



Strategic Plan 2019

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 works to create 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](#), quarterly newsletter, Twitter (@CAPA_Arthritis), and [Youtube channel](#). We welcome all Canadians with and affected by arthritis and those who support CAPA's goals to join our community.

ourreflections

Since 2013, CAPA has set out an annual strategic plan to guide its operational activities. These plans are publicly available on CAPA's website to ensure transparency and accountability to members. In the section that follows, we highlight our achievements with respect to the 2018 CAPA strategic plan.

ourachievements2018

The priorities of CAPA's 2018 Strategic Plan are outlined below along with an update on accomplishments with respect to each of these.

One | Maintained an active, effective organization.

Strategic Actions:

- 1 | Continued to fundraise for administrative needs and to support planned initiatives.
- 2 | Developed a Funding Policy available on CAPA's website.
- 3 | Continued to engage new and existing membership through outreach and participation in the arthritis community.

Two | Continued to reach out to our members.

Strategic Actions:

- 1 | Launched an updated CAPA brand and website. We listened to the needs of our community and developed a website that is mobile-friendly, more visual, thematically organized and more intuitive to navigate.
- 2 | Our quarterly member newsletter continued to have good read rates (40% average open rate). We also expanded our reach with other arthritis communications by partnering with and sharing information, resources, and stories with arthritis bloggers (e.g. *The Seated View*, *Mamas Facing Forward*) and other organizations including *CreakyJoints* and the *European League Against Rheumatism (EULAR)*.
- 3 | Continued communications via social media (Facebook - 522 likes and 530 Facebook Followers, and Twitter – 2,166 likes and 890 Twitter Followers).
- 4 | Rather than host a webinar, CAPA posted the results of its membership survey on its website and sent these to the CAPA community. We also presented the membership survey and results as a poster at the *EULAR* Conference, which was posted on our website.

Three | Initiated grassroots action.

Strategic Actions:

- 1 | Continued supporting individual members' grassroots initiatives that align with CAPA's interests and promote CAPA values and efforts.

- 2 | Continued to participate in all aspects of the SPOR Chronic Pain Network and the SPOR Evidence Alliance Network (governance and other activities in both Networks), providing the voice of people living with arthritis and pain.
- 3 | Continued to engage with Health Canada on issues of importance to CAPA members through participating in *Health Canada's* stakeholder engagement session *Regulation and Health Innovation* (June 2018), conducted a survey on the use of opioids by people living with chronic daily pain and presented the results at *Health Canada's Opioid Symposium* (September 2018). Represented CAPA and participated in a round table with the *Federal Health Minister* before the *Opioid Symposium* which allowed us to voice support for the concept of a *National Pain Task Force*. Represented the patient voice in a [Health Canada video](#) about providing input to health policy.
- 4 | Numerous CAPA Steering Committee members participated in person at National Pharmacare Consultation meetings across the country.
- 5 | Continued to work with other patient organizations to provide input to various government or organizations at arms-length from government on topics related to pharmaceutical pricing, etc. We were engaged in the consultations concerning the Ontario Health Sector Payment Transparency regulations and provided a policy submission to the Ontario government.

Four | Continued involvement in the Arthritis Alliance of Canada.

Strategic Actions:

- 1 | Remained as an active member on the patient organization coalition.
- 2 | Supported the *Alliance's* continued efforts to bring together a united voice in the Canadian arthritis community.

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

Strategic Actions:

- 1 | Continued to meet with leadership at a national level, partnering in appropriate ways and providing patient input at many levels. Held regular meetings and facilitated regional collaborations.
- 2 | Remained as active members on advisory boards.
- 3 | Collaborated on all CADTH patient input submissions for arthritis in 2018, including: Ixekizumab for psoriatic arthritis, csDMARDs for rheumatoid arthritis, Nucynta for the treatment of pain, DMARDs post-MTX-IR (also in collaboration with the *Ontario Rheumatology Association* and the *Canadian Rheumatology Association*). Patient input submissions are also listed on our website.

- 4 Participated in the research and training program: by contributing to research and training grant reviews, advising on and participating in the trainee day meeting (October 2018), and finalizing two sets of slides that are posted on CAPA's website: [Information About Research and Peer Review for Grant Applications](#).
- 5 Participated as collaborators on *The Arthritis Society*-funded research grants/projects.

Six | Worked closely with other organizations.

Strategic Actions:

- 1 Remained active members of *The Best Medicines Coalition*.
- 2 Worked with *Health Canada* by providing input at their *Opioid Symposium* and by providing continued feedback on their opioid initiatives. See Section 3 above for more information
- 3 Worked 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 solicit patient input and to encourage the expansion of the patient input process overall. We also submitted abstracts to the CADTH conference. This work was undertaken in collaboration with the *Arthritis Society* in 2018 – see Section Five above for specific information. The CAPA President was part of a panel for the *2018 CADTH Annual Symposium* in Halifax (Nova Scotia) presenting our Methotrexate Resource for the first time.
- 4 Continued to build our relationships with *Arthritis Health Professionals Association (AHPA)*, and disseminate information through the *AHPA* communications to members) and the *Canadian Rheumatology Association*.
- 5 Built and enhanced existing and new industry partnerships.
- 6 One Steering Committee member continued to be an Institute Advisory Board member of the *Canadian Institutes of Health Research's Institute of Musculoskeletal Health and Arthritis* as well as a member of its *Research Ambassadors*.
- 7 Continued involvement with the *Cochrane Collaboration*.
- 8 Continued membership in the *Better Pharmacare Coalition*.
- 9 Remained on the *Ontario Citizen Advisory Council* and on the *Council of the College of Occupational Therapy Ontario*, as well as the *Patient Partner Working Group of the Ontario SPOR Support Unit* and expanded reach of other groups such as *Health Quality Ontario* and local hospital groups, such as *The Ottawa Hospital*.

- 10 Continued to participate as collaborators on research teams such as the *Saskatchewan and Ontario SPOR Support Units*' projects and surgical safety research, especially with respect to designing research questions that are important to patients and ensuring knowledge translation beyond the research community. Participated as members of the team that produced and delivered the *Partners in Research* web-based modules with researchers based at *St. Michael's Hospital* (Toronto).
- 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).
- 12 Continued to engage with other patient organizations, both nationally and internationally, such as *Cannabis Canada Association*, *CreakyJoints*, *People with Arthritis and Rheumatism (PARE)*, *Irish Children's Arthritis Network (iCAN)*, *Mother to Baby*, *ReumaLiga*, and the *International Alliance of Patients' Organizations*.
- 13 Joined the *National Pain Care Forum* led by McMaster University, allowing CAPA to provide continued input and support for a *National Pain Task Force*.

Seven | Executed CAPA-led projects.

CAPA successfully delivered on a number of its own initiatives in 2018. We plan to continue to build on these successes in the 2019 Strategic Plan outlined below.

Strategic Actions:

- 1 Continued to disseminate educational and support materials on living with arthritis and pregnancy and having a family to the broader arthritis and medical community and actively engaged in research projects on this topic including the development of an infographic relating to family quality of life. Hosted a Tweetchat on this topic to celebrate *Arthritis Awareness Month* in September. Using the hashtag #arthritisparent, there were 28 participants, and 340 tweets with almost a million Twitter impressions. The results are available on our website.
- 2 Completed resources based on our findings from the methotrexate survey (English and French) and disseminated this information via our website (1,339 pageviews, 1,051 unique pageviews), social media, in person at the *CADTH* and *EULAR* Conferences. This resource was also translated in to Spanish and is currently being translated in to simplified Chinese. We have recently adapted the survey for response by parents of children who have arthritis with the *iCAN*.
- 3 Developed a survey for our community 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*. The survey garnered 396 responses, and the results were presented as a poster at *EULAR* in June 2018.

- 4 | Launched an updated CAPA brand and accompanying overhauled website to address needs of the CAPA community and support engagement. As a note, our website had 14,152 pageviews in 2018, of which 11,020 were unique.
- 5 | Updated CAPA's biosimilars position paper to reflect our consideration of current relevant evidence, joined the *Alliance for Safe Biological Medicines*, and continued to work on resources and materials related to this class of therapeutics.
- 6 | Continued to reach out to international arthritis organizations including *CreakyJoints*, *PARE* (patient organizations that are part of *EULAR*), to build relationships and share resources and materials.
- 7 | Continued to promote CAPA resources, including the Arthritis Patient Charter, position papers and other activities.
- 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.
- 9 | Worked to increase community engagement with the research community – both in academia and industry. Established an informal collaboration with *The Arthritis Program at Southlake Hospital* via sharing the methotrexate survey.

ourplan2019

We believe that CAPA has continued to deliver on its strategic plan and goals, and continues to achieve progress as a small grassroots organization. Each year we also grow so we can further develop our own independent projects where we see gaps and opportunities for us to share resources and information with our community. Our plan for 2019 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 and grow the CAPA community.
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Two | Continue to reach out and meet the needs of the CAPA community.

Strategic Actions:

- 1 | As a virtual organization, our website is integral to this work. We will continue to add new resources and information to our website.
 - 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 three Steering Committee Members.
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Three | Initiate grassroots action.

Strategic Actions:

- 1 | CAPA will continue to support CAPA community 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* and *Evidence Alliance*, 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.
 - 4 | Continue to engage in dialogue related to pharmacare, drug pricing, and other issues of relevance to the CAPA community.
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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, and holding 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. Aim to host at least one webinar that is also taped and hosted on CAPA's website either with respect to research in general or grant reviews.
- 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 *CADTH*, as well as the parallel provincial agencies that solicit patient input and to encourage the expansion of the patient input process overall. Submit at least one abstract to the *CADTH* conference.
- 4 | Continue to build our relationships with *AHPA* and the *CRA*.
- 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 *Ontario Citizen Advisory Council* and on *Council of the College of Occupational Therapy Ontario* and continue to expand reach to other groups.
- 10 Continue to participate as collaborators on research teams such as the *SPOR SUPPORT Unit* projects, *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*, *CreakyJoints*, *PARE*, *iCAN*, *ReumaLiga* and the *International Alliance of Patients' Organizations*.

Seven | Execute CAPA-led projects.

CAPA successfully delivered on a number of its own initiatives in 2018. We plan to continue to build on these successes in the 2019 Strategic Plan outlined below.

Strategic Actions:

- 1 Continue to disseminate educational and support materials on living with arthritis and pregnancy and 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. Work with *iCAN* to develop a resource based on survey results and disseminate this resource.
- 3 Finish development of tools and resources related to the needs of people with arthritis related to work in collaboration with the *Institute for Work and Health*, and disseminate these resources.
- 4 Summarize findings from the opioid survey of people who live with arthritis and other conditions. Develop a resource based on the survey and start its dissemination.
- 5 Continue to reach out to international arthritis organizations, to build relationships and share resources and materials.
- 6 Continue to promote CAPA resources, including the Arthritis Patient Charter and position papers.

- 7 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.
 - 8 Work to increase member engagement with the research community – both in academia and industry.
 - 9 Develop a resource on aids and gadgets for daily living that have been tried and tested by people living with arthritis.
 - 10 Launch a Medical Advisory Committee to guide CAPA formally from a medical perspective, and develop all associated governance and infrastructure materials for this Committee.
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