



**The Canadian Arthritis Bill of Rights and Responsibilities:
History from the Patient Perspective
Prepared by: Linda Wilhelm, Anne Dooley, and Jean Légaré
April 2014**

2001 saw transformational change for people living with Rheumatoid Arthritis (RA), the most prevalent type of inflammatory arthritis. Awareness of the seriousness of this disease was very poor but revolutionary new therapies had recently been approved: the most expensive drugs ever to come to market. Governments and insurers were refusing to cover the cost of these new drugs as the disease was not perceived to be serious.

It was in this environment that The Arthritis Society (TAS) brought together numerous arthritis organizations for the very first time to work on an Arthritis Bill of Rights and Responsibilities. Clinicians, researchers and patients were included and worked together on this extremely challenging endeavour that required countless drafts to ensure all important points were covered. After the Bill was finalized, TAS organized an arthritis awareness day in January of 2002, and brought several patients to Ottawa to meet with their Members of Parliament and high profile cabinet ministers.

In retrospect, the impact of the Arthritis Bill of Rights and Responsibilities on the lives of people living with arthritis probably would not be considered a huge success. However there were tremendous outcomes from the work that was done:

1. The Arthritis Bill of Rights and Responsibilities brought many organizations in the world of Arthritis together on a single project for the very first time. The number of drafts required to produce the final document is testimony to just how difficult that was to do.
2. The Bill included the perspective of people living with arthritis and gave them the motivation to continue lobbying government and insurers to cover biologic medications. This fundamentally led to continued arthritis patient involvement in health policy development and increased awareness of the seriousness of inflammatory arthritis.
3. This was the first ever political lobbying effort from the Arthritis community, and it began the process of busting the myth that arthritis is just inevitable aches and pain as a result of aging.

Note that this document only refers to RA because, in 2001, RA had a very low public awareness of how serious the disease is, and there was no awareness of the other forms of inflammatory arthritis. The new drugs only had approval for RA and some rheumatologists would carefully word their special authorization forms for patients with other kinds of arthritis. It was a few years for these drugs to also be approved for psoriatic arthritis and ankylosing spondylitis.