November, 2006 at the Southern Sun Elangeni Congress Hotel in Durban, South Africa. Professor Girish Mody, NAN coordinator, South Africa, modyg@ukzn.ac.za is hosting this year's meeting.



City Hall in Durban

Each NAN has been invited to the meeting in Durban and to send two persons, the coordinator or another NAN representative and a patient representative to participate in the Annual Network Meeting and the Patient Advocacy Symposium (see below for more information).

The theme of this year's conference is: ***“Strategies for the Prevention of Bone and Joint Disorders”***. In addition the Standards of Care document on Osteoporosis/Hip fracture and Chronic Pain, initiated at the 2005 World Network Conference in Ottawa, Canada will be

proposed to be globally adopted by the conference.

The conference will start with a Welcome Reception on the evening of Thursday, November 2, and continue through November 3 and 4, Friday and Saturday.

BJD International Patient Advocacy Symposium
1-2 November, 2006

BJD World Network Conference
November 2-4, 2006

Venue: Southern Sun Elangeni, Durban, South Africa

Start planning your attendance now, and watch for further announcements on www.boneandjointdecade.org

Please contact the BJD Secretariat bjd@ort.lu.se for any enquiries.

The BJD 2006 PATIENT ADVOCACY SYMPOSIUM

We're very pleased to announce that the 2nd Bone and Joint Decade International Patient Advocacy Meeting will be held on Wednesday and Thursday 1 – 2 November in Durban, South Africa as part of the 2006 BJD World Network Conference (2-4 November).

The focus of this year's Patient Advocacy Meeting will be practical advocacy skills training, with the objective of building an understanding of patients' roles in delivering messages, particularly messages about prevention, evidence-based medicine, minimum standards of care, and practitioners and patients working together. The targets for these messages are the media and the public affairs, as cornerstone in how advocates can directly influence public policy on bone and joint health.

At the meeting there will be two integrated training seminars focusing on these themes. Participants will be taken through a practical approach to obtaining the skills necessary to translate this work appropriately for their individual countries.

Invitations will be sent to NANs and their proposed delegates in the coming month. All delegates of the Patient Advocacy Meetings will be automatically registered for the Network Conference as well, with the prospect of greatly increasing the effectiveness and energy of the NAN meeting itself.

Please contact the BJD Secretariat bjd@ort.lu.se for any enquiries.

BJD Pals Website Launched!

We're proud to announce the new BJD Pals (Patient Advocate Leaders) website has launched! Please visit us at www.bjdpals.org to see the latest in our musculoskeletal web presence. The objective of BJD Pals is to provide a dynamic and user-friendly web space dedicated to advocacy in musculoskeletal issues where patient advocates can describe their work, voice concerns, exchange stories and experiences, and access resources. We have recruited volunteer BJD Pals Reporters from each region of the world to contribute articles reflecting issues and opportunities for

leadership in patient advocacy within their countries.

Please join us on www.bjdpals.org ! If you would like to get involved, please contact BJD Communications Manager, Sara Martin smartin@skynet.be.

International Steering Committee Meeting

The BJD International Steering Committee met in Sweden on 6 – 7 May, 2006. The meeting was focused on our organisation's international strategy for the next four years and beyond 2010. The outcome of this meeting - the BJD Strategic Plan - will be presented during the BJD World Network Conference in Durban.

May eLecture: The Management of Chronic Pain

This month, as part of the Bone and Joint Decade eLecture series, we're very honoured to introduce ***Dr. Angela Mailis-Gagnon***, founder and director of the Comprehensive Pain Program of the Toronto Western Hospital, Canada, a nationally known treatment centre for patients with intractable chronic pain. Dr Mailis-Gagnon is also a senior investigator with the Krembil Neuroscience Centre and the Toronto Western Research Institute, and professor in the Faculty of Medicine, University of Toronto and a founding member of the University of Toronto Centre for the Study of Pain. Dr Mailis-Gagnon has produced a comprehensive eLecture for us encapsulating the latest thinking on ***The Management of Chronic Pain***.

Surf to

<http://www.bjdonline.org/default.aspx?contid=1593> to access the eLecture.

BJD Award and Scholarships to Support Cartilage Research in OA

The Bone and Joint Decade is pleased to announce that the BJD Award Scientific Committee for Awards consisting of:

Prof Dick Heinegård, Lund University, Sweden

Dr Regis O'Keefe, University of Rochester, USA

Prof Wolfhart Puhl, Orthopädische Spezialklinik Oberstdorf. Germany

has decided to give the BJD Award for Clinical and Experimental Cartilage Research in Osteoarthritis for 2006 of 25,000 Euro to:

Prof Stefan Lohmander, Sweden.

The official Award Ceremony will be held during the BJD World Network Conference in Durban, South Africa, 3-4 November, 2006.

In addition, the BJD Scholarships for 2006 of 2500 Euro each have been given to:

Martin Englund, MD, PhD, USA
Richard H Osborne, PhD, Australia

The BJD Award and Scholarship programme to promote documented research and ongoing projects in experimental or clinical cartilage research in osteoarthritis has been made possible by the support of Gelita AG, one of our Corporate Partners for Technical Development.

For more information please go to www.bjdonline.org

Pennsylvania Researchers Discover Gene Causing FOP

By Dr Fred Kaplan – published in BJDonline, 2006-04-25

Researchers at the University of Pennsylvania School of Medicine have located the genetic key which when damaged causes the body's skeletal muscles and soft connective tissue to undergo a metamorphosis into bone, progressively locking joints in place and rendering movement impossible. Identifying the gene that causes Fibrodysplasia Ossificans Progressiva (FOP), one of the rarest and most disabling musculoskeletal conditions known to humans and a condition that imprisons its childhood victims in a "second skeleton," has been the focus at Pennsylvania's Center for Research in FOP and Related Disorders for the past 15 years. This important discovery is relevant, not only for patients with FOP, but also for those with more common musculoskeletal conditions. <http://www.musconline.org/default.aspx?contid=1596> for the full press release

The Bone and Joint Decade deeply regrets to announce that ***Professor Olof Johnell***, Malmö, Sweden, died too early and unexpectedly on Monday, April 24, 2006.

I will personally miss our almost daily contacts, but we will all miss his large engagement in osteoporosis research both nationally and on the international arena.

Lars Lidgren
Chair
International Steering Committee
The Bone and Joint Decade

NATIONAL ACTION NETWORK NEWS

FINLAND: Tarja Halonen, the recently re-elected President of the Republic of Finland, will also continue as Patron for the BJD in Finland. Please visit http://en.wikipedia.org/wiki/Tarja_Halonen

Associate Professor Markku Heliövaara, a prominent musculoskeletal epidemiologist from the Finnish Institute of Public Health, has been newly elected as Chairman of the Finnish Bone and Joint Association. The Finnish NAN wishes Dr. Heliövaara welcome and thanks former chairman Professor Pär Slätis for his ardent support of the Bone and Joint Decade in Finland.

For more information please contact Assoc Prof. Mats Grönblad, NAN coordinator, Mats.Gronblad@hus.fi

HUNGARY: The Hungarian Minister of Health committed to the Hungarian Bone and Joint Decade Foundation to work out a 15-year National Program for Better Musculoskeletal Health based on the European Action Towards Better Musculoskeletal Health.

The Hungarian Osteoporosis and Osteoarthrology Society presented the first results of the “No More Fracture Program” and called for participants from all of Europe. For more information please contact Dr Géza Balint, bjd@t-online.hu

NORTH AFRICAN REGION: Dr Thami Benzakour, BJD Coordinator for North Africa, held a meeting in April with the NAN coordinators of the North African countries. The attendees were Mustapha Trafef (Morocco), Mohammed L. Benazzouz (Algeria), S. Bendalla (Libya) and Khelil Ezzaouia (representing the NAN of Tunisia). This was a good opportunity to try to agree on coordinated

actions against musculoskeletal diseases in the region. There are a few on-going activities at the national level such as: rheumatism epidemiology in Morocco, densitometries studies in Algeria, osteoporosis in Tunisia and Libya and episodic studies of road traffic accidents in all of these countries. Dr Benzakour reported that the general obstacles facing the North African NANs are essentially the problem of sponsorship and difficulties in contacting authorities to incorporate BJDs objectives in their activities. For more information please contact Dr Thami Benzakour, email: t.benzakour@menara.ma



From left to right: Dr Khelil Ezzaouia (Tunisia), Mustapha Trafef (Morocco), Thami Benzakour (North Africa), Laid Benazzouz (Algeria), Sedig Bendalla (Libya)

NORWAY:

The Norwegian Government has recently decided, partly as a consequence of various initiatives of the Norway NAN, (called MST= the Muscle and Skeletal Decade in Norway) to initiate and stimulate increased activities focusing on, and allocating resources to muscle and skeletal disorders. For instance, the Directory of Health and Social Affairs is to develop a total plan of what is to be done regarding research, education and health services in Norway, and the Norwegian Research Council has for 2006 been given 4 mills NOK for funding of clinical research, in particular within the field of spinal disorders. This funding is going to be increased over the years to come

and it is positive news for the BJD in Norway.

In addition, this autumn the Norway NAN will arrange, in collaboration with The Directory of Health and Social Affairs, its annual "one day conference" on the topic Inflammatory and Degenerative Joint Diseases. Target groups are health policy decision makers, media and key network clinicians.

Simultaneously, a large scale governmental public campaign is to be commenced to promote increased physical activity among the Norwegian population in order to enhance health and wellness and to prevent a broad spectrum of diseases, e.g. those related to the muscle and skeletal apparatus. Norway NAN will, in collaboration with Rotary, be involved in these efforts with its own projects.

As Chairman of the Steering Committee of Norwegian NAN, Professor Even Lærum, Head of Communication unit of the Norwegian Back Pain Network, will be replaced by Jack Skrolsvik, who is the present secretary general of the Norwegian Rheumatism Association. As the first Chair of the Norwegian MST, professor Lærum, says: *"I think the Norway NAN with just two years of existence, and with very limited resources, has achieved significant results.... not least due to the enthusiastic, and not paid, efforts of the 10 members of the Steering Committee and their network."*

For more information please contact Mrs Anne Ording Haug, NAN coordinator, anne.ording.haug@vha.no

SLOVENIA: The Slovenia NAN held its annual meeting focusing on current problems in rheumatology (insufficiency of rheumatologists, too long waiting time intervals for first visit of rheumatologist), osteology (fight for National Health Insurance Institute's reimbursement for DEXA measurement in women with high

risk of osteoporosis), and orthopaedic & trauma surgery (uniform organisation of urgent centers in regional hospitals, new funds for hip and knee replacement surgery).

The regional meeting including the Hungarian-Croatian-Slovenian NANs will be held on May 26 and will be reported in the next Infoletter. For more information please contact Dr Radko Komadina, Slovenia NAN coordinator, sbcrdi@guest.arnes.si

TURKEY: An Osteoporosis Platform was established for the National Osteoporosis Program in Turkey. This platform is formed by the following societies

- Turkish Osteoporosis Society
- Osteoporosis Patient Society of Turkey
- The Society of Life with Osteoporosis
- Turkish Joint Diseases Foundation
- Turkish Endocrinology and Metabolism Society

A National Osteoporosis Program will be carried out in 2006-2008 in cooperation with the International Osteoporosis Foundation. This program is aiming to increase the national awareness, lobbying activities, and the quantity and quality of research for osteoporosis in Turkey. For more information please contact Prof O. Sahap Atik, NAN coordinator, atik@tr.net

USA: On April 6 representatives of rare bone disease patient organisations met in Washington DC, to discuss common issues they face, opportunities for collaboration, and how to bring them into the "bone community".

The meeting had three main purposes:

- 1) To introduce the rare bone disease organizations within the larger bone community;
- 2) To provide an opportunity for the rare bone disease groups to meet and to network;

3) To discuss potential bone-related projects relating to rare bone diseases during the Bone and Joint Decade.

The meeting concluded agreeing that a proposal should be made to the USBJD for creation of a new coalition of rare bone diseases organization under the Decade.

All 125 U.S. medical schools have now declared their support for the Decade

For more information on USBJD activities please find the USBJD eNewsletter of April 2006 at www.usbjd.org or contact usbjd@usbjd.org

Change of NAN coordinators in Austria, Sweden and Philippines

Austria: Prof Rainer Kotz, BJD Ambassador, has resigned as NAN coordinator and Prof Josef Smolen, past president of EULAR, has been elected new NAN Coordinator.

We welcome Prof Smolen and at the same time we extend our thanks to Prof Kotz for all his excellent work in the Austrian Network. For more information please contact josef.smolen@wienkav.at

Sweden: New NAN coordinator is Inga-Britt Lindström, chairperson of the Swedish Association of Occupational Therapists. Lena Öhrsvik has stepped down as NAN coordinator. We welcome Inga-Britt Lindström and thank Lena Öhrsvik for her time as coordinator. For more information info@rorg.se

The local Swedish BJD Foundation supporting the NAN activities has announced Dr Ingemar Petersson, Rheumatologist, as new chair.

Philippines: The Philippine Orthopaedic Association (POA) is the lead agency for the Bone and Joint Decade Council for 2006, following the Philippine Rheumatology Association. For this year, the POA is hosting and delegating all the BJD activities. The NAN coordinator for 2006 is Dr. George Winston B Estera, email: poa@bayandsl.com. He has replaced Dr Ester Pensergera. We welcome Dr Estera and thank Dr Pensergera for her time as coordinator.

BJD Coordinator in UAE

Dr Humeira Badsha, Specialist Rheumatologist, Dubai Bone and Joint Center, has become BJD coordinator in the United Arab Emirates (UAE). She is trying to involve other societies to establish a National Action Network. Recently The Emirates Arthritis Foundation has signed the BJD declaration of support. In affiliation with Dubai Bone and Joint Center, The Emirates Arthritis Foundation (EAF) will focus on raising awareness of arthritis and educating the public, as well as healthcare providers, about arthritis. For more information please contact humeira.badsha@dbaj.ae

To date a total of 96 countries have become involved in the Bone and Joint Decade.

Our current status:
96 BJD National Coordinators
60 Supporting Governments
60 National Action Networks

ACT NOW!
The BJD Action Week
October 12 – 20,
Every year

Start planning for the Action Week 2006
Already today!

The days are:

October 12 - **World Arthritis Day**
October 16 - **World Spine Day**
October 17 - **World Trauma Day**
October 20 - **World Osteoporosis Day**

The Bone and Joint Decade Secretariat

If you have any questions or need any assistance please feel free to contact Agneta Jönsson, bjd@ort.lu.se

Next Infoletter

Will be sent on June 28, 2006. For information to be included, please submit before June 15.

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