



Strategic Plan 2017

ourbelief

The Canadian Arthritis Patient Alliance (CAPA) is a grassroots, patient-driven, independent, national advocacy organization with members and volunteers from across the country. We firmly believe 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.

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 all levels of government, academic researchers, healthcare professionals, industry, not for profit organizations, and other individuals and organizations. 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 Twitter (@CAPA_Arthritis). CAPA welcomes all Canadians with arthritis and those who support CAPA's goals, to become members.

ourreflections

Since CAPA's efforts to re-establish an effective and functional organization in 2013, strategic plans have been set each year since to guide its activities. 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 2016 CAPA strategic plan.

ourachievements 2016

We've chronicled our achievements against our 2016 Strategic Plan below.

One | Maintained an active, effective organization.

Strategic Achievements:

- 1 | We continued to fundraise to maintain current administrative needs and provide support for planned initiatives.
 - 2 | We continued to develop policies as required. Enhanced the Honorarium Policy and drafted a Social Media Policy.
 - 3 | We recruited more than 65 new members and mentored two new Steering Committee Members, supporting individual advocacy efforts in their specific regions.
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Two | Continued to reach out to our members.

Strategic Achievements:

- 1 | We continued to update our website with new CAPA projects – Parenting and Arthritis, Biosimilars, TEAM Modules, Methotrexate, and regular news and articles. We also worked with partners, and provided resources to our members. We continued our quarterly member newsletter and explored opportunities to expand our reach with other arthritis organizations where possible. We conducted four surveys to better learn the needs of our membership - one to understand how the Arthritis Patient Charter is used, a survey with Better Pharmacare to help them understand what individuals in BC know about government drug policies, a survey about methotrexate and how people with arthritis successfully manage it as a medication, and a survey on behalf of Manulife insurance to understand perceived impacts of preferred pharmacies on people living with arthritis.
 - 2 | We have continued to build our social media efforts. We have over 350 followers providing likes and comments on Facebook, and 312 followers on Twitter with an average 100 tweets per month.
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Three | Initiated grassroots action.

Strategic Achievements:

- 1 | CAPA has supported individual members' grassroots initiatives that are firmly aligned with our interests and allowed 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, 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), participating in the Cochrane Collaboration, participating in the Drug Safety and Effectiveness Network

Steering Committee, and participating in the CIHR SPOR Chronic Pain Network

- 2 CAPA continued to promote its Arthritis Patient Charter and provide print outs (posters and postcards) to organizations that request it (<http://arthritispatient.ca/projects/arthritis-patient-charter/>). This year the Charter was presented as an oral presentation at the European League Against Rheumatism (EULAR) Conference. This was CAPA's first oral presentation at EULAR.
- 3 Spearheaded a letter-writing and meeting campaign with government on biosimilars. Continuing on the previous year's meetings, we hosted meetings with key stakeholders in BC (Members of Parliament), Saskatchewan (Minister of Health), and Manitoba (Executive Director of the Provincial Drug Program).
- 4 Provided feedback on a number of consultations: CADTH Common Drug Reviews (Etanercept biosimilar for rheumatoid arthritis and ankylosing spondylitis, Sarilumab for rheumatoid arthritis, input in to the RA Therapeutics Review of Biologics). Where provincial input is taken in to consideration from patient organizations, CAPA provided input (www.arthritispatient.ca/projects/cadth-patient-input-submissions/). We also provided input into the CADTH patient input template revisions.
- 5 Continued to build relationships with other patient groups in Canada, including Arthritis Consumer Experts, Patient Partners, Canadian Spondylitis Association, Canadian Psoriatic Arthritis Network, Cassie and Friends, and Crohn's & Colitis Canada. Internationally we also continued our membership in the International Association of Patient Organizations, and created new links to Creaky Joints, the National Data Bank for Rheumatic Diseases, the PanAmerican League of Associations for Rheumatology (PANLAR) and individual arthritis related bloggers.

Four | Continued involvement in the Arthritis Alliance of Canada.

Strategic Achievements:

- 1 We remained active members on key committees, including the Advocacy and Awareness, Models of Care, and the Consumer Group.
- 2 Met with government representatives in Ontario and New Brunswick on arthritis in the workplace and the burden of arthritis, respectively.
- 3 Continued to support the Alliance's efforts to bring together a united voice in the Canadian arthritis community, and participated in its annual meeting in October 2016.

Five | Continued to work closely with The Arthritis Society.

Strategic Achievements:

- 1 | Remained an active member of the Saskatchewan advisory board.
- 2 | Held regular meetings and facilitated regional collaborations. Continued meeting with leadership at a national level, partnered where appropriate and provided patient input at many levels.
- 3 | Presented to the national education staff about a patient's viewpoint of living with arthritis.
- 4 | Participated in the research and training program: in the research and training grant reviews, trainee day meetings, etc.
- 5 | Participated as collaborators on The Arthritis Society-funded research grants/projects.
- 6 | Collaborated on a joint patient input submission to CADTH.
- 7 | Participated in a project about biosimilars along with other patient organizations. The project has included outreach to patients as well as conducting focus groups. The project continues in to 2017 and will be presented as a poster at the Canadian Rheumatology Association Annual Conference.

Six | Worked closely with allied partners.

Strategic Achievements:

- 1 | Remained an active member of The Best Medicines Coalition.
- 2 | Participated in development of a clinical trials informational website: www.itstartswithme.ca/ / www.cacommeceavecmoi.ca supported by the Network of Networks.
- 3 | Worked with the CADTH 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. Also provided input to the Patented Medicines Pharmaceutical Review Board and the pan-Canadian Pharmaceutical Alliance.
- 4 | Met with Canadian Pharmacists Association about medical cannabis.
- 5 | Presented at the Arthritis Health Professional Association workshop on CAPA and continued to mutually share information.
- 6 | Built and enhanced existing, and new industry partnerships - AbbVie, Amgen, Eli Lilly, GSK, Janssen, Merck, Novartis, Pfizer, Pfizer/Hospira, Purdue, Roche, Sanofi, UCB.
- 7 | Collaborated with and participated in Canadian Institutes for Health Research committees. Participated as a Research Ambassador on IMHA. Participated in the Ontario SPOR

- Support Unit Masterclass on patient-oriented research.
- 8 Continued to build existing relationships with the Canadian Rheumatology Association. Two Steering Committee members are on the CRA-RA Guideline Update Committee as well as participating in the CRA-RA Core Data Set Identification project.
 - 9 Continued to be a member and actively participated in the Better Pharmacare Coalition.
 - 10 One Steering Committee member remained on the Consumer Advisory Panel for the College of Physiotherapy Ontario and was also appointed as a lay member of the Council of the College of Occupational Therapy Ontario.
 - 11 Continued 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.
 - 12 Started 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). These activities were evidenced by meetings with various private insurance companies, and one Steering Committee member providing perspective and talks at three Benefits Canada meetings as well as presenting and participating in the Innovative Medicines Conference on employee benefits plans.
 - 13 Contributed to the development of a postcard about the importance of taking methotrexate with biologics and posted the resource on our website (<http://arthritispatient.ca/information-resources/medications/>).

Seven | Executed CAPA-led projects.

Strategic Achievements:

- 1 Numerous activities related to the pregnancy and parenting with arthritis project, including: analysis of survey findings and communication to various groups; advocacy efforts related to medication use during pregnancy and breast feeding; presentation of three posters on the project (Canadian Rheumatology Association, International Conference on Reproduction, Pregnancy, and Rheumatic Diseases, and Canadian Association for Health Services and Policy Research) discussions with researchers and clinicians on the project; development of a website around resources. An abstract was submitted to the 2017 Canadian Rheumatology Association Conference on this work.
- 2 Developed a principles paper on national pharmacare (English and French) as part of our membership in the Best Medicines Coalition.
- 3 Developed a survey for membership on their thoughts on pharmacists and their services and presented the results at the Canadian Pharmacy Foundation meeting (2016).
- 4 Developed a survey for membership (English and French) on their experiences with methotrexate. The survey was reviewed by a rheumatologist and shared via our typical methods, as well as with other international organizations with which we have developed

relationships. Abstracts on this survey were submitted to the 2017 Canadian Rheumatology Association Conference and the CADTH Conference.

- 5 Worked with Manulife to create and distribute a survey to members about their thoughts on preferred pharmacies and how this may impact them.
- 6 Updated our biosimilar position paper (bilingual) based on new evidence (<http://arthritispatient.ca/projects/biosimilars/>). Created a biosimilar video (bilingual) to explain the differences amongst small molecules, generics, biologic and biosimilar drugs. Posted the video on our website and created a Youtube site as well (<https://www.youtube.com/channel/UCJPsVsvUYNwrEtYMK0Fx1Bzg>). The video has close to 500 views in English and nearly 200 views in French in about 6 months.

ourplan 2017

We believe that CAPA has continued to deliver on its strategic plan and goals, and shows excellent progress for such a small grassroots organization. Each year since re-establishing stable operations (2013), 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 the next year 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, specifically a social media strategy and policy.
- 3 Engage new and existing membership. Further mentor two new Steering Committee Members, enabling individual advocacy efforts in their specific regions.

Two | **Continue to reach out to our members.**

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 conduct a survey to better learn the needs of our membership.

- 2 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.

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 Participate in the SPOR Chronic Pain Network, providing the voice of people living with arthritis and pain throughout all Network activities.
- 3 Meet with Health Canada regarding projects such as the pregnancy and parenting with arthritis and opioid use in patients living with chronic daily pain.

Four | **Continue involvement in the Arthritis Alliance of Canada.**

Strategic Actions:

- 1 As in the past, we will continue to remain active members on key committees.
- 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 The Arthritis Society.**

Strategic Actions:

- 1 Remain active members on advisory boards.
- 2 Hold regular meetings and facilitate regional collaborations. Continue to meet with leadership at a national level, partnering in appropriate ways and providing patient input at many levels.
- 3 Identify and execute projects together where possible and 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.
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Six | **Work closely with allied partners.**

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.
 - 10 | Continue 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.
 - 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).
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Seven | Execute CAPA-led projects.

CAPA's 2016 Strategic Plan represented the first time in many years that CAPA planned and executed a number of its own initiatives and is representative of its continued growth. We plan to continue to build on CAPA's successes in the 2017 Strategic Plan as outlined below.

Strategic Actions:

- 1 | Develop educational and support materials on living with arthritis and pregnancy/having a family. E-booklets (English and French) will be created on survey results and reviewed by medical and scientific experts. We will also continue to work to disseminate these items to the broader arthritis and medical community.
 - 2 | Develop 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 and develop plans to meet these.
 - 4 | Update the CAPA website to better meet member needs including accessibility via mobile devices.
 - 5 | Host at least one member webinar to communicate CAPA's vision, efforts in the past year, and to gain input and insight from members.
 - 6 | Continue to work with Manulife to interpret survey results on preferred pharmacies and develop resources that communicate back to membership on the survey results.
 - 7 | Continue to promote the Arthritis Patient Charter.
 - 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.
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