



## Strategic Plan 2016

### **our**belief

The Canadian Arthritis Patient Alliance (CAPA) is a grassroots, patient-driven, independent, national advocacy organization with members and volunteers from across the country. CAPA's fundamental belief is that the first expert on arthritis is the individual who lives with the disease, and who provides a unique perspective that is all too often absent.

### **what**wedo

CAPA builds links between Canadians with arthritis and their support systems. Our strategic priorities are achieved through collaboration and partnership with other patient and advocacy organizations, representatives from all levels of government, academic researchers, healthcare professionals, industry members, not for profit organizations, and other individuals. CAPA communicates the latest news on health policy, research, technology and emerging issues relevant to members through our website, Facebook page, a quarterly newsletter, and new Twitter account. CAPA welcomes all Canadians with arthritis and those who support CAPA's goals, to become members.

### **our**reflections

Since CAPA's efforts to establish an effective and functional organization in 2013, strategic plans have been set each year since to guide its activities in the next year. These strategic plans are publicly available on CAPA's homepage to ensure transparency and accountability to its members. In the section that follows, we highlight our achievements with respect to the 2015 CAPA strategic plan.

# our achievements 2014-2015

We have chronicled our achievements here against our 2015 Strategic Plan.

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## **One** | Re-establish an active, effective organization.

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### Strategic Achievements:

- 1 | Fundraised for main administrative needs and to provide support for planned activities.
  - 2 | Created and implemented an Honorarium Policy for Steering Committee Members who undertake roles related to specific activities.
  - 3 | Welcomed two new Steering Committee Members.
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## **Two** | Reach out to our members.

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### Strategic Achievements:

- 1 | Continued to refine and update our website ([www.arthritispatient.ca](http://www.arthritispatient.ca)), maintained an active Facebook page (approximately 100 likes), and created a Twitter account (@CAPA\_arthritis).
  - 2 | Produced 4 newsletters that saw above-industry average opens (60-66%) and click-throughs (mean 23%).
  - 3 | Produced 2 surveys of CAPA Membership to gather thoughts and ideas on pregnancy and parenting with arthritis as well as relationship with and services at the pharmacy.
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## **Three** | Initiate grassroots action.

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### Strategic Achievements:

- 1 | CAPA has supported individual members' grassroots initiatives that are firmly aligned with its interests and allow an opportunity for members to promote CAPA. Some of the supported activities that members have undertaken include working with researchers as collaborators on their teams

(e.g. in pediatric rheumatology, workplace issues, peer to peer mentoring, etc.), attending regional research meetings, attending and participating in health policy meetings (Pan-Canadian Pharmaceutical Alliance patient-input meetings, Canadian Agency for Drugs in Technology Health conference and webinar information sessions), attending the Cochrane Symposium, participating in the Drugs Safety and Effectiveness Steering Committee, participating in the CIHR SPOR Patient Engagement Framework, participating in a research meeting regarding pregnancy and rheumatic disease, making presentations to Health Canada drug reviews on the patient perspective regarding regulatory processes, attending and participating in various roundtables related to subsequent entry biologics, attending, presenting a poster on the Arthritis Patient Charter, and actively participating in the Canadian Rheumatology Association's Annual Meeting.

- 2 CAPA continues to promote its Arthritis Patient Charter and provides print outs (posters and postcards) to organizations that request it (<http://arthritispatient.ca/projects/arthritis-patient-charter/>). This year the Charter was presented as a poster at the Canadian Rheumatology Association Meeting.
- 3 Spearheaded a letter-writing and meeting campaign with government on subsequent entry biologics (SEBs). A template letter was written that was personalized and sent to the Ministries of Health and provincial drug plans in Newfoundland, Prince Edward Island, Nova Scotia, New Brunswick, Quebec, Ontario, Saskatchewan and British Columbia. In many instances, other patient and charitable organizations co-signed the letter, and presentations were made to government officials (in some cases Ministers of Health) about CAPA's position on SEBs.
- 4 Developed a video of patient involvement in research and training reviews in collaboration with the Arthritis Society which includes information on what letters of intent are, parts of a grant application, etc. (<http://arthritispatient.ca/research/>).
- 5 Provided feedback on a number of consultations: CADTH Common Drug Reviews (three in total: Actemra (subcutaneous administration) for rheumatoid arthritis, Cimzia for ankylosing spondylitis, Otezla for psoriatic arthritis). Where provincial input is also taken in to consideration from patient organizations, CAPA provided input ([www.arthritispatient.ca/projects/cadth-patient-input-submissions/](http://www.arthritispatient.ca/projects/cadth-patient-input-submissions/)).
- 6 Continued to build relationships with other patient groups in Canada, including Arthritis Consumer Experts, Patient Partners, Canadian Spondylitis Association, Canadian Psoriatic Arthritis Network, Crohn's & Colitis Canada, as well as the International Association of Patient Organizations.

- 7 | Presented a poster at the Annual CADTH Symposium entitled “Common Drug Review Patient Input Process.”
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## **Four** | **Continue involvement in the Arthritis Alliance of Canada.**

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### **Strategic Achievements:**

- 1 | CAPA has retained membership of the Arthritis Alliance of Canada and continues to sit on key committees of Advocacy and Awareness and Models of Care of Inflammatory Arthritis. The patient (also called consumer) organizations that have Alliance membership meet regularly to share and disseminate information, and to liaise with a patient representative whom they have chosen to represent them on the Alliance Board. We were also key contributors to the Annual Arthritis Alliance of Canada Meeting and presented a poster on what CAPA is, what CAPA does, and highlighted some of its efforts in the past year.
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## **Five** | **Build stronger ties with The Arthritis Society.**

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### **Strategic Achievements:**

- 1 | Remaining active members on advisory boards (Saskatchewan and Newfoundland).
- 2 | Holding regular meetings and facilitate regional collaborations. See below.
- 3 | Regular meetings between the national Chief Mission Officer and CAPA’s Vice President occur to discuss areas of mutual interest and collaborate where possible.
- 4 | Collaborating and sharing information with TAS regional advocacy committees – e.g. such as members have to date in Atlantic Canada.
- 5 | Participating in the Arthritis Society’s research and training program, including research and training grant reviews, trainee day meetings, etc.
- 6 | Continuing to mutually disseminate information that is applicable to both The Arthritis Society stakeholders and CAPA membership (e.g. information about CAPA’s position papers in the Arthritis Society’s newsletter, dissemination of surveys from the Arthritis Society on CAPA’s Facebook page and newsletter, etc.)

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## **Six** | **Work closely with allied partners.**

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### **Strategic Achievements:**

- 1** | CAPA has remained an active member of The Best Medicines Coalition, with our President sitting on the Operations Committee.
- 2** | Our members have continued to work with Health Canada on critical initiatives, including development of patient tools to assess benefits/risks/uncertainties of medications, policy changes on drug review/approval/clinical trials), attending and presenting to Standing Committees on Health, participating on the acetaminophen safety working group, providing input to the tamper-resistant packaging concept for opioids for chronic pain, and responding to requests for input on the Drug Shortage of Canada website. Steering Committee members have also made various presentations at Health Canada meetings as well as the Drug Information Association meeting.
- 3** | This year, CAPA submitted to the Canadian Agency for Drugs and Technologies in Health Common Drug Review on patient input for Actemra (subcutaneous formulation), Cimzia, and Otezla.
- 4** | We have continued to build our relationship with Canadian Medical Association, through in person attendance and participation in their Annual Governing Council Meeting, contributions to and dissemination of information on their Seniors' Strategy and continued membership by our Vice President on the CMA's Wait Times Alliance.
- 5** | We continue to work with the Arthritis Health Professionals Association to develop a formal consumer grant review function.
- 6** | Our Executive has invested significant time and energy to re-introduce CAPA and its goals and capabilities to various pharmaceutical industry members, including BIOTECanada, Innovative Medicines Canada (formerly Rx&D), AbbVie, Janssen Ortho, UCB, Roche, Amgen, Novartis, Pfizer, GSK, Purdue Pharma, and Sanofi.
- 7** | When opportunities have been afforded, we have participated in Canadian Institutes for Health Research committees and workshops, including in the Strategy for Patient-Oriented Research (SPOR) Patient Engagement Strategy. Our Vice President is a member of the Institute for Musculoskeletal Health Advisory Board and the Arthritis Research Ambassador group.

## Seven | Execute CAPA-led projects.

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### Strategic Achievements:

- 1 We have started to develop educational and support materials on living with arthritis and pregnancy/having a family. A survey is currently with Membership and it will be used to inform the direction of the educational and support materials that will be developed. The survey was promoted through the CAPA newsletters and through the assistance of our many partners (for example through a number of well-known arthritis bloggers).
- 2 We developed a position paper on medical cannabis (English and French) that was posted on the CAPA website and Facebook pages for September (Arthritis Month) (<http://arthritispatient.ca/projects/medical-cannabis/>). It was also promoted by the Arthritis Society in their newsletter, highlighted in the CAPA newsletter, and shared via members' personal social media accounts.
- 3 We established a relationship with the Arthritis Health Professionals Association that included promoting the Arthritis Patient Charter as well as mutually promoting each other's organizations.
- 4 We have updated the Together Enhancing Arthritis Management (TEAM) slide decks that were previously developed, and will be posted in early 2016 on our website. We are developing plans around educational modules on topics such as pain and mental health related to arthritis. We also participated and supported patient participation in research priority-setting for patients who live with chronic pain via a CIHR SPOR Chronic Pain Network application.
- 5 We have posted videos on our website about SEBs and about how drugs are approved in Canada. We have developed our own slide deck that not only discusses SEBs, but also provides an explanation of our position paper ([www.arthritispatient.ca/files/5614/3792/5904/CAPA\\_SEB\\_July2015\\_web.pdf](http://www.arthritispatient.ca/files/5614/3792/5904/CAPA_SEB_July2015_web.pdf)).
- 6 We have added information to our website about the Choosing Wisely Canada Campaign ([www.arthritispatient.ca/projects/choosing-wisely-canada/](http://www.arthritispatient.ca/projects/choosing-wisely-canada/)) and have continued to contribute to the Canadian Rheumatology Association's efforts through providing input on their pamphlet on small molecules and biologics.

# ourplan

We believe that CAPA has continued to deliver on its strategic plan and goals, and shows excellent progress for such a small grassroots organization. The past year has proven to be one of CAPA's most challenging, potentially since its formation. While establishing operations and administrative rigour and processes, we have been engaged in active outreach to members, have taken on significant CAPA-driven projects, and have more plans to continue to grow next year. Our plan for the next year is outlined below.

## ourpriorities

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### **One** | **Maintain an active, effective organization.**

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#### **Strategic Actions:**

- 1 | Continue to fundraise to maintain current administrative needs and provide support for planned initiatives.
  - 2 | Continue to develop policies as required.
  - 3 | Mentor and recruit new membership and Steering Committee Members, supporting individual advocacy efforts in their specific regions.
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### **Two** | **Continue to reach out to our members.**

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#### **Strategic Actions:**

- 1 | Building on last year, we have updated our website to better reflect CAPA projects, work with partners, and provide resources for our members. We will continue our quarterly member newsletter, and explore opportunities to expand our reach with other arthritis communications where possible. We will also consider conducting surveys to better learn the needs of our membership.
- 2 | Enhance CAPA's social media profile through continued posts on CAPA's Facebook page plus through the creation of our Twitter account (@CAPA\_arthritis, 51 followers one month after set up) and is managed by

one Steering Committee Member (with input from others).

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### **Three** | **Initiate grassroots action.**

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#### **Strategic Actions:**

- 1 | CAPA will continue to support individual members' grassroots initiatives that are firmly aligned with CAPA's interests and allow an opportunity for members to promote CAPA.
  - 2 | CAPA has created a letter writing campaign for Steering Committee Members and its general Membership to reach out to government officials to increase their understanding of the impact of arthritis and the issues facing patients trying to manage their disease (<http://arthritispatient.ca/information-resources/make-your-voice-heard/>). Through the creation of template letter, advocacy will be enabled for those who might not otherwise take action. Tools will be provided to Members to customize and utilize at their own community level.
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### **Four** | **Continue involvement in the Arthritis Alliance of Canada.**

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#### **Strategic Actions:**

- 1 | As in the past, we will continue to remain active members on key committees, including the Advocacy and Awareness, and Models of Care, as well as the Consumer group that continues to meet regularly.
  - 2 | We will continue to support the Alliance's efforts to bring together a united voice in the Canadian arthritis community.
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### **Five** | **Continue to work closely with The Arthritis Society.**

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#### **Strategic Actions:**

- 1 | Remaining active members on advisory boards.
- 2 | Holding regular meetings and facilitate regional collaborations. Continuing to meet with leadership at a national level, partnering in appropriate ways and providing patient input at many levels.



- 3 Collaborating with The Society's regional advocacy committees, such as members have to date in Atlantic Canada.
- 4 Participating in the research and training program, such as participating in the research and training grant reviews, trainee day meetings, etc.
- 5 Participating as collaborators on The Arthritis-Society-funded research grants/projects.

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## **Six** | **Work closely with allied partners.**

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### **Strategic Actions:**

- 1 Remaining active members of The Best Medicines Coalition.
- 2 Working with Health Canada on critical initiatives, including developing patient tools to assess benefits/risks/uncertainties of medications, policy changes on drug review/approval/clinical trials), and more.
- 3 Working with the Canadian Agency for Drugs and Technologies in Health on patient input into the Common Drug Review, as well as the parallel provincial agencies that also solicit patient input and to encourage the expansion of the patient input process overall.
- 4 Enhancing the relationship with Canadian Medical Association, especially through their National Senior Strategy, Patient Forums and the Wait Times Alliance.
- 5 Working to formalize the consumer grant review function with the Arthritis Health Professionals Association.
- 6 Building and enhancing existing, and new industry partnerships - AbbVie, Janssen Ortho, UCB, Roche, GSK, Novartis, Pfizer, Amgen, and others.
- 7 Collaborating with and participating in Canadian Institutes for Health Research committees.
- 8 Continuing involvement with the Cochrane Musculoskeletal Group.
- 9 Continuing to build existing relationships with the Ontario and Canadian Rheumatology Associations, as well as build a relationship with pharmacists associations.

- 10 Continuing to be a member and actively participate in the Better Pharmacare Coalition.
- 11 Remaining on the College of Physiotherapy Citizen Advisory Council.
- 12 Continuing to participate as collaborators on research teams where appropriate partnerships can be built and where meaningful engagement is ensured, especially with respect to designing research questions that are important to patients and ensuring knowledge translation beyond the research community.
- 13 Starting to build relationships with the private payer community to ensure there is an understanding of arthritis, the importance of therapeutic options for patients, and the overall impact of arthritis on individuals in all capacities (at home, work, being a productive and functioning member of society).

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## **Seven** | **Execute CAPA-led projects.**

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CAPA's 2015 Strategic Plan represented the first time in many years that we as CAPA planned to undertake our own initiatives, and is representative of how far we have come in the past two years. We plan to continue to build on our successes in the 2016 Strategic Plan as outlined below.

### **Strategic Actions:**

- 1 Developing educational and support materials on living with arthritis and pregnancy/having a family. E-booklets (English and French) will be created based on a survey of needs, and will be reviewed by a medical expert. We will also work to communicate the pregnancy and parenting survey results to the broader arthritis and medical community.
- 2 Developing a principles paper on national pharmacare (English and French) and will be disseminated to members.
- 3 Developing a survey for Membership on their thoughts on pharmacists and their services. Develop appropriate resources for Members and potentially for pharmacists based on findings from the survey.
- 4 Creating relationships with pharmacists and other allied health professionals to promote use of the Arthritis Patient Charter in their pharmacies and clinics.

- 5 | Hosting a webinar about CAPA for membership to help them understand the work that CAPA has done in the past year, or about a specific topic of interest.
  - 6 | Creating a grassroots letter-writing campaign as outlined above, for Members to engage with their politicians to understand the issues faced by those living with arthritis and their concerns about the healthcare system and access to treatments.
  - 7 | Continuing to build upon the success of projects initiated in 2015 on topics around medical cannabis, subsequent entry biologics, and the TEAM educational modules.
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