



Canadian Arthritis
Patient Alliance

2022 Accomplishments

ourbelief

The Canadian Arthritis Patient Alliance (CAPA) is Canada's only independent, volunteer-based arthritis patient organization run by patients for patients. CAPA supports a community of people living with arthritis across the nation, believing that the first expert on arthritis is the person who lives with arthritis. Individuals with arthritis provide a critical voice and perspective that needs to be heard in research and decision-making.

ourgoals

CAPA uses the power of information, research, and communication to help people living with arthritis find their voice and to support others. The following goals guide CAPA's activities:

1. Help patients: understand arthritis, manage their health, and contribute to decision-making.
2. Advocate for patient access to treatments, health care professionals, and services.
3. Build awareness about arthritis including the impact on people with arthritis and their families, the health care system, and society.
4. Ensure patients are involved in decision-making, such as co-producing arthritis research, health care policies, and other policies that affect the arthritis community.

whatwedo

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 for those who support them. Arthritis is a number of



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debilitating diseases which may affect Canadians of all ages and backgrounds. By collecting and producing patient resources and policy papers, and carrying out various 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 its work and information in many ways: [website](#), [monthly newsletters](#), [Facebook](#), [Twitter](#), [YouTube](#), and [Instagram](#). CAPA has a [Medical Advisory Committee](#) that reviews our resources to ensure information is based on the scientific evidence.

CAPA's strategic priorities are achieved through collaboration and partnership with other patient organizations, representatives from government, policymakers, 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.

COVID19

2022 has seen the pandemic continue to impact the globe. CAPA and the arthritis community have continued to respond to the pandemic in many unplanned ways. This work will be highlighted throughout the reflections in 2022 and includes: continuing to update an evidence-based COVID-19 website; offering a webinar about arthritis and vaccines; and contributing to guideline and decision-aid development related to COVID-19 vaccination; contributing to research efforts and, more.

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 2022 CAPA strategic plan.



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ourachievements2022

The priorities of CAPA's 2022 Strategic Plan are outlined below along with an update on our accomplishments and achievements during the year.

One | Maintain an active, effective virtual, not for profit organization

Strategic Actions:

- 1 Continued to fundraise to maintain current administrative needs and provide support for planned initiatives. Continued to diversify fundraising efforts including our first-ever fundraiser with Sparkplug Coffee called Coffee for CAPA.
- 2 Welcomed new Steering Committee members from Ontario and Alberta who bring a range of arthritis and health care experiences.
- 3 Engaged and grew the CAPA community, including a new team of patient partners in research with representation from Alberta, Saskatchewan, New Brunswick, and Ontario, as well as representation from different rheumatic conditions and youth.
- 4 Hired a part-time managing director (Laurie Proulx) who lives with arthritis and has been involved with CAPA for over fifteen years, to manage, plan, and execute CAPA activities.

Two | Continue to reach out and meet the needs of the CAPA community

Strategic Actions:

- 1 Added new resources and information to our website in a timely way (e.g., drug shortages, Health Canada alerts), shared monthly newsletters, and implemented a social media strategy.
- 2 Continued to enhance CAPA's reach via social media and monthly newsletter (2284 Twitter followers, 940 Facebook followers, 401 Instagram followers, 223 YouTube subscribers, and over 700 newsletter subscribers).



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- 3 Updated [Living with Chronic Pain: Tips for Patients by Patients](#) including a [French version](#).
- 4 Developed a resource [Tips and Tricks When Taking Methotrexate For Kids Living with Arthritis and Their Parents](#) in collaboration with the [Irish Children's Arthritis Network](#) (ICAN), including a [French version](#).
- 5 Continued to offer educational programming, like a youth-led [Instagram live](#) event with [Take a Pain Check Foundation](#), a [webinar](#) about autoimmune rheumatic diseases and vaccines, a [Twitter Spaces event](#) about navigating the workplace with arthritis, and a Twitter chat with [Creaky Joints](#) and Take a Pain Check Foundation on World Arthritis Day.

Three | Initiated grassroots action

Strategic Actions:

- 1 Continued supporting community initiatives that align with CAPA's priorities and allowed an opportunity to promote CAPA and share its resources, including opinion articles and policy submissions relating to the [pan-Canadian health data strategy](#), [medical cannabis](#), the [Canada Disability Benefit](#), and [drug pricing](#).
- 2 Continued to participate in the [SPOR Chronic Pain Network](#), [SPOR Evidence Alliance](#), and the newly created [PEPR: Partnership for Engagement of People with Chronic Pain in Health Research](#) providing the voice of people living with arthritis and pain throughout their activities.
- 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, in response to their request for input on a biosimilar handbook, as a member of the Health Canada Data Working Group. We were a member of Clinical Trials Ontario [Health Charities and Patient Organizations group](#) where we responded to government consultations on [modernizing the clinical trials regulatory environment](#) and the Canadian Institutes of Health Research (CIHR) [consultations on clinical trials](#).



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- 4 Continued to engage in dialogue related to pharmacare, drug pricing, and other issues. We provided input to the Canadian Agency for Drugs and Technologies in Health's (CADTH) five drug-specific patient input submissions including anifrolumab for Systemic Lupus Erythematosus, belimumab for lupus nephritis, guselkumab for psoriatic arthritis and [Pan Canadian Drug Formulary consultation](#). We were part of consultations with the Ontario Ministry of Health with respect to its biosimilars policy.
 - 5 Continued to actively engage in the [Best Medicines Coalition](#) as a member of the drug policy and drug pricing working groups. We provided input and submissions related to the Patented Medicines Pricing Review Board proposed guidelines.
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Four

Continue to work closely with our strategic partner, Arthritis Society Canada

Strategic Actions:

- 1 Continued to meet with national leadership, partnering and providing patient input at many levels, and facilitating regional collaborations.
 - 2 Collaborated on all CADTH patient input submissions for arthritis in 2022 (see #4 in previous section for details) which are [posted](#) on our website.
 - 3 Participated in the research and training program including as collaborators on Society-funded projects.
 - 4 Participated in the Canadian Arthritis Research Conference as presenters, moderators, and participants including as part of a session dedicated to sexual and reproductive health in rheumatic diseases.
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Five | **Work closely with other organizations and advocates**

Strategic Actions:

- 1 Provided CADTH patient input submissions in collaboration with the Arthritis Society Canada, Canadian Psoriasis Network, Canadian Skin Patient Alliance, Canadian Spondylitis Association, and Creaky Joints Canada, and to parallel provincial agencies that solicit patient input. We also provided input to encourage the expansion of the patient input process overall.
- 2 Continued the collaborative project “[Baring it All](#)” with the [Canadian Psoriasis Network](#), [Canadian Association of Psoriasis Patients](#), and [Canadian Spondylitis Association](#) including presenting at the European Alliance of Associations for Rheumatology (EULAR) Congress and moderating and presenting a symposium at the Canadian Arthritis Research Conference.
- 3 Continued to build our relationships with the Arthritis Health Professions Association (AHPA) and the Canadian Rheumatology Association (CRA) and presented a webinar on sexual and reproductive health to AHPA. Attended the CRA meeting and reported ([Meet Dr. Cheryl Barnabe](#) and [Meet Dr. Bindee Kuriya](#)) in our newsletter and through live Tweets.
- 4 Collaborated with and participated in CIHR committees, including on the Institute of Musculoskeletal Health and Arthritis (IMHA) Patient Engagement Research Ambassadors and its Institute Advisory Board. CAPA board members also participated in the Patient Partner Working Group of the Ontario SPOR Support Unit and on the Patient Partner Advisory Committee of the Saskatchewan Centre for Patient Oriented Research.
- 5 Continued involvement with international initiatives, such as the Cochrane Collaboration and Outcome Measures in Rheumatology (OMERACT), and engaged with other patient organizations, both nationally and internationally, such as CreakyJoints, EULAR People with Arthritis/Rheumatism across Europe (PARE), iCAN, International Association of Patient Organizations (IAPO), and the COVID-19 Global Rheumatology Alliance.
- 6 Member of the Clinical Trials Ontario patient organizations and health charities group where we provide input and feedback into resources developed in



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collaboration with patients, patient organizations and health charities including CIHR and Health Canada consultations relating to patient engagement with clinical trials.

- 7 Provided patient perspective in the peer review grant process for the CIHR and also for its Strategy for Patient Oriented Research initiative.
 - 8 Continued 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). Presented at the Benefits Canada Chronic Disease at Work Conference and provided [tips to private insurance plans](#) about plan design.
 - 9 Contributed to the literature and capacity building on patient engagement and the patient experience, including: [A How-to Guide for Patient Engagement in Research, Identifying potential barriers and solutions to patient partner compensation \(payment\) in research](#), [Bringing the patient voice into the operating room: engaging patients in surgical safety research with the Operating Room Black Box®](#), [Advancing Patient-Partnered Research: Empowerment, Innovation and Evolution](#), and [Practices of patient engagement in drug development: a systematic scoping review](#).
 - 10 Participated and contributed to the work of the Canadian Pain Care Forum, that applies expertise in evidence-based medicine to identify, collate, review, revise, update and develop clinical practice guidelines for the treatment of chronic pain.
 - 11 Partnered with the CRA in developing guidelines for transition of care for patients living with Juvenile Idiopathic Arthritis, Rheumatoid Arthritis, and COVID-19 vaccine recommendations. We also participated as patient partners in developing the virtual care best practice statement.
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Six | Executed CAPA-led projects

Strategic Actions:

- 1 Continued to disseminate educational and support materials on living with arthritis and pregnancy and having a family, methotrexate, work and arthritis, the Baring it All report, and living with chronic pain, to the broader arthritis and medical communities, private payers, and policymakers. CAPA is participating with Canadian arthritis patient organizations on an awareness activity concerning the value of virtual care post COVID-19.
- 2 Launched a project “[*Make Rheum for Youth*](#)” with Take a Pain Check Foundation focused on understanding the needs of young people living with rheumatic diseases including increasing our visibility and content on Instagram
- 3 Continued 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.
- 4 Launched a patient partner in research [training and mentoring program](#) to support the expansion and capacity building of people with arthritis to contribute their lived experiences to research.
- 5 Hosted a webinar with [Action Dignity](#) to start to develop relationships with organizations so CAPA can ensure its resources and materials best reflect the diversity of the Canadian population and reach more of the population.

Seven | COVID-19 related work

- 1 Updated a [resource page](#) about COVID-19 for people who live with arthritis and hosted a [webinar](#) about autoimmune rheumatic diseases and vaccines.
- 2 Contributed to efforts of the Canadian arthritis community with respect to ensuring access to necessary medications and information about this, for example, some of which were brought about by the pandemic.



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- 3 Continued to actively participate in the COVID-19 Global Rheumatology Alliance as a member of its Steering Committee and various working groups. Contributed to the literature on COVID-19 and rheumatic diseases, such as [Early impacts of the COVID-19 pandemic on children with pediatric rheumatic diseases.](#)