



Canadian Arthritis
Patient Alliance

2024 Strategic Plan

whatwedo

Many people think arthritis affects only older people, or that it is merely a word for aches and pains. At the Canadian Arthritis Patient Alliance (CAPA), we work to clear up these misconceptions and to create a better Canada for people living with arthritis and for those who support them. Arthritis is a number of debilitating diseases which may affect people in Canada of all ages and backgrounds. We believe that people living with arthritis (commonly known as patients in health care) are experts in living with their condition(s) and that this expertise is valuable in policy decision making, research, clinical care, and education. By collecting and producing patient resources and policy papers, and carrying out various outreach projects, CAPA seeks to support people living with arthritis so they can live life well with arthritis without experiencing barriers in various aspects of life, like health care, work, and in different life roles. 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 most up to date scientific evidence.

CAPA is a small, volunteer-driven organization with no full-time employees. Our organization was founded in 2002 by people living with arthritis and we have continued to stay true to this – today, 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. The organization achieves our goals through the part-time support of a Managing Director (up to one day/week) and Communications Assistant who both live with arthritis and through part-time administrative and accounting support. When adding up the paid staff available to manage day to day activities, it accounts for **less than one full-time equivalent employee**.



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CAPA achieves its goals 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. Our organization welcomes all people in Canada with and affected by arthritis and those who support CAPA's goals to join our community. The work of our organization is supported by a strong and effective virtual organization and we continue to find opportunities to maximize our impact and diversify funding sources.

partnerships

One of CAPA's core values is collaboration where partnering with Canadian and international organizations is crucial to support people living with arthritis. We have many long-standing collaborations:

- a strategic partnership with [Arthritis Society Canada](#) which has [been in place](#) since 2017.
- an active member of the [Best Medicines Coalition](#) where we are actively involved in many of their working groups.
- an affiliate member of the [Canadian Skin Patient Alliance](#) which we joined in 2023.

We also work regularly with a wide range of organizations, such as [Creaky Joints Canada](#) and [Take a Pain Check Foundation](#), and will continue to work with partners that share our collaborative approach and mutual respect.

context

The Canadian health care system continues to present many challenges and barriers to people living with arthritis. Wait times to access health care services continue to rise and create barriers to timely diagnosis and in managing arthritis. Once diagnosed, patients still have difficulties accessing the multidisciplinary care they need from rheumatologists, physiotherapists, occupational therapists, mental health professionals,



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and more. People with arthritis need to manage an increasing number of co-morbidities and navigate life and health in a world that also includes COVID-19. Patient organizations, like CAPA, are well placed to respond to these challenges. Now - more than ever - we need community-built solutions to these challenges and need to continue to invest in our organization's capacity to deliver and respond to the challenges faced by patients. Our grassroots representation and patient-oriented policy work remains a priority and a feature that differentiates our organization from other organizations.

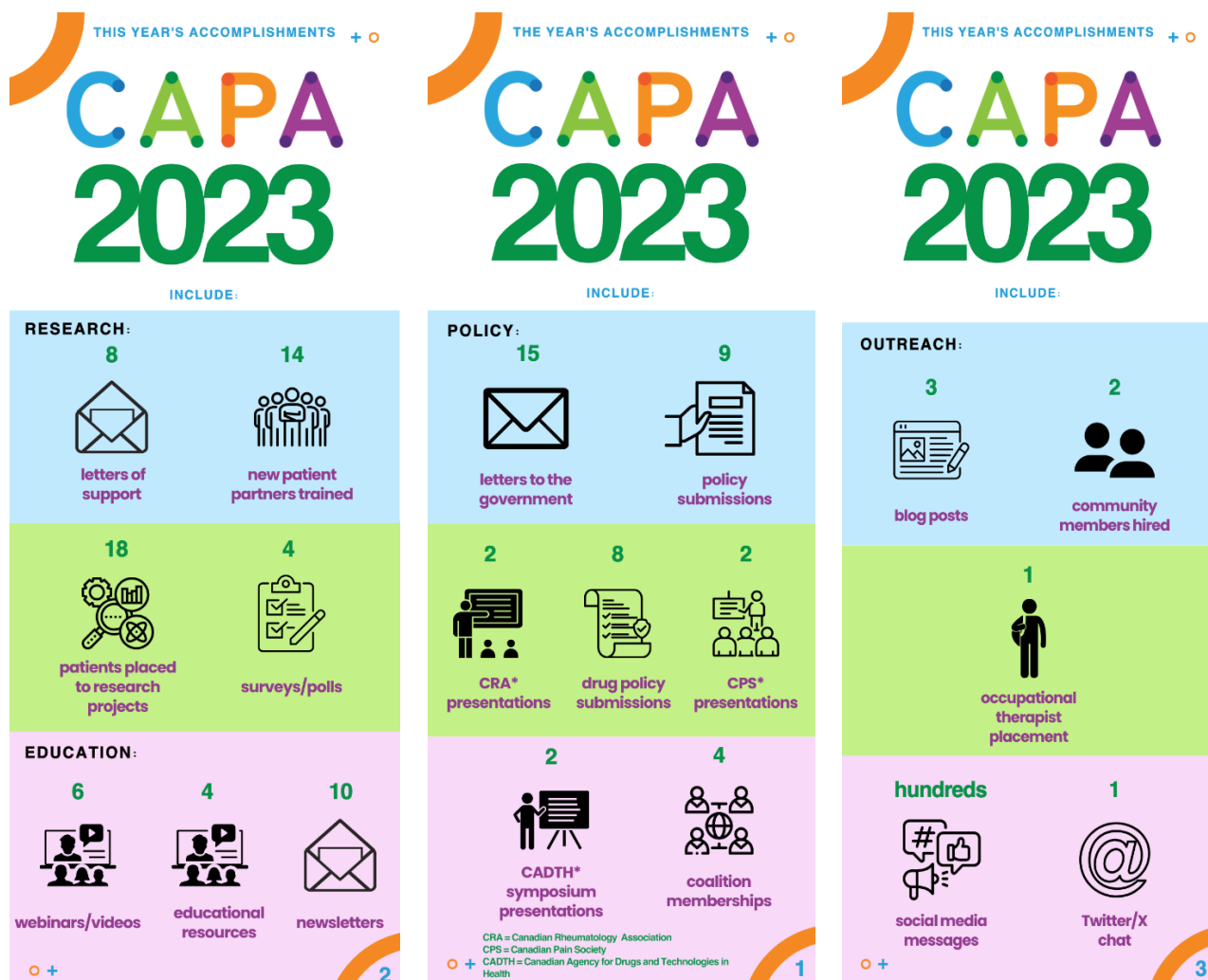
There are opportunities despite these challenges – the federal government has a number of key policy priorities like the National Pain Action Plan, the Canadian health data strategy, National Pharmacare, the evaluation of the medical cannabis legislation, and the Canada Disability Benefit regulations. Improvements are being made to health care delivery where virtual care has become a more common way to access care and people with arthritis are beginning to access their health data to better manage their health.

2023 accomplishments

CAPA achieved a lot in 2023 despite minimal financial resources. We focused on building a bigger community of people with arthritis who are trained and equipped to become partners in health research, decision-making, and health system improvement. We continued to add to our educational resources and offered webinars and education to people with arthritis throughout the year. Our organization also increased our policy activities by sharing patient perspectives with decision makers across Canada. Refer to the infographics shared below to learn more about our 2023 accomplishments.



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ourvision

CAPA uses the power of information, research, and communication to help people living with arthritis find their voice and to support others. Our organization envisions a world where people living with arthritis can lead fulfilling lives without experiencing barriers in accessing health care and health care professionals needed for their health. CAPA



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envisioning that people with arthritis can meaningfully participate in work, leisure, and daily activities, and have the support and tools needed to live their lives as they wish. A foundational pillar of our work is to integrate equity considerations into all aspects of CAPA's work, such as educational programming and policy work, to address the full range of needs of the arthritis community.

our objectives

CAPA has continued to deliver on its strategic plan and goals, and continues to achieve progress as a small, volunteer-based organization. Each year we develop independent projects where we see and address gaps and opportunities for people living with arthritis in the healthcare system and other policies. Our plan for 2024 is outlined below according to our annual objectives:

1. Highlight patient-oriented perspectives in policy decision making.
2. Build capacity of people living with arthritis to contribute to health and policy decision-making by offering training, support, and matching people to projects and opportunities.
3. Address the unmet educational needs of people living with arthritis by developing resources to provide support.
4. Increase awareness about arthritis including the impact on people with arthritis and their families, the health care system, and society.



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Our 2024 Plan

One | **Highlight patient-oriented perspectives in policy decision making.**

Strategic Actions:

- 1 Provide policy submissions for topics of interest to people living with arthritis, such as drug pricing, pain management, health policy regulation, public and private insurance, drug shortages, Canada Disability Benefit, medical cannabis, and other key topics, as needed.
- 2 Provide patient input submissions for arthritis prescription medications and other reviews to the Canadian Agency for Drugs and Technologies in Health (CADTH) and attend and present at the CADTH annual symposium.
- 3 Create and implement a dissemination and outreach plan about patient use of personal health information/data and advocate for patient access to information.
- 4 Present at key health conferences like the Canadian Agency for Drugs and Technologies in Health (CADTH) annual symposium, Canadian Arthritis Research Conference, Ontario Family Physician Summit, and other key health policy and research meetings in Canada and internationally.
- 5 Host a collaborative workshop with the University of British Columbia (UBC) researcher Dr. Mary de Vera, focused on reproductive health that will bring together people with arthritis, researchers, and policy makers.
- 6 Analyze the Patient Support Program survey results and communicate findings to decision makers, providers, and people living with arthritis.
- 7 Develop educational materials to help CAPA members understand the drug approval and reimbursement policy making process in Canada, including a description of federal



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organizations involved in making decisions (e.g., Canadian Agency for Drugs and Technologies in Health (CADTH), pan-Canadian Pharmaceutical Alliance).

- 8 Write opinion and academic papers about key topics focused on patient experiences and perspectives.
- 9 Continue to participate in working groups and committees relating to health policy, such as the Best Medicines Coalition (BMC) drug pricing and drug policy working groups, Health Canada Data Working Group, treatment guidelines, etc.
- 10 Work with our strategic partner, Arthritis Society Canada, in supporting people with arthritis by collaborating on policy submissions, working together on educational programming, and other appropriate projects.

Two	Build capacity of people living with arthritis to contribute to health and policy decision-making by offering training, support, and matching people to projects and opportunities.
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Strategic Actions:

- 1 Continue to support newly trained patient partners in research and match these individuals to new and existing research and policy projects.
- 2 Continue our patient partner in research and policy intermediate/advanced training program in collaboration with the Ottawa Hospital Research Institute.
- 3 Expand on the “Make Rheum for Youth” project (in collaboration with [Take a Pain Check Foundation](#)) by developing youth specific resources and developing the capacity of youth to contribute to decision making.
- 4 Recruit and mentor new community members to learn about advocacy in drug policy in order to expand the community of patient leaders.



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- 5 Recruit new board members considering the diversity of Canada and the arthritis community, and prioritizing adding a member of our youth committee to the board.
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Three	Address the unmet educational needs of people living with arthritis by developing resources to provide support.
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Strategic Actions:

- 1 Re-organize and promote our existing educational resources with a focus on the patient experience.
 - 2 Develop and launch an environmental analysis and develop a wider range of resources about assistive devices and other aids to help people with arthritis in activities of daily living.
 - 3 Develop educational resources about managing COVID-19 infection, accessing vaccines, and create awareness of these tools with national and provincial policy makers of patient needs.
 - 4 Continue to offer webinar series with a focus on understanding blood tests and co-morbidities, pregnancy, and parenting.
 - 5 Translate our website to French to expand access to our materials to the francophone community with arthritis in Canada.
 - 6 Expand on the plain language summaries section of the website by collaborating with researchers we've worked with and supported.
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Four	Increase awareness about arthritis including the impact on people with arthritis and their families, the health care system, and society.
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Strategic Actions:

- 1 Develop and implement an outreach and social media strategy to raise the profile of arthritis throughout the year (#Arthritis365).
- 2 Continue to develop monthly newsletters for our community.
- 3 Host Twitter/X chats throughout the year in collaboration with Creaky Joints / Global Healthy Living Foundation and others.
- 4 Analyze metrics to find ways to expand reach on various platforms and to broader audiences.