



Strategic Plan 2018

ourbelief

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

whatwedo

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 government, researchers, healthcare professionals, industry, not for profit organizations, and other individuals and organizations. CAPA communicates news on health policy, research, technology and emerging issues relevant to members through a variety of ways: our website, Facebook page, a quarterly newsletter, our Twitter feed (@CAPA_Arthritis), and our Youtube channel. We welcome all Canadians with and affected by arthritis and those who support CAPA's goals to become members.

ourreflections

Since 2013, CAPA has set out annual strategic plans to guide activities. These strategic plans are publicly available on CAPA's homepage to ensure transparency and accountability to members. In the section that follows, we highlight our achievements with respect to the 2017 CAPA strategic plan.

ourachievements 2017

We've chronicled our achievements against our 2017 Strategic Plan below.

One | Maintained an active, effective organization.

Strategic Actions:

- 1 | Continued to fundraise to maintain current administrative needs and to provide support for planned initiatives.
- 2 | Continued to develop policies as required, including a social media strategy and policy.
- 3 | Engaged new and existing membership. Our membership survey (discussed further below) was conducted and results shared. We hosted a membership drive and gained 50 new members. Two new individuals joined and were mentored as a Steering Committee Members.

Two | Continued to reach out to our members.

Strategic Actions:

- 1 | We have continued our quarterly member newsletter (open rate of over 45% and click through rate of over 13% - even with increasing our membership base significantly) and created innovative opportunities to expand our reach with other arthritis communities where possible. This year we started to share more information with Creaky Joints (a US-based arthritis advocacy organization) as well as the European League Against Rheumatism's PARE (People with Arthritis/Rheumatism across Europe). We also actively supported the International Alliance of Patients' Organization-promoted Patient Solidarity Day on December 2, 2017. We conducted a survey to better learn the needs of our membership and found general satisfaction with CAPA's activities and approach. The membership survey results are posted on our website and were emailed to members.
- 2 | Continued to enhance CAPA's social media profile through posts on CAPA's Facebook page and Twitter as manned by two Steering Committee Members. The last year saw 448 likes and 446 followers on Facebook and our Twitter account has 626 followers. CAPA also made use of different techniques to achieve higher ranked posts and views.

Three | Initiated grassroots action.

Strategic Actions:

- 1 | CAPA continued to support individual members' grassroots initiatives that are firmly aligned with CAPA's interests and allows an opportunity for members to promote CAPA. Examples of other organizations or activities that align with those of CAPA include: The Best Medicines Coalition, the Chronic Pain community, the SPOR Evidence Alliance, local hospital advisory committees, workplace awareness presentations, provincial health consultations and

support for researchers.

- 2 Participated in the SPOR Chronic Pain Network, providing the voice of people living with arthritis and pain throughout all Network activities, including in the governance of the network and as members of the Patient Engagement Committee.
- 3 Met with Health Canada regarding projects and topics such as the pregnancy and parenting with arthritis and biosimilars. Initiated a dialogue with Health Canada on behalf of chronic pain patients regarding the impact of opioid policy development on access to medications and pain treatment access. Participated in multi-stakeholder meeting hosted by Health Canada to learn more about perspectives on and attitudes towards biosimilars.

Four | Continued involvement in the Arthritis Alliance of Canada.

Strategic Actions:

- 1 CAPA provided input and representation on the patient organization coalition and attended Alliance's 2017 Annual Meeting "*Change is Good: Implementing Arthritis Models of Care*" in Vancouver.
- 2 We continued to support the Alliance's efforts to bring together a united voice in the Canadian arthritis community, including on-going participation in regular Alliance meetings.

Five | Continued to work closely with The Arthritis Society.

Strategic Actions:

- 1 CAPA and the Society announced a strategic partnership in February 2017. As a strategic partner, we have remained active members on advisory boards. We also participated in efforts of the Society in the continued development of its Mission and Strategy, including participation in the Arthritis Society's: Pain Symposium (May 2017), visioning session (September 2017), and Arthritis Hackathon (September 2017).
- 2 Where possible, we have held regular meetings and facilitated regional collaborations, as well as continue to meet regularly with leadership at a national level, partnering especially with respect to consistent messaging about biosimilars and pain and providing patient input at many levels.
- 3 We have been working with the Society to share information and resources, for example, with respect to the pregnancy and parenting materials, patient input submissions for CADTH, and for the research program (providing input on materials that are under development for consumer reviewers and researchers). We continued to identify and execute projects together where possible and where there were appropriate synergies such as updating our respective biosimilar position papers, working on materials to better familiarize patient reviewers of the research and grant application review processes, and collaborating on projects related to arthritis in the workplace.

- 4 We have continued to participate in the Society's research and training program. Examples include participation in the research and training program as grant reviewers, efforts to provide input to new training materials for potential new consumer reviewers and participating in the planning for and on the day of a trainee day meeting.
- 5 Many individual CAPA members participated as collaborators and partners on The Arthritis-Society-funded research grants/projects.

Six | **Worked closely with other organizations.**

Strategic Actions:

- 1 Continued to actively participate as members of The Best Medicines Coalition.
- 2 Engaged with Health Canada on critical initiatives, including opioid policy development, drug review policy, biosimilars, and other patient engagement initiatives.
- 3 Provided patient input on the Common Drug Review for the Canadian Agency for Drugs and Technologies in Health, as well as the parallel provincial agencies that also solicit patient input (i.e. input in to the CADTH biosimilar patient input template, input in to the biosimilar review process at CADTH, baricitinib for rheumatoid arthritis, etanercept for rheumatoid arthritis, ankylosing spondylitis, canakinumab for systemic juvenile idiopathic arthritis) and to encourage the expansion of the patient input process overall. A number of these were submitted in collaboration with the Arthritis Society and/or with other patient organizations. Submitted abstracts to the CADTH conference, and successfully presented a poster on our methotrexate survey results. CAPA also actively participated in CADTH's symposium planning committee, reviewed workshop and poster abstracts, presented at a panel regarding improvements to the patient input process and co-facilitated a workshop on the benefit, risk and uncertainty treatment decision guide. We also provided feedback that was incorporated to CADTH's biosimilar information tools for patients.
- 4 Continued to build our relationships with Arthritis Health Professionals Association (AHPA) and the Canadian Rheumatology Association (CRA). We have continued to interface regularly with CRA leadership on issues that affect our stakeholders and two Steering Committee members are on the RA Guideline update committee. We have started regularly communicating with AHPA communications leads to provide information about CAPA projects and resources that are helpful for AHPA members as well as participated on an AHPA grant review committee.
- 5 Where possible, we have continued our outreach efforts and continued to enhance existing and new industry partnerships.
- 6 Collaborated with and participated in Canadian Institutes for Health Research committees and initiatives. Specifically, one of our Steering Committee Members is a Research Ambassador as part of the CIHR's Institute for Musculoskeletal Health and Arthritis and is also on an Institute Advisory Board for CIHR, while another participated in the workshop for the Inflammation in Chronic Disease Networking event and spoke on the topic of patient engagement in research.

- 7 Continued involvement with the Cochrane Collaboration. One of our Steering Committee members is very involved with the Cochrane Collaboration and attended the Symposium in May 2017.
- 8 Continued to be a member and actively participated in the Better Pharmacare Coalition.
- 9 Remained on the College of Physiotherapy Citizen Advisory Council and as a lay member on The Council of the College of Occupational Therapists Ontario.
- 10 Continued to participate as collaborators on research teams where appropriate partnerships and meaningful engagement are ensured, especially with respect to designing research questions that are important to patients and ensuring knowledge translation beyond the research community. Examples include the co-development and facilitation of the SPOR Masterclass on Patient Oriented Research, the SPOR CIHR national core curriculum, presenters in Partners in Research (PiR), patient involvement in research webinars, acting as a collaborator on a SPOR Evidence Alliance research grant, as well as co-leading work on patient engagement outcomes. We are also involved in the Patient-Focused Medicines Development initiative that is globally-focused on developing best practices in patient engagement related to research and medicines development.
- 11 Continued 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). Numerous presentations by Steering Committee members were undertaken at a variety of these meetings representing this patient perspective, and one Steering Committee member is part of a Private Payer Working Group.

Seven | Executed CAPA-led projects.

CAPA's 2017 Strategic Plan continued to build on successful CAPA planned and executed initiatives as started in 2016.

Strategic Actions:

- 1 Developed educational and support materials on living with arthritis and pregnancy/having a family. Specifically, an e-booklet (English, French translation is underway) was created on survey results and reviewed by medical and scientific experts. Much work went in to dissemination of this resource, including at the Canadian Rheumatology Association Conference 2017 (poster presentation), the European League Against Rheumatism (EULAR) Conference 2017 (oral presentation), and outreach continues to other organizations such as Mother to Baby, arthritis bloggers and non-profit organizations. CAPA also collaborated with Creaky Joints by reviewing patient guidelines on family planning and arthritis.
- 2 We are currently developing resources based on our findings from the methotrexate survey (English and French) and will disseminate to members and other organizations that could benefit from this information. We presented posters at the Canadian Rheumatology Association Conference (2017) and at the CADTH Symposium (2017) about this work. We are also in discussions with a rheumatology clinic so they may use the survey questions with their patients to see what other information can be gleaned from them on the use of

methotrexate.

- 3 We developed and conducted a survey for membership to better understand their needs and develop plans to meet these. The results of the survey are found [here](#).
- 4 We have identified key areas for improvement for the CAPA website to better meet member needs including accessibility via mobile devices and searchability. Website redevelopment will continue in 2018.
- 5 A member webinar to communicate CAPA's vision, efforts in the past year, and to gain input and insight from members will be scheduled for February 2018.
- 6 Continue to work with private payers so they understand patient perspectives with respect to various potential topics, including preferred pharmacies, biosimilars, etc. Steering Committee members have participated in numerous events with private and public payers over the course of the last year on such topics.
- 7 Continued to promote the Arthritis Patient Charter. The Charter was one of CAPA's most well-known products by its members (as ascertained by the members' survey).
- 8 Continued to bring awareness to topics such as pain management and medical cannabis that impact people living with arthritis and require continued attention, advocacy and research. We have written various letters to Health Canada and the federal Minister of Health about pain, presented at the Conference Board of Canada April 2017 meeting, are part of a multi-patient organization/health charity campaign against taxing medical cannabis, and have had numerous discussions with our MPs about arthritis priorities.

ourplan 2018

We believe that CAPA has continued to deliver on its strategic plan and goals, and shows excellent progress for such a small grassroots organization. We continue to grow and further develop our own independent projects where we see gaps and opportunities for us to share with our community. Our plan for 2018 is outlined below.

ourpriorities

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

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 | Engage new and existing membership.
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Two | Continue to reach out to our members.

Strategic Actions:

- 1 | As a virtual organization, our website is integral to this work. CAPA's website redevelopment will be responsive (e.g. mobile-friendly) and better support members (e.g. better navigation).
 - 2 | We will continue our quarterly member newsletter, and explore opportunities to expand our reach with other arthritis communications by partnering with arthritis bloggers and other health influencers where possible.
 - 3 | Continue to enhance CAPA's social media profile through continued posts on CAPA's Facebook page and Twitter as manned by two Steering Committee Members.
 - 4 | Host a webinar to inform members of CAPA activities. This will also be made available on our Youtube channel.
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Three | Initiate grassroots action.

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 | Continue to participate in the SPOR Chronic Pain Network, providing the voice of people living with arthritis and pain throughout all Network activities.
 - 3 | Continue to engage with Health Canada regarding issues of importance to CAPA members, including opioid use in patients living with chronic daily pain and use of medical cannabis.
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Four | Continue involvement in the Arthritis Alliance of Canada.

Strategic Actions:

- 1 | As in the past, we will continue to remain active members on the patient organization coalition.
- 2 | We will continue to support the Alliance's efforts to bring together a united voice in the Canadian arthritis community.

Five | **Continue to work closely with our strategic partner, The Arthritis Society.**

Strategic Actions:

- 1 | Continue to meet with leadership at a national level, partnering in appropriate ways and providing patient input at many levels. Hold regular meetings and facilitate regional collaborations.
- 2 | Remain active members on advisory boards.
- 3 | Develop joint strategies and take action on key projects where there are appropriate synergies.
- 4 | Participate in the research and training program, such as participation in the research and training grant reviews, trainee day meetings, etc.
- 5 | Participate as collaborators on The Arthritis-Society-funded research grants/projects.

Six | **Work closely with other organizations.**

Strategic Actions:

- 1 | Remain active members of The Best Medicines Coalition.
- 2 | Work with Health Canada on critical initiatives.
- 3 | Work on patient input on the Common Drug Review for the Canadian Agency for Drugs and Technologies in Health, as well as the parallel provincial agencies that also solicit patient input and to encourage the expansion of the patient input process overall. Submit abstracts to the CADTH conference.
- 4 | Continue to build our relationships with Arthritis Health Professionals Association and the Canadian Rheumatology Association.
- 5 | Build and enhance existing, and new industry partnerships.
- 6 | Collaborate with and participate in Canadian Institutes for Health Research committees and initiatives.
- 7 | Continue involvement with the Cochrane Collaboration.
- 8 | Continue to be a member and actively participate in the Better Pharmacare Coalition.

- 9 Remain on the College of Physiotherapy Citizen Advisory Council and on Council of the College of Occupational Therapy Ontario and expand reach other groups such as Health Quality Ontario and local hospital groups.
- 10 Continue to participate as collaborators on research teams such as the SPOR Evidence Alliance and surgical safety research, and 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.
- 11 Continue 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).
- 12 Continue to engage with other patient organizations, both nationally and internationally, such as Cannabis Canada Association, Creaky Joints, People with Arthritis and Rheumatism (PARE) and the International Alliance of Patients' Organizations.

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

CAPA successfully delivered on a number of its own initiatives in 2017. We plan to continue to build on these successes in the 2018 Strategic Plan outlined below.

Strategic Actions:

- 1 Continue to disseminate educational and support materials on living with arthritis and pregnancy/having a family to the broader arthritis and medical community.
- 2 Complete resources based on our findings from the methotrexate survey (English and French) and disseminate to members and other organizations that could benefit from this information.
- 3 Develop a survey for membership to better understand their needs related to work and arthritis and develop support materials to help address these needs in collaboration with the Institute for Work and Health.
- 4 Update the CAPA website to better support member engagement, including better navigation and responsive technology (i.e., mobile devices).
- 5 Update CAPA's biosimilars position paper and continue to work on resources and materials related to this class of therapeutics such as the biosimilar information pamphlet.
- 6 Continue to reach out to international arthritis organizations, to build relationships and share resources and materials.
- 7 Continue to promote CAPA resources, including the Arthritis Patient Charter and position papers.

- 8 | Continue to bring awareness to topics such as pain management and medical cannabis that impact people living with arthritis and require continued attention, advocacy and research.
 - 9 | Work to increase member engagement with the research community – both in academia and industry.
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