

## **Canadian Rheumatology Association's Annual Scientific Meeting**

### **Overview**

Chris Debow represented CAPA at the CRA's Annual Scientific Meeting (2014) in Whistler, BC. CAPA was part of a patient initiative that involved the attendance of four other organizations:

- Arthritis Consumer Experts (ACE)
- Arthritis Research Centre of Canada – Patient Advisory Board (ARCCPAB)
- Canadian Spondylitis Association (CSA)
- Sjogren's Society of Canada (SjSC)

As patient delegates, our job was to represent our respective organizations and arthritis patients in Canada at a conference of rheumatologists, researchers, and pharmaceutical companies. I saw my role on behalf of CAPA involving:

- Regular daily attendance at the patient information booth.
- Disseminating information on CAPA to conference participants.
- Attending plenary and workshop sessions when possible.
- Engaging in discussion with conference participants about the role of patients and CAPA in arthritis research, guideline development, models of care development, and the pharmaceutical industry.
- Networking with other arthritis patient groups.
- Networking with CRA members and Directors.
- Providing patient-centered input during workshop sessions.

### **DAY 1 – Wednesday February 26**

- Arrived in Whistler mid-afternoon and went to the conference to meet with other patient reps:
  - Anita Chan (Arthritis Consumer Experts)
  - Manon Roberge (Canadian Spondylitis Association)
  - Marilyn Muldoon (Sjogrens Society of Canada)
  - Kelly English (Arthritis Research Centre of Canada – Arthritis Patient Advisory Board)
  - Janis McCaffrey (ARCC – PAB)
- Signed CAPA up for shifts at the consumer info booth and committed to participant interviews.
- Attended National Update on the CRA/SPARCC Treatment Recommendations for the Management of Spondyloarthritis (Sherry Rohekar).
- Attended Finite Resources and Health Care: Choosing Wisely (Shirley Chow).

### **DAY 2 – Thursday February 27**

- Represented CAPA at the consumer info booth from 6:30 AM to noon.
- Networked, discussed our role and organization with conference attendees and other exhibitors.
- Attended Making Sense of Spondyloarthritis (Vinod Chandran & Nigil Haroon).
- Arranged *Arthritis Broadcast Network* interviews with Dr. Haroon, Carter Thorne (President CRA).
- Represented CAPA at info booth off-and-on in the afternoon.
- Interviewed Dr. Haroon for ABN.
- Attended poster session and networked with investigators.
- Attended evening CRA GREAT DEBATE: Be it Resolved that we are doing too much Monitoring of DMARDs and Biologics, and doing too much Screening before Initiating Biologic Therapy.
- Attended Cathy Hofstetter's patient presentation on the experience of living with Rheumatoid Arthritis and gaps in care

### **DAY 3 – Friday February 28**

- Represented CAPA at the consumer info booth from 6:30 AM to noon, as well as off-and-on throughout the day.
- Attended Exercises for Low Back, Knee, Rotator Cuff, Plantar Fasciitis (Angelo Papachristos).
- Arranged ABN interview with Angelo Papachristos.
- Interviewed Angelo Papachristos for ABN.
- Interviewed Carter Thorne for ABN.
- Attended networking reception / poster session.
- Attended Gala Dinner Reception.

### **DAY 4 – Saturday March 1**

- Attended exhibition area in the morning.
- Morning sessions were mostly closed-door meetings, CRA AGM.
- Conference closed at 1:00 PM.

### **Accomplishments / Impressions**

- CAPA's attendance at the CRA was important and beneficial.
- Standing in unity with other patient organizations strengthened patient presence at the meeting.
- Communicating the existence and work of CAPA was important, as many (most) conference participants had not heard of us. Representatives from APAB, SjSC were also unaware of CAPA, although were familiar with Dawn and Linda.
- Providing input during workshops helped raise awareness of patient specific issues, as well as the existence of patient groups like CAPA.
- The opportunity to network with CRA members is invaluable. Spoke with all companies present



- Completing interviews for ABN to be posted on CAPA website was another benefit to attendance (although maybe somewhat embarrassing for the interviewer once the blooper reel is released).
- The level of interest in patient group attendance by CRA members was disheartening. Despite a very well designed booth and ABN “studio”, very few approached us for information.
- Conference provided excellent opportunity to meet other patient reps and discuss possibilities for working collectively to increase patient organization profile.
- I came away with the impression that much more can and should be done to put patient organizations and issues in the forefront of CRA, industry, and rheumatologist awareness.