

UPDATE FROM THE ARTHRITIS ALLIANCE OF CANADA

TOWARDS A FRAMEWORK FOR ARTHRITIS

September 14, 2012
4 days to the launch!

Only four days to the release of [JOINT ACTION ON ARTHRITIS: A Framework to Improve Arthritis Prevention and Care in Canada.](#)

Welcome to the pre-launch edition of our Alliance newsletter. We would like to share with you some exciting next steps for the launch of the Framework – *Joint Action on Arthritis*.

Launch activities

THE LAUNCH EVENT

We are very excited that the Framework launch will be held at the **McCaig Tower-Foothills Medical Centre** in **Calgary, Alberta** at **10:00 am Mountain Time** on **September 18, 2012**. We are expecting 60 guests and local dignitaries to participate at the launch.

Speakers at the event include:

- Dianne Mosher, President, AAC
- Janet Yale, President and CEO, The Arthritis Society
- Dr. Cy Frank, Alberta Bone and Joint Institute
- Linda Wilhelm, patient with Rheumatoid Arthritis

WHAT IF I CAN NOT ATTEND?

For those of you who cannot attend the event in person, we will be webcasting the event live and recording it for posting on the Alliance website.

Date: Tuesday, September 18, 2012

Time: 10:00-10:30 a.m. MT (12 noon Eastern Time)

Link to live webcast: <https://new.livestream.com/accounts/1413790/arthritis>

Webcast coordinates will also be circulated via email prior to launch.

The recording will be available a few days after the event at www.arthritisalliance.ca.



SUPPORTING THE LAUNCH EVENT

The Alliance has been working very closely with Edelman to promote the launch of the Framework with the public and engage the Federal and Provincial governments in some of the proposed initiatives.

- **National media relations campaign**

Edelman and the Alliance have been leading the development and execution of a national media relations campaign. Over the past month, special interest stories have been presented to the media on the impact and economic burden of arthritis on Canadians. We are pleased to report that several media outlets have expressed strong interest in these stories and the content of the Framework itself.

On the day of the event, further efforts will be made to promote the launch through a press release on Canadian Newswire and national media outreach featuring local spokespeople. We look forward to seeing the media coverage that is generated, and will share it with you in our next newsletter.

- **Multi-staged outreach to the Federal Government and Provinces**

We have conducted a multi-staged outreach to government officials across Canada both in the Framework development process and in the lead-up to the launch. We have followed up with meeting requests to discuss the Framework and some of the initiatives which may be of particular interest to them. Meetings with AAC and local representatives have occurred in Alberta and Ontario, and others are being scheduled shortly.

Next steps for stakeholder support and action

WONDERING HOW YOU CAN HELP?

The Framework represents years of effort. It will take everyone's best efforts to keep the momentum moving forward so that the full benefit and value of the Framework can be realized. In short, we need your help to promote the Framework!

To help promote the launch of the Framework, the following materials are currently being developed for your promotional activities:

- Summary paragraph describing the Framework to post on your websites
- Executive summary of the Framework
- Weekly newsletters
- Framework report
- Template for letters to government

With these materials in place, we are asking that you:

1. **Post materials about the Framework prominently on your website.** The launch will occur at 10:00 am MT (12:00 noon ET) on September 18th, so we ask that you post the materials at that time (and not before).
2. **Send Framework promotion materials to your membership.** Again, please time the release of these materials to your membership to be during or after the launch of the Framework scheduled for 10:00 am MT (12:00 noon ET) on September 18th.
3. **Let Governments hear your support of the Framework.** We have prepared template letters that you can modify and send to your local MP or MPP. The more we increase government's attention to this problem, the better chance we have of effecting change.

THE END OF THE BEGINNING

In the words of Sir Winston Churchill during the Second World War, "*Now this is not the end. It is not even the beginning of the end. But it is, perhaps, the end of the beginning.*"

Alliance members have worked very hard for the last few years to get to this point. A great celebration is in order. However, there is so much more that must be done to help the 4.6 million Canadians living with arthritis. The Alliance and its members will be approaching governments and other arthritis stakeholder organizations with specific requests for support and participation in implementing its initial priorities and actions.

To accomplish this, the Alliance will formally establish three working groups:

<u>Working Group</u>	<u>Leaders</u>
Awareness	Ms Tracy Folks Hanson Mr. Denis Jeans
Models of Care	Dr. Cy Frank Dr. Michel Zummer
Research	Dr. Claire Bombardier Dr. David Hart

Along with the Alliance's Board of Directors, the working groups will lead the development and implementation of action plans, activities and stakeholder asks to realize the initial priorities identified. ***You are encouraged to come forth and express immediate interest in supporting any specific pillar of the Framework.***

MOVING FORWARD

To ensure that the momentum achieved with the launch of the Framework is maintained, the Alliance Executive is committed to continuing to send our newsletter on a regular basis. The newsletter will give you an idea of all of the activities underway by each member, and will help identify partnership opportunities.

What Can You Do Now?

In the interim, you can also help and get involved by:

- Visiting www.ArthritisAlliance.ca
- Providing feedback. Give us your ideas
- Giving us an update to share with the group
- Telling us about your upcoming events, initiatives, and announcements that are aligned with the Framework
- Helping us to promote the launch of the National Framework
- Telling our story and telling yours
- Telling your friends and family
- Writing and calling your local MP/MPP, your Premier, Minister of Health, etc
- Sharing on Twitter, Facebook, and other social media channels

Updates from our members

Canadian Spondylitis Association

The CSA was formed in 2006 and is an all-volunteer patient support and advocacy group catering to those with any of the Spondyloarthritis diseases. Membership in the CSA is free. We have Chapters in B.C., Manitoba, Ontario and Newfoundland and representatives in Alberta, Nova Scotia and Quebec. Over the next 12 months, we hope to establish viable Chapters in the latter three Provinces. We have a website <http://www.spondylitis.ca/> and a Facebook group "Canadian Spondylitis Association." We are also on Twitter: @spondyinfo. We produce a quarterly newsletter for our members called "TalkBack." In partnership with SPARCC (the Spondyloarthritis Research Consortium of Canada) and The Arthritis Society, we have held patient forums in Vancouver, Edmonton, Toronto, Montreal and St. John's. We are funded by restricted and unrestricted grants from our industry partners.

We are in the process of re-branding and re-building our website. We are also about to start a three-pronged awareness campaign. The first thrust will be to rheumatologists to make them aware of the CSA. The second will be to family physicians to make them more aware of Ankylosing Spondylitis (AS) and of the existence of the CSA. The third will be to general health care providers and the public to create awareness of AS and the CSA. Launch is planned for September, but may be slightly delayed.

Calendar of Events

September

Arthritis Awareness month

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| September 13 | Arthritis Alliance of Canada Steering Committee and AGM teleconference (5:00 pm ET) |
| September 18 | Launch Event for the Framework, 10:00 am (MT), McCaig Tower, Calgary, AB |
| September 21-23 | The Arthritis Society/CAN Trainee Workshop, Deerhurst, Huntsville, ON |
| September 26-30 | Hip Hip Hooray! 2012 – Step Up to the Challenge! The Canadian Orthopaedic Foundation |
| October 12 | World Arthritis Day |
| October 13 | Arthritis - Active for Life!, 9:30 am - 1:00 pm (PT), Pacific Vancouver Public Library (live web stream) |
| October 16 | World Spine Day |
| October 17 | World Trauma Day |
| October 19 | World Pediatric Bone & Joint Day |
| October 20 | World Osteoporosis Day |

THE ARTHRITIS ALLIANCE NEEDS TO HEAR YOUR SUCCESSES, STORIES AND PROJECTS THAT WILL SUPPORT THE FRAMEWORK EFFORT. IF YOU WOULD LIKE YOUR ORGANIZATION TO BE FEATURED HERE, PLEASE FORWARD YOUR SUBMISSIONS TO JCOISH@MTSINAI.ON.CA.

ABOUT THE ARTHRITIS ALLIANCE OF CANADA

The Arthritis Alliance of Canada, formerly the Alliance for the Canadian Arthritis Program (ACAP), was formed in 2002. Its goal is to improve the lives of Canadians with arthritis.

With more than 20 member organizations, the Arthritis Alliance brings together arthritis health care professionals, researchers, funding agencies, governments, voluntary sector agencies, industry and, most importantly, representatives from arthritis consumer organizations from across Canada. While each member organization continues its own work, the Alliance provides a central focus for national arthritis-related initiatives.

For more information about the Arthritis Alliance, please contact:

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www.arthritisalliance.ca