

2005 ANNUAL REPORT

Influencing health care policy outcomes in arthritis patient treatment and care.

“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”

Canadian Arthritis Patient Alliance

Working with The Arthritis Society to make a difference in the lives of people with arthritis 

2006 Strategic Plan

Positively influencing health policy outcomes in arthritis patient treatment and care is the undertaking of CAPA members throughout the country. Members recognize that existing disparities, both in the provision of health services and in access to medications from region to region in Canada, run counter to the equity principles of the Canada Health Act.

We are confident that by working with federal, provincial and territorial government representatives, the policy barriers promoting or sustaining treatment disparities can be better understood and progressively eradicated, enabling all Canadians living with chronic diseases to share equally in health benefits intended for all. Our strategic priorities support these initiatives, and our involvement as expert patients at arthritis research decision-making forums ensures that evidence-based best-practice models of arthritis care prevail.

Our strategic plan is evaluated annually to ensure that our focus continues to include the quality of life issues of all our arthritis constituents. This year we have added Spondyloarthritis to our list of priorities for 2006, with an emphasis on Ankylosing Spondylitis. We are also addressing the issue of Pain, which is increasingly identified as the arthritis symptom that is most difficult to assess and self-manage.

CAPA is the voice of arthritis patients and CAPA priorities reflect patient needs.



President's Report

Anne Dooley

In CAPA's first four years our achievements led us to be recognized across Canada and internationally as a leading patient health advocacy organization. Our success is due to our cross-Canada, grass-roots nature, our informed and growing membership, and our many networks and collaborations. Our strength stems from the leadership of our skilled and knowledgeable Steering Committee, and the many CAPA members from coast-to-coast who increasingly volunteer their time and talents in a variety of ways to help improve the lives of people with arthritis.

Our 2005 Strategic Priorities have been met in many ways. We had many new speaking and participation opportunities, to which members contributed identifiable and quantifiable knowledge, perspectives, and judgment. We participated on government advisory committees and panels, and in the planning and participation of many workshops and conferences, including that of the Summit on Standards for Arthritis Prevention and Care. We have been asked to provide guidance to other health organizations that want to build their advocacy activities on the CAPA model. Our members are stepping forward in ever-greater numbers to bring the consumer perspective to research projects and workshops. They contribute to position papers and write letters, belong to the Cochrane Consumer Network, teach and participate in Arthritis Self Management and in exercise and local support groups, Patient Partners in Arthritis and much more. We have been busy.

CAPA is guided by the belief that the first expert in arthritis is the person who has it. We define advocacy as education with persuasion, and the education component may take some unusual forms. One example is the [Conference Planning Checklist](#). Four CAPA members who called upon their considerable conference planning and participation experience, created the Checklist to ensure access of people with arthritis and disabilities to workshops, meetings and conferences. This planning tool is being used across Canada and internationally. Another example is [The Back to School Checklist for Parents of JA Children](#) compiled by a CAPA member with the disease, and extensive classroom experience in teaching these children. This Checklist is being used across Canada to help children; parents and teachers work together to deal with the problems these children face. Innovative CAPA advocacy helps improve the lives of people with arthritis.

In the Fall, some of our valued CAPA SC members stepped down. We owe much to the good judgment, vision, knowledge and leadership of Ann Qualman, Jean Legare, and Lisa Cirella, all of whom were with CAPA from our fledgling advocacy days, and June Henderson who later joined the SC. These informed and dedicated members have been instrumental in shaping CAPA into the strong and effective organization it is. We're pleased that they remain active CAPA advocates, and that each is a willing source of information and guidance for the current SC, and its new and continuing members.

Our Strategic Plan for 2006 demonstrates our continued commitment to advocacy. We will maintain our current direction, add some new interests and continue our activities, memberships and collaborations. CAPA is a unique, successful and distinctly Canadian organization, but we have much we can learn from advocacy and patient groups in other countries. To gain and share insights and information, CAPA became a member of the International Alliance of Patients' Organizations (IAPO). Their motto, "Nothing about us, without us," demonstrates a belief shared with CAPA, that consumers have a right to participate in all areas and at all levels of health care decision making. CAPA is working to make that happen.

Strategic Priorities for 2006

- > To raise awareness about arthritis to ensure timely and uniform access to appropriate medications, health professionals and services.
- > To ensure a meaningful voice in arthritis research at all decision making levels, and to develop a strategy to increase CAPA involvement in policy planning and development.
- > To create 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.



Research Report

Researchers, granting agencies, research institutions and governments are increasingly recognizing the benefits that flow from obtaining the patient's experiential knowledge in key decision-making stages in all levels and areas of health care. Accordingly, the knowledgeable, responsible, and contributing patient is much in demand. It's nice to be wanted.

CAPA members now find themselves called upon to participate in and to speak at a wide range of conferences such as the CARE III conference, CAN Annual Scientific Conference, Bone and Joint Decade, and The Summit on the Standards for Arthritis Prevention and Care. Our members are often asked to participate as collaborators and advisers in research projects, and our experience is tapped to help researchers define consumer roles for their projects so that consumers can more effectively be included on their research teams.

CAPA involvement in issues involving research ethics is also on the rise, as both the problems and importance of bio-banking, and the security and confidentiality of health information become more significant and as clinical trials and basic research are recognized as important gateways to improved health. Our members have also helped inform organizations and governments by facilitating and participating in thoughtful and wide-ranging discussions on the necessity and the benefits of giving a vote to all members of peer review panels – including consumers. Recently, this has led to a pilot project by a government-funding agency to examine the efficacy of instituting an equitable peer review policy.

In 2006, we plan to step up our program of consumer activism by building upon and further expanding our many successful collaborations —thus ensuring that the needs and the knowledge of people with arthritis comprise fundamental elements in future health care decisions.

2005 – A year in Review

This year will be remembered for the solid progress made by consumers in having the federal government and its decision-makers pay serious attention to the patient perspective. Never before has CAPA experienced this level of meaningful patient dialogue and involvement on health policy.

Cox-2 inhibitors

Health Canada included two CAPA representatives, both with voting member status, on the Expert Advisory Panel appointed to review the safety of Cox 2 inhibitors. Prior to the Panel deliberations, consumers were invited to present their concerns at a national forum hosted by Health Canada, and those consumers unable to attend the meetings in Ottawa were encouraged to provide their personal perspective via the Health Canada website. For the first time, the patient experience was a significant consideration impacting decisions being made about the medications people with arthritis take daily.

National Pharmaceutical Strategy (NPS)

Health Canada demonstrated its commitment to transparency in 2005 when it included patients as equal stakeholders at a working conference on one major element of the proposed National Pharmaceutical Strategy (NPS) – Strengthening Real World Drug Safety and Effectiveness.

The development of a comprehensive NPS was a recommendation that came out of the First Ministers' meeting on Health Care in September 2004. Along with encouraging the use of digital technology and evidence-based medicine, the NPS proposal included, in part, catastrophic drug coverage, accelerated access to breakthrough medications through an improved drug review and drug approval process, and a national drug formulary. The NPS task force is to submit its report to the First Ministers in June 2006.

Cross-border Internet Pharmacy

The growth in Cross-border Internet pharmacies (CBIP) has been a major cause for alarm over the past few years for Canadians living with chronic disease. Patient safety, ethical practices, liability, and supply/demand concerns resulting in drug shortages in Canada have been key issues brought to the attention of federal and provincial politicians. Despite the federal government's public commitment to shutting down CBIP, progress has been slow. This year, however, Health Canada involved patients as equal stakeholders on CBIP. In addition to the two-day consultation, CAPA contributed to a paper prepared by members of the Best Medicines Coalition on Cross-Border Internet Pharmacies. The paper, titled, What are the Issues? What is less obvious? is available at www.haworthpress.com/web/JPM.

In addition to involvement at the government level, our members focused on the gaps in health practices and services for people with arthritis.

National Home Care

Concerned about access to Home Care resulting from the increased demand created by hospital bed closures, early discharge from surgical units and a shrinking Home Care work force edging ever closer to retirement, CAPA members addressed the potential of capacity building through health charities. Recommendations integrating innovative models of patient and health professional partnerships in the delivery of home care services have been developed and incorporated into the National Home Care Position Statement. The Paper will be presented to federal, provincial and territorial governments in 2006.

CARE III Conference

Advancing arthritis care was the theme of the international CARE III conference held in Toronto last spring. Central to the conference, whose overarching aim was improving disease management for people with arthritis, was the participation of consumers. CAPA members presented their views on existing and innovative models of care, research design, outcome measures, and knowledge translation and exchange. Seventy-seven delegates representing nine North American and European countries attended. The conference concluded with a statement of support for the ACAP Summit on Standards for Arthritis Prevention and Care.

Standards of Arthritis Prevention and Care

The Standards of Arthritis Prevention and Care Summit held in Ottawa in November marked the first time in history that an entire disease community came together to set evidence-based national health system standards to ensure optimal arthritis care for all Canadians. CAPA members were part of the 200-member delegation, the largest component of which was patients. Delegates provided input and ideas in nine key areas: physical activity, injury prevention, access to a diagnosis, access to medications, access to surgery, manpower and models of care, participation, general public and consumer awareness and medical/health professional education and awareness. CAPA will continue to work closely with the Alliance for Canadian Arthritis Programs (ACAP) in devising ways to bring the Standards to fruition.

Steering Committee Members



Colleen Maloney – BC

Access to Care, Outreach & External Relations



Cheyne Parkinson – AB

Pain Issues



Anne Dooley - SK

Research, Communications & External Relations



Corrie Billedeau - MB

Juvenile Inflammatory Arthritis



Mary Kim – ON

Parliamentary Relations and Elections



Laurie Proulx – ON

Juvenile Inflammatory Arthritis & Pain Issues



Louise Bergeron – PQ

Research & Communications



Marcel Ruest – PQ

Spondyloarthritis



Linda Wilhelm – NB

Access to Medications and Care & External Relations



Colleen Murray – PEI

Pain Issues, Access to Care

John Fleming and Julie Wysocki,

Arthritis National Office are ex officio members of the Steering Committee providing materials and staff to support the work of CAPA.

Membership Information

If you are not yet a member or associate member of CAPA, we invite you to join at www.arthritis.ca/capa. CAPA has no membership fees.

Member Benefits

- > 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 thousands of hours to advocacy in 2005, raising the visibility of arthritis and the needs of people living with it.

**Canadian Arthritis
Patient Alliance**

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