

The Arthritis Patient Charter

By Dawn P. Richards, PhD

The effort to create a new Arthritis Patient Charter has been sincerely grassroots, with all Canadian arthritis stakeholders collaborating under the Canadian Arthritis Patient Alliance's (CAPA's) leadership. The landscape of arthritis and healthcare continue to change and evolve; to reflect those changes, CAPA wishes to provide patients and the community with a tool that states the rights and responsibilities of today's arthritis patients. CAPA also hopes that this updated Charter and the original Canadian Arthritis Patient Bill

the current landscape of arthritis in Canada, create an easily-accessible format (e.g., available as post-cards in healthcare providers' offices and online at CAPA's website²), and better reflect the condensed nature in which our world now operates.

A new draft of the Canadian Arthritis Bill of Rights, renamed the Arthritis Patient Charter, was created with initial support from the ORA, engagement of patient groups (including Arthritis Consumer Experts [ACE], the Canadian Spondylitis Association, Patient Partners in Arthritis) and individual patients, along with input and support from The Arthritis Society (TAS), the CRA, and the Arthritis Alliance of Canada (AAC). Furthermore, all of these groups sought input from their own stakeholders through an online survey that collected feedback on the draft Charter's contents. Over 730 stakeholders from across Canada responded,

and their comments are incorporated in the final Charter. In just eight short months, CAPA mobilized the Canadian arthritis community to create this new Charter.

References

1. Canadian Arthritis Bill of Rights, 2001. Available at: www.arthritis.ca/document.doc?id=565.
2. Canadian Arthritis Patient Alliance. Arthritis Patient Charter, 2014. Available at: www.arthritispatient.ca/projects/arthritis-patient-charter/.

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of Rights demonstrate just how far the Canadian arthritis community has come.¹ CAPA will continue to work together with the arthritis community to enable people with arthritis to reach their full potential.

In early 2014, CAPA began conversations with the Ontario Rheumatology Association's (ORA) Models of Care Committee about potentially updating the 2001 Bill.¹ There was consensus between these two groups that, in the 13 years since the Bill's creation, there have been significant positive changes in the arthritis community. The original Bill was really an advocacy document (thus still relevant in that capacity) but required an update. This update was envisioned to: revise the rights and responsibilities to better reflect

People with arthritis have the right to:

- **Be treated with dignity, respect and consideration.** This includes being heard by healthcare providers who respect privacy and confidentiality.
- **A timely and accurate diagnosis.** Arthritis leads to significant joint damage when left undiagnosed and untreated.
- **Timely access to all types of high-quality care.** This includes access to all qualified healthcare providers and professionals.
- **Readily available current information, education and support programs about arthritis and evidence-based arthritis care.** People living with arthritis have the **responsibility** to learn about arthritis and arthritis care.
- **Be informed and participate with their healthcare providers in all treatment decisions.** This includes discussing treatment risks and benefits and timely access to medical records. People with arthritis have a **responsibility** to live a healthy lifestyle, speak openly with their healthcare providers, ask questions about treatment and follow the agreed upon course of treatment.
- **Equal public reimbursement and timely access in all provinces and territories to available medication and non-medication treatments.** Surgery and rehabilitation therapy that improve activities of daily living and quality of life should not be considered elective.
- **Live their lives fully without discrimination.** Enjoying life to its fullest potential includes taking part in family, social activities, school and employment. This may require removal of barriers and access to disability programs.
- **See that research is underway to find a cure and improve quality of life.** Arthritis research must: be funded to an amount equal to other chronic illnesses and include people with arthritis to help set priorities, participate as research partners or in clinical trials and benefit from its discoveries.
- **Be included in the development of health policies and programs that affect them.** The voices of people living with arthritis must be considered to develop the most relevant and meaningful policies and programs.

This charter can be found online at:
<http://arthritispatient.ca/projects/arthritis-patient-charter/>