



## Strategic Plan 2020

### ourbelief

The Canadian Arthritis Patient Alliance (CAPA) is a grassroots, patient-driven, independent, national organization with a community of individuals across the country. Our belief is that the first expert on arthritis is the person who lives with arthritis and provides a critical voice and perspective that needs to be heard in decision-making. .

### whatwedo

CAPA uses the power of information, research, and communication to help people living with arthritis find their voice and support others. Many people think arthritis only affects older people, or that it is merely a word for aches and pains. At CAPA, we work to clear up these misconceptions to create a better Canada for people living with arthritis and their support groups. Arthritis is a collection of debilitating diseases which affect Canadians of all ages and backgrounds. By collecting and producing patient resources, policy papers, and outreach projects, CAPA seeks to educate and empower people living with arthritis so they can continue to positively contribute to society and improve their health care experiences. CAPA communicates in many ways: our [website](#), [Facebook page](#), monthly updates to members, Twitter (@CAPA\_Arthritis), and [Youtube channel](#).

CAPA' s strategic priorities are achieved through collaboration and partnership with other patient organizations, representatives from government, researchers, healthcare professionals, industry, not-for-profit organizations, and other individuals and

organizations. We welcome all Canadians with and affected by arthritis and those who support CAPA's goals to join our community.

## our reflections

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 2019 CAPA strategic plan.

## our achievements 2019

The priorities of CAPA's 2019 Strategic Plan are outlined below along with an update on accomplishments with respect to each of these.

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### One | Maintained an active, effective organization.

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#### Strategic Actions:

- 1 | Continued to fundraise for administrative needs and to support planned initiatives.
- 2 | Developed policies as required.
- 3 | Continued to engage new and existing membership through outreach and participation in the arthritis community.

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### Two | Continued to reach out and meet the needs of the CAPA community.

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#### Strategic Actions:

- 1 Continued to add new resources and information to our website.
- 2 Continued our quarterly member newsletter, which moved to monthly distribution due to the quantity of information and requests to share information that we have been receiving. The 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 CAPA' s social media efforts (Facebook - 522 likes and 530 Facebook Followers, and Twitter – 2,166 likes and 890 Twitter Followers).

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## Three | Initiated grassroots action.

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### Strategic Actions:

- 1 Continued supporting CAPA community initiatives that are aligned with CAPA' s interests and allowed an opportunity to promote CAPA.
- 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 the CAPA community through a leadership role on the Canadian Pain Task Force and through participating in national consultation efforts.
- 4 Engaged in dialogue related to pharmacare, drug pricing and other issues relevant to the CAPA community, mainly through participation as a member of the Best Medicines Coalition, and also through attending CADTH and the Patented Medicines Pricing Review Board meetings and the Canada Health Infoway Partnership Conference. Updated our biosimilars position paper to reflect new evidence. Participated in consultation with Alberta with respect to their policy on biosimilars, have been invited by Ontario to do the same in 2020.

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## Four | Continued involvement in the Arthritis Alliance of Canada.

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### Strategic Actions:

- 1 | Remained as an active member on the patient organization coalition.
- 2 | Supported the *Alliance's* continued efforts in its final year to bring together a united voice in the Canadian arthritis community.
- 3 | A partner on grants to further disseminate Alliance tools and resources throughout 2020 contributing to the AAC legacy.

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

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### Strategic Actions:

- 1 | Continued to partner in appropriate ways and provide patient input at many levels. Held regular meetings and facilitated regional collaborations.
- 2 | Collaborated on all CADTH patient input submissions for arthritis in 2019, including: Benlysta for lupus (given a warning added to its product monograph by Health Canada, Ixekizumab (Taltz) for ankylosing spondylitis (also collaborated with the Canadian Spondylitis Association) and Upadacitinib for rheumatoid arthritis, and baricitinib (Olumiant) for rheumatoid arthritis. Patient input submissions are also listed on our website.
- 3 | Participated in the research and training program by contributing to research and training grant reviews.
- 4 | Participated as collaborators on *The Arthritis Society*-funded research grants/projects.

- 5 Worked collaboratively in the development and dissemination of the Arthritis Society' s workplace tools including review of their educational resources, promotion activities, and our Board Member Annette McKinnon was featured in a podcast focused on arthritis in the workplace.

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## Six | Worked closely with other organizations.

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### Strategic Actions:

- 1 Remained active members of *The Best Medicines Coalition*. One Steering Committee member has been on the working group at BMC related to patient engagement in health policy and its development of a white paper.
- 2 Worked with *Health Canada* by being a member of the Canadian Pain Task Force and participating in national consultations related to living with chronic pain. See Section 3 above for more information. Provided input to Health Canada to: its draft guidance document on "*The Distinction Between Promotional and Non-promotional Messages and Activities for Health Products*" independently and as part of a submission led by Clinical Trials Ontario; its draft guideline document "*Consultation: Release of Draft (Step 2) ICH Guidance: E8(R1) Revision on General Considerations for Clinical Trials*" through a submission led by Clinical Trials Ontario.
- 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. This work was undertaken in collaboration with the *Arthritis Society* in 2019 – see Section Five above for specific information. The CAPA Vice President was supported by CADTH to attend its *2019 CADTH Annual Symposium* in Edmonton (Alberta), participated in a presentation on "Tackling the Thorny Issue of Patient Partner Compensation in Research and Health Care" with Zal Press of Patient Commando, and presented a poster on "Healthcare Transformation: The Other Story: The Needs of People who Live with Chronic Pain." A report provided back to

CADTH on the symposium experience opened the doors for: a call with CADTH to provide input in to the patient participant experience at its symposium, and led to a webinar hosted by a Steering Committee member on tweeting at conferences. Steering Committee members participated in CADTH' s Biosimilar Consultation in fall 2019, as a member of the Advisory Committee and as participants in the in person consultation and subsequent processes. Submitted an abstract for a workshop at the 2020 CADTH Symposium.

- 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*. We participated at their 2019 annual meeting where we presented two posters, one showcasing the results of a TwitterChat on pregnancy/parenting with arthritis, and one showcasing the educational resources developed by CAPA. Our 2<sup>nd</sup> Vice President also presented at the AHPA meeting about the pregnancy and parenting project.
- 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*, another Steering Committee member is part of *CIHR' s Citizen Advisory Committee*.
- 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, *Outcome Measures in Rheumatology (OMERACT)*, and maternal health research projects, 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). Presented at the *Ontario SPOR SUPPORT Unit* information session held in Ottawa in May 2019.

- 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)* and *EULAR' s Patient Research Partner group*, *Irish Children' s Arthritis Network (iCAN)*, *ACTion Council*, and the *International Alliance of Patients' Organizations*. CAPA' s 2<sup>nd</sup> Vice-President attended the annual PARE conference in April 2019 and presented at their best practices fair. The CAPA 1<sup>st</sup> Vice-President attended EULAR' s Patient Research Partner meeting in November 2019 and made a presentation on communications between researchers and patient research partners.
- 13 Engaged with *Clinical Trials Ontario* on submissions to Health Canada as well as to provide input and feedback in to resources developed in collaboration with patients, patient organizations and health charities (including their website and clinical trials finder).
- 14 Contributed to the *Drug Safety and Effectiveness Network* through one Steering Committee member being part of it.

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## Seven | Executed CAPA-led projects.

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CAPA successfully delivered on a number of its own initiatives in 2019. We plan to continue to build on these successes in the 2020 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 an Ontario wide

study on the pregnancy experiences of people with disabilities. We also expressed the importance of pursuing a medication safety service to the *Society of Gynecologists and Obstetricians*.

- 2 Hosted a survey for parents of and children with arthritis with iCAN. Development of a resource based on this survey and including input from parents and their children with arthritis, including a medical review, is underway.
- 3 Finished development of tools and resources 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*. Hosted a Tweetchat on this topic to celebrate *World Arthritis Day* on October 12 in collaboration with popular UK blogger, Simon Stones, and U.S. based patient group Creaky Joints. Using the hashtag #ArthritisAtWork, there were 110 participants, and 565 tweets with over 3 million Twitter impressions. The results are available on our website.
- 4 Presented findings from the opioid survey of people who live with chronic pain at the *CADTH 2019 Symposium*. Started to build resources associated with this survey that will be presented as a poster at the *2020 Canadian Rheumatology Association* conference.
- 5 Continued to reach out to international arthritis organizations including *CreakyJoints*, *PARE*, *iCAN*, etc., to build relationships and share resources and materials. One Steering Committee member participated in EULAR's Patient Research Partners conference in October 2019, and presented on the importance of communication in collaboration between patient research partners and researchers. CAPA's 2nd Vice-President attended the annual PARE conference in April 2019 and presented at their best practices fair.
- 6 Continued to promote CAPA resources, including the Arthritis Patient Charter, position papers and other activities.
- 7 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.



- 8 | Worked to increase community engagement with the research community – both in academia and industry. Steering Committee members contribute to the *Patient Focused Medicines Development* initiative.
  - 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.
  - 11 | Started the update of the Together Enhancing Arthritis Management (TEAM) modules with a medical expert.
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## ourplan2020

We believe that CAPA has continued to deliver on its strategic plan and goals, and continues to achieve progress as a small, volunteer-based grassroots organization. Each year we 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 2020 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. Diversify fundraising base to include funding from research

projects that CAPA members participate in as collaborators, government organizations, and other public sources.

- 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.

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### Strategic Actions:

- 1 As a virtual organization, we will continue to add new resources and information to our website in a timely way.
- 2 Our member newsletter switched to a monthly format in late 2019. We will continue to 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 managed by three Steering Committee Members.

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## Three | Initiate grassroots action.

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### Strategic Actions:

- 1 CAPA will continue to support Ccommunity 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.
  - 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 to work closely with our strategic partner, The Arthritis Society.

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### 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 Develop joint strategies and take action on key projects where there are appropriate synergies.
  - 3 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.
  - 4 Participate as collaborators on *The Arthritis-Society*-funded research grants/projects.
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## Five | Work closely with other organizations.

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### 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 predatory journal research? (just to give them a plug), 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 public and private payer communities 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*, and the *International Alliance of Patients' Organizations*.

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

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CAPA successfully delivered on a number of its own initiatives in 2019. We plan to continue to build on these successes in the 2020 Strategic Plan outlined below.

### Strategic Actions:

- 1 Continue to disseminate educational and support materials on living with arthritis and pregnancy and having a family, methotrexate, work and arthritis, and living with chronic pain, to the broader arthritis and medical communities, as well as to policy-makers.
- 2 Work with *iCAN* to finalize development and begin dissemination of a resource based on survey results of children with arthritis and their parents.
- 3 Finish the update of the Together Enhancing Arthritis Management (TEAM) modules. Provide an update to the CAPA community as well as various organizations that could benefit from these modules.
- 4 Continue to reach out to international arthritis organizations, to build relationships, work collaboratively and share resources and materials.
- 5 Continue to promote CAPA resources, including the Arthritis Patient Charter and position papers.
- 6 Continue to bring awareness to topics such as pain management, medical cannabis, medication safety during pregnancy/breastfeeding and other issues that impact people living with arthritis and require continued attention, advocacy and research.
- 7 Work to increase member engagement with the research community – both in academia and industry.
- 8 Develop a resource on aids and gadgets for daily living that have been tried and tested by people living with arthritis.
- 9 Launch a Medical Advisory Committee to guide CAPA formally from a medical perspective, and develop all associated governance and infrastructure materials for this Committee.
- 10 Update the resource on pregnancy and parenting in partnership with health care professionals and disseminate to the arthritis community.

- 11** Create a resource that helps the public, decision-makers and policy-makers see how life with inflammatory arthritis has changed in the past two decades due to changes in treatment practice and therapies.
  - 12** Undertake a project to help CAPA members understand the different organizations in the health policy and research landscape in Canada. Short videos created in collaboration with organizations such as CIHR, CADTH, CIHI, pCPA, PMPRB, Health Canada, and others would be posted on the CAPA YouTube site.
  - 13** Explore ways to diversify CAPA' s funding sources.
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