



Building on *partnerships*



to create a world free from arthritis.

Canadian Arthritis
Patient Alliance

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

2004 ANNUAL REPORT

President's Report



As CAPA has become better known, there have been an amazing number of opportunities to speak, comment and collaborate.

Ann Qualman
President,
Canadian Arthritis
Patient Alliance

CAPA's third year was marked by growth in membership, partnerships and activity. Our membership topped 400 Canadians with arthritis. CAPA has enjoyed strong leadership from the Steering Committee as well as grassroots leadership. Many members have joined our working committees and are making their presence felt within CAPA and within other organizations.

We think of advocacy as a process of education and persuasion and we advocate with many people and organizations to increase awareness, policies and programs to benefit people with arthritis. Our principal approach to achieving our objectives is to work in partnership with other organizations. In 2004, CAPA collaborated with two dozen organizations. The most active involvement was with The Arthritis Society (TAS), the Alliance for Canadian Arthritis Program, the Best Medicines Coalition, the Canadian Arthritis Network, the Cochrane Musculoskeletal Review Group, Health Charities Coalition for Tax Fairness, members of the Canadian Pediatric Rheumatology Association, and Health Canada.

It is impossible to acknowledge by name all the CAPA members and associate members who are making outstanding contributions as arthritis advocates. Many are educators with Patient Partners in Arthritis and TAS's Arthritis Self-Management Program. Others are involved on an individual and personal basis with such diverse organizations as Canadian Blood Services National Liaison Committee, Arthritis Consumer Experts, Advocare, the Consumer Advisory Board of The Arthritis Research Centre of Canada, and Ward Health. Several members have joined the research teams of arthritis research projects. Many advocate for better information and responsible management of arthritis by being involved in arthritis self-help groups.

As CAPA has become better known, there have been an amazing number of opportunities to speak, comment and collaborate. In 2004, improved communications with members enabled CAPA leaders to identify increasingly large numbers of informed and articulate members who had the time and the skills needed to bring an arthritis consumer/patient perspective to various conferences, workshops and consultations. These events were sponsored by government bodies, non-governmental organizations, research organizations, health coalitions, etc.

Working with CAPA members and in partnership with other organizations requires more than dedication. We greatly appreciate the on-going material and moral support of The Arthritis Society (TAS), particularly that of John Fleming, the CEO of TAS, and Lisa Cirella, who very ably serves as the CAPA secretariat along with the help of Julie Wsocki. Our partnership with TAS was formalized in 2004 with the signing of a Memorandum of Understanding and reflects the strong relationship that has existed between our two organizations from the outset. CAPA is deeply grateful to Denis Morrice, President of TAS to the end of 2004, for his unwavering commitment to the empowerment of people with arthritis. He led the groundwork for the TAS-CAPA partnership that is today recognized beyond the arthritis community as a model of respectful and effective collaboration between a health charity and the people it serves.

CAPA has been faithful to its mission, advocating on several fronts. In 2004, we were active during the federal election and participated in numerous other events during the year. The committee reports and the quarterly issues of our electronic newsletter CAPA Voices provide more details. In 2005, we will continue to push hard on issues that concern our members. We are proactive in pursuing our priorities while remaining flexible to seize opportunities that arise. Thanks to our growing and active membership, the material support of TAS and the moral and practical support of our associate members, we will continue to defend with passion and integrity the rights and responsibilities of people with arthritis.

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www.arthritis.ca/capa

2005 Strategic Plan

CAPA expanded its umbrella of involvement this fall when it laid out its Strategic Plan for 2005 at its Annual General meeting in Toronto. Aligning its direction with the national focus of the First Ministers' Ten Year Plan, CAPA added Home Care and Pharmacare to its list of priorities along with Juvenile Inflammatory Arthritis.

CAPA, with roots that stretch across the country is committed to improving practices and services for people with arthritis. CAPA has the experience, the expertise and the passion to work with federal, provincial and territorial Ministers of Health in accelerating health care reform. We recognize that new and innovative approaches are needed to shape health care delivery, improve and broaden services and support research into the prevention of disease.

Canadian's expectations for care and services are high particularly within the arthritis community. CAPA's Strategic Priorities for 2005 reflect these expectations.



Strategic Priorities for 2005

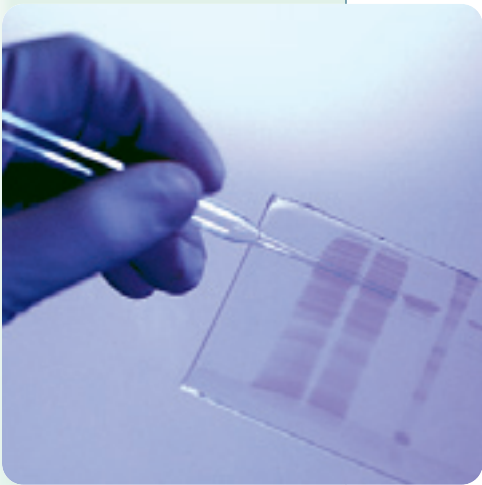
To ensure timely and uniform access to appropriate medication, health professionals and services.

To ensure a meaningful voice in arthritis research, 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 them in obtaining access to care and reimbursement, and other services they require to cope with, or prevent, disability, deformity and pain.

2004 Summary

Research



From the beginning one of CAPA's objectives has been to help set the arthritis research agenda and to be part of research from the planning stage to the dissemination of results. We've been very successful. There are CAPA members across Canada acting as collaborators, advisers and investigators on several current and important arthritis research projects, and we receive requests for members to assist in new studies. To be beneficial, results of research must be communicated to users, and this is where Knowledge Translation and Exchange comes in. We collaborate with the Cochrane MSK Group and others as part of this process. Biomedical ethics is an increasingly important interest and CAPA is recognized as a stakeholder organization in this field. In 2005 we will remain active in these areas, and will add pain issues to the mix. CAPA achievement in these areas is the result of the constant interest and increasing participation of our members.

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Election and Political Involvement

CAPA members from coast to coast called for a National Day of Action June 17, 2004 to raise awareness of arthritis during the federal election campaign. Some gathered around conference tables while others worked individually endorsing the key planks in the election platform identified by CAPA and TAS National and adding a plank of their own: Transparency - beginning with televising the Health Care Summit in the fall. Members wrote, FAXed and/or talked to all party candidates stating that they want timely access to proper medications, the services of healthcare professionals, and surgery. They want increased funding for arthritis research. They want transparency in a publicly funded, publicly provided national health care system. They said, "If you vote for me, I'll vote for you". The CAPA Executive sent letters to the leaders of the five main national parties and to the Ministers of Health and Public Health calling attention to the needs of people with arthritis. Raising political awareness of the needs and determination of people with arthritis continues in 2005.

Disabilities

The Disability Tax Credit (DTC) reform initiative launched in 2001 concluded late this year with the report from the Technical Advisory Committee (TAC) on Tax Measures for persons with Disabilities. Key recommendations in the report, *Disability Tax Fairness*, submitted to the Ministers of Finance and National Revenue in December 2004 include expanding the eligibility requirements for Disability Tax Credit and encouraging the Canada Revenue Agency to continue improving DTC Form T2201 through consultations with stakeholders. CAPA members will remain vigilant in monitoring the government's progress in implementing all twenty-four TAC recommendations

In the New Year, CAPA committee members will turn their attention to Home Care and the programs and services needed to create a framework for the development of a national system of home care delivery.

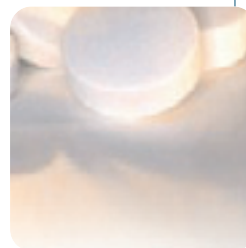
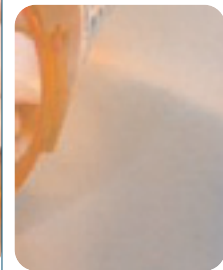
Access to Medication

CAPA participates with other patient/consumer organizations in monitoring the progress of the Common Drug Review (CDR). The federal, provincial and territorial health ministers established the CDR in 2002 to create an efficient and effective single, common review process. Thus far it is another step in an already lengthy, complicated drug review system. CDR's first year performance audit, scheduled to begin in December 2004, is being watched by CAPA and its partners for several reasons, chief among them being CDR's lack of transparency and accountability. Patients/consumers have been shut out at all levels of the CDR process. In 2005 CAPA will participate with its partners in conducting an independent audit of CDR's performance. Our ultimate goal is to achieve meaningful patient/consumer participation at all levels of the decision-making process.

Cross Border Internet Pharmacy

CAPA members breathed a collective sign of relief this fall following the Health Minister's statement that Canada would not be a drug store for the United States. After approximately a year of constant pressure from patient and professional organizations, including CAPA, Cross Border Internet Pharmacy (CBIP) was realized as a threat to Canadians. Minister Ujjal Dosanjh, who is strongly opposed to CBIP, is committed to ending the practice. Collectively and individually CAPA members are raising awareness of issues that impact access to care.

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CAPA External Relations

CAPA is a member of:

ACAP

Alliance for the Canadian Arthritis Program

BJD

Bone and Joint Decade

BMC

Best Medicines Coalition

IAPO

International Association of Patient Organizations

CAPA is an affiliate of:

CAN CAC

Canadian Arthritis Network

Consumer Advisory Council

Getting a Grip on Arthritis

CAPA

is represented on:

CARE III

Planning of

May 2005 conference on non-pharmacological and non-surgical treatments of arthritis and models of care.

Coalition for Disability Tax Credit Reform

Patient and Consumer Information and Training Programme of Health

Canada's Health Products and Food Branch – Joint Steering Group

Standards of Arthritis Prevention and Care – planning of November 2005 conference

CAPA members have been appointed to:

PRE

Interagency Advisory Panel on Research Ethics

CAPA

is guided by the belief

that the first expert in arthritis

is the person who

lives with it.

In 2004, CAPA advocates

gave thousands of hours

individually and collectively

building partnerships

to guide practices and services

for people living

with arthritis.

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www.arthritis.ca/capa

CAPA Steering Committee

Contact List

Name	Province	Responsibility	Email
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*indicates ex officio member.

Membership Information

If you are not yet a member or associate member of CAPA, we invite you to join at www.arthritis.ca/capa

The benefits of being a member include:

- 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 advocacy issues as they happen
- Helping to make a difference

CAPA has no membership fees. Once you have filled out the online form and clicked "submit" you will receive an email message to confirm that your information was received and to welcome you to the CAPA organization.

IMHA KETF

Knowledge Exchange Task Force of the Institute of Musculoskeletal Health and Arthritis

CAPA collaborates with:

ACE

Arthritis Consumer Experts

Advocare

ARC CAB

Arthritis Research Centre Consumer Advisory Board

CMSG

Cochrane Musculoskeletal Review Group

CPRA

Canadian Pediatric Rheumatology Association

IMHA

CIHR Institute of Musculoskeletal Health and Arthritis

OCAPI

Office of Consumer and Public Involvement, Health Products and Food Branch, Health Canada

TAS

The Arthritis Society national, division and branch offices

CAPA liaises informally with:

AHPA

Arthritis Health Professionals Association

Canadian Institute for the Relief of Pain and Disability

CRA

Canadian Rheumatology Association

CRRC

Canadian Rheumatology Research Consortium

*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.*



www.arthritis.ca/capa

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