

Canadian Arthritis Patient Alliance

2006 ANNUAL REPORT

Patient Experience, Patient Perspective, Patient's Voice



President's Report

Anne Dooley

In our fifth year, CAPA reached a new level of strength, maturity and recognition. Throughout 2006 we carried the message of arthritis awareness with the conviction borne of experience that much can be done and we can help do it. We believe that arthritis

patient stakeholders must be part of the health care discussion and decision-making process that affects our health.

Our Strategic Plan for 2006 followed the direction set in previous years and maintained our strong commitment to arthritis awareness and advocacy. With TAS and ACAP we met with the federal Minister of Health's top advisors, and as individuals we met with staff of provincial ministries of health. We maintained our numerous collaborations, memberships, alliances, and partnerships and initiated relationships in new areas. We worked closely with the Consumer Advisory Council of the Canadian Arthritis Network, The Arthritis Society, Consumer Advisory Board of the Arthritis Research Centre of Canada, Bone and Joint Decade, Arthritis Consumer Experts, Cochrane Musculoskeletal Group, the Alliance for the Canadian Arthritis Program, Best Medicines Coalition, Better PharmaCare Coalition and a great many more. Numerous organizations and individuals asked for our help in modeling their advocacy efforts on CAPA's success. We served on boards and were appointed to panels; we received invitations to conferences, workshops and consultations to share our hard-won knowledge through presentations, discussion and thoughtful conversation. And in every instance our knowledge increased to help inform our advocacy activities.

Across the country our members contributed their perspective, talents, and objective knowledge to more arthritis related areas of interest and in greater numbers than ever before. It all counts, and makes a difference. We wrote letters to editors, to Ministers, MLAs, Members of Parliament and Senators. We contributed policy and position papers, taught Arthritis Self-Management courses, collaborated on and participated in research projects, kept active with exercise and attended local support groups. The difference we make extends beyond the world of arthritis. For instance, CAPA V.P., Linda Wilhelm, received a four-year ministerial appointment to one of N.B.'s eight Health Authority Boards. Patients will benefit from her knowledge of access to medication issues. V.P. Colleen Maloney, submitted a proposal for a consumer booth at the Canadian Rheumatology Association (CRA) Annual Meeting. The CRA accepted the proposal with the result that rheumatologists will better understand the roles informed patients play in health care. CAPA Research Co-Chair, Louise Bergeron lives with Lupus, one form of inflammatory arthritis. Louise was guest speaker at The National Summit on Episodic Disabilities and Labour Force Participation, contributing the arthritis perspective. Laurie Proulx presented at the Childhood Arthritis Rheumatology Research Alliance meeting in Denver. And I was invited to present at the first Canadian Agency for Drugs and Technologies in Health (CADTH) Invitational Symposium, co-presenting with Nancy Santesso of the Cochrane Musculoskeletal Group. We spoke about the importance of inclusion of the patient perspective in health technology assessment.

CAPA is a grass-roots, patient-driven, self-governing national organization of and for Canadians with arthritis. Since our inception in 2001, we have been funded and Secretariat support has been provided through a Memorandum of Understanding (MOU) with The Arthritis Society (TAS). This forward-thinking on the part of TAS has enabled a true arthritis patient stakeholder group to sit at policy making tables at all levels to help inform the decisions that affect the health of people with arthritis. We are grateful to TAS for their generous support and encouragement as we developed into a successful and able organization. However, changes resulting from the evolution of both CAPA and TAS helped us make the decision that it was time for us to become a truly independent organization. On January 31, 2007, CAPA activated the termination clause contained in the MOU.

CAPA's Strategic Plan for 2007 builds on our successful track record. We intend to continue to advocate on behalf of people with arthritis, continue to fully and beneficially participate as a stakeholder organization in the arthritis community and beyond, continue to demonstrate that knowledgeable and experienced patients/consumers are necessary and beneficial to informed decision making, and continue to productively work with TAS and all other organizations, agencies and individuals we partner and collaborate with in our extensive formal and informal networks. We contribute the patient experience, patient perspective and patient's voice.



CAPA Core Values

The Canadian Arthritis Patient Alliance (CAPA) defines itself as a voluntary advocacy organization dedicated to improving arthritis care and services for people living with arthritis.

CAPA's beliefs and values influence its direction, guide its work and articulate its motivation. All CAPA members volunteer their time and energy to defining and influencing health policies and issues that affect access to health care services, medications, and patient support.

- > CAPA believes that the first expert in arthritis is the person with arthritis.
- > CAPA believes that people with arthritis have the right and responsibility to be included in all policy and health care decisions related to their health and quality of life.
- > CAPA believes that patients have the right to be included in making research related decisions affecting their health and quality of life.
- > CAPA believes children and youth with arthritis have the right and deserve the opportunity to fully develop physically and mentally and that people with arthritis of all ages have the right to participate freely and equally in all aspects of life.
- > CAPA believes in the value of its members and associates, and provides opportunities for them to obtain the knowledge they need to become effective advocates for themselves and others living with arthritis.

2007 Strategic Plan

Equity in accessing health care services and medications in all provinces of Canada begins with the patient experience and the willingness of all stakeholders to enter a dialogue that addresses solutions to removing disparities.

Since its inception six years ago CAPA has been building relationships based on mutual respect with the medical community, government officials and agencies, industry, non-governmental organizations, and patient/consumer groups to raise the visibility of the needs of people living with chronic disease and the regional inequality within the health care system. Our work is shaped by the belief that all Canadians in every province must have equitable and timely access to publicly delivered and publicly funded health care services and medications. But we are not content with access alone; we believe that for health care to be economically effective it must be steered by evidenced-based best practice guidelines and measured outcomes. We consider research, knowledge creation, knowledge transfer and the application of research knowledge essential components to informing quality health care and improving quality of life. What is more, we demonstrate our conviction by contributing to research decision-making and participating in policy development. We are members of research boards, ethics boards, health coalitions, and formal and ad hoc committees. We attend conferences, prepare and deliver presentations, moderate panel debates, and lead discussions.

CAPA is committed to continue working with its partners to ensure the health care system, as a whole and with all its intricacies, is responsive fully and equitably to the needs of all children and adults living with arthritis. Our strategic priorities for 2007 reflect the needs of our constituents and our commitment to them.

Strategic Priorities for 2007

- > To raise awareness about arthritis and to ensure timely and uniform access to appropriate medications, health professionals and services.
- > To ensure a meaningful voice in arthritis research at decision making levels, and to increase CAPA involvement in policy planning and development.
- > To be a source of information for adults and children with arthritis and their support communities.
- > To assist adults and children in obtaining access to care and reimbursement, and other services they require to cope with or prevent disability, deformity and pain.



2006 – A Year in Review

The recognition of patient experience is critical in redefining health systems, and the interest in including patients in all aspects of policy decision-making across the full health care spectrum have kept CAPA members engaged and in demand.

Access to Medications

2006 saw CAPA build on accomplishments from 2005. Initiatives that began the previous year with Health Canada continued.

The National Pharmaceutical Taskforce held consultations across the country in late spring and early summer ending with a final information session in Ottawa in June. Two CAPA Steering Committee members received and accepted invitations to attend. The interim report was released by the Taskforce in September 2006 with the commitment to include all stakeholders in future deliberations.

The Patient Engagement Framework initiated through a grant from the Voluntary Sector was finalized with a meeting of stakeholders and Health Canada in the fall. The process of defining "next steps" is currently underway.

The Dialogue on Health, initiated by the Liberal government to engage consumers, patients, stakeholders, and industry was effectively shut down by the newly elected Conservative government. Recognizing the value of the process, movement to revive the initiative has begun within Health Canada. CAPA members are optimistic.

Health Policy Development

CAPA was again invited to engage in dialogue on numerous fronts on health policy development. CAPA members contributed to Health Canada's Blueprint for Renewal on Drug Regulatory reform and in the Patent Medicines Pricing Review Board workshop on Excessive Pricing Guidelines. In addition, members presented the patient perspective at the Canadian Agency for Drugs, Technology in Health annual symposium. In Ontario, CAPA members contributed to formal discussions on Bill 102 legislation. CAPA insists that quality of life issues must be a consideration for listing medications.

Partnerships and Collaborations

Collaborating with other groups has played a significant role in the work we do. CAPA continued its partnership with The Best Medicines Coalition and saw participation grow to include The Canadian Medical Association, The Canadian Nurses Association, The Canadian Pharmacists Association and The Canadian Healthcare Association. Our collaboration succeeded in bringing a strong statement to government on the National Pharmaceutical Strategy. We also joined a larger group that included the Canadian and Ontario Pharmacists Association and the Canadian Association for Pharmacy Distribution Management to address the re-emerging threat of Cross Border Prescription drugs exportation. We believe that the federal government must move to ban the bulk exportation of prescription drugs to the United States that are meant for Canadians. CAPA ended the year by partnering with Arthritis Consumer Experts (ACE). In a letter sent to each provincial Minister of Health, CAPA and ACE drew attention to two new breakthrough biologics recently approved by Health Canada to treat people with moderate to severe rheumatoid arthritis who have had an inadequate response to an anti-TNF agent. In British Columbia, CAPA is a member of the Better PharmaCare Coalition where pressure continues on the government to decrease the amount of time it takes to approve drugs for listing and reimbursement on the provincial formulary.

Access to health care services

CAPA members are involved in creating a chronic disease management strategy framework with representatives from The Arthritis Society – BC and Yukon Division (TAS-BC), the Osteoporosis Society of Canada, and the British Columbia provincial government. The service framework model of disease management for rheumatoid arthritis, osteoarthritis and osteoporosis is portable and adaptable and may well serve the needs of primary care providers and people living with arthritis in all provinces. Collaboration continues.

Members of CAPA's Childhood Arthritis Committee helped set the direction of future research at a Canadian Arthritis Network workshop in January 2006 by presenting the childhood arthritis perspective. Members were instrumental in providing input that acknowledged the psychosocial impacts of pain, defined the different types of pain, and categorized pain measures and assessment tools.

Outreach and Education

Member support through outreach and education programs grew during the past year. CAPA members served as leaders in Arthritis Self-Management Programs, Chronic Pain Management Programs, Support Group organizations, and in presenting the patient perspective to disease and special interest groups. In addition CAPA members identified gaps in established programs and developed a new program titled Patient-to-Patient. It is currently being piloted to arthritis consumers, community groups and healthcare professionals. The program raises awareness of:

- > Current affairs and the role arthritis advocacy groups play in influencing health policy related to access to care and services
- > Research – its value to people living with arthritis, how it is done and who is doing it
- > Recent, evidence-based examples of practical arthritis research for everyday living.

CAPA members of the Consumer Advisory Board of the Arthritis Research Center of Canada (ARC) with its partners at ARC and with TAS-BC and the Canadian Institute for the Relief of Pain and Disability, crafted promoted and hosted the Roundtable on Arthritis Research (ROAR) event during arthritis awareness month last year. The event brings researchers and people with arthritis together for a day of dialogue to raise awareness and understanding of the value of research and to identify the research priorities of people living with arthritis. ROAR will be held again in 2007.

Members involved in raising awareness of Childhood Arthritis launched a web-based survey for patients, parents and others impacted by juvenile inflammatory arthritis (JIA). Survey results prompted collaboration with paediatric rheumatologists in the development of information materials that could lead to heightened awareness of this disease, and to closer relationships within the childhood arthritis community.

Research Report

Arthritis research takes many forms and well-informed CAPA members facilitate and participate in research in many ways. In addition to the established areas of our research involvement, our participation also extends into new and developing arthritis areas, and to health policy and health technology assessment.

Research into juvenile idiopathic arthritis (JIA) has taken off in Canada, and many CAPA members across the country are enthusiastically involved. Our members are actively promoting and participating in research into systemic auto-immune rheumatic diseases (SARD) to investigate scleroderma, Sjogren's, vasculitis, lupus and myositis. We've initiated new partnerships with the Canadian Working Group on HIV and Rehabilitation and the Episodic Disabilities Project. We have taken our first steps into the area of health technology assessment, and into health policy development. We believe the real-life experience of people who depend on health policy decisions and who rely on technology for their quality of health is necessary to help inform these decisions.

In 2007, CAPA will continue with our research related activities. We will seek to strengthen our many successful research related collaborations and relationships that encourage innovative research and help inform governments of the many beneficial roles that well informed, responsible and participating patients can play in planning and promoting the successful future of health care in Canada.

Canadian Arthritis Patient Alliance

About Us

CAPA is a grass-roots, patient-driven, self-governing national advocacy organization of and for Canadians with arthritis. We also welcome others wishing to support arthritis advocacy through CAPA.

CAPA may be reached by calling - 416. 979.7228, or emailing - capasecretariat@arthritis.ca

“CAPA's mission is to create links between Canadians with arthritis, assist them to become more effective advocates and seek to improve the quality of life of all people living with arthritis”

Membership Information

If you have not yet joined and would like to support CAPA objectives and priorities, we invite you to join us. CAPA has no membership fees.

Benefits of Membership

- > Interaction with other arthritis advocates across the country via email and the CAPA Discussion Board
- > 4 issues of CAPA Voices electronic newsletter per year
- > Opportunity to contribute to CAPA Voices newsletter
- > News Alert updates on health and advocacy issues as they happen
- > Helping to make a difference

CAPA members gave over 7650 hours to advocacy in 2006, raising the visibility of arthritis and the needs of people living with it.

Steering Committee Members

John Fleming, TAS President and CEO, and Lynn Moore, Director of Public Policy were ex officio members of the Steering Committee for 2006-07.



Colleen Maloney
- BC

Access to Care, Communications, Outreach, and External Relations



Anne Dooley
- SK

Research, Communications, and External Relations



Corrie Billedeau
- MB

Juvenile Inflammatory Arthritis, and Pain Issues



Mary Kim
- ON

Parliamentary Relations & Elections, and Research



Laurie Proulx
- ON

Juvenile Inflammatory Arthritis, and Elections



Louise Bergeron
- PQ

Research, and Communications



Marcel Ruest
- PQ

Pain, and Spondyloarthritis



Linda Wilhelm
- NB

Access to Medications and Care, Spondyloarthritis, and External Relations



Colleen Murray
- PEI

Pain Issues, Research, and Access to Care