

# Canadian Arthritis Patient Alliance

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



## “Back and to the Future”

*2002: A year in review 2003: A look at next year*



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- Middle** - Ann Qualman, CAPA President presents Canadian Arthritis Bill of Rights and Responsibilities to Liberal MP, Dr. Carolyn Bennett
- Bottom** - Denis Morrice, TAS President and CAPA Member, Linda Wilhelm, Jean Legare, "Launching the Canadian Arthritis Bill of Rights and Responsibilities on Parliament Hill"

## Foreword



**Ann Qualman**

President  
Canadian Arthritis Patient Alliance

**W**hat an amazing year! CAPA was officially launched in August 2001 by an assembly of some 80 arthritis advocates from across Canada, meeting in Edmonton. A Steering Committee was then elected and held its first meeting later that year. This report takes us through 2002 and into our plans for 2003. As you'll see in this report, we've made tremendous progress in bringing the faces of arthritis – our faces – to so many organizations, consultations, workshops and meetings.

We have grown in number from nearly 200 members in August 2001 to more than 300 by the end of 2002. More importantly, we are making our presence felt as we seek out opportunities to collaborate with other organizations and individuals to make arthritis better known, remove its devastating effects and create better lives for people with arthritis.



**Denis Morrice**

President & CEO  
The Arthritis Society

**A**s the President of the Arthritis Society it is my privilege to be involved with the Canadian Arthritis Patient Alliance. The importance of consumer involvement at healthcare decision making tables has never been more critical in our world than today.

As you will recognize from reading through the Annual Activity Report, there has been tremendous arthritis consumer involvement from coast to coast. I am extremely proud of the talented and dedicated advocates all across the country committed to making life better for people with arthritis!

# Message from the CAPA Steering Committee

Dear CAPA Members,

The Canadian Arthritis Patient Alliance (CAPA) is only one year old and take a look at everything that has been accomplished during this first year. Members have been active in advancing all of our four key advocacy priorities which are:

- To increase the level of public & and political awareness of arthritis
- To ensure better access to medications
- To ensure better access to health care professionals
- To increase patient involvement in establishing the arthritis research agenda

As a result, many politicians and members of the public have a better understanding about the scourge of arthritis. We have established relations with the arthritis professional organizations. Most significantly, there have been important gains in access to medication, and arthritis patients are involved as never before in establishing research priorities. We all know how much more remains to be done but our efforts have been rewarded and we are witnessing important gains for people with arthritis.

Thanks go to all our members for all that you have done to make this happen. As CAPA has a national focus, this annual report records advocacy achievements at the national level only. What is not recorded are the innumerable and equally important gains for people with arthritis that you have accomplished among your family, friends, colleagues, your community and your province or territory. We have seen this year the power of individual and group effort. We have all made a difference in the lives of people with arthritis. We thank all those organizations — public, private, non-profit — that have cooperated and collaborated with us. We thank our Associate Members for their moral and active support. We particularly thank The Arthritis Society for their logistical support and for partnering with us in so many activities nationally, provincially and locally.

Sincerely,

*Past & Present CAPA Steering Committee*

# Past & Present CAPA Steering Committee

**British Columbia and Yukon:** Glen Urquart (09/2001 – 01/2002),  
Helen Klassen (09-2002 - 04/2003)  
Colleen Mahoney: (09/2002)

**Alberta & NWT:** Linda D'Angelo (09/2001 – 06/2002),  
Ida Tjosvold (04/2003)

**Saskatchewan:** Anne Dooley (09/2001- present)

**Manitoba:** Susan Kapilik (10/2001 – present)

**Ontario:** Lynn Cooper 10/2001- present)

**Québec:** Ann Qualman (09/2001 – present),  
Jean Légaré (10/2001- present)

**New Brunswick:** Linda Wilhelm (09/2001 – present)

**Nova Scotia & PEI:** Mel Comeau (09/2002 – 01/2003),  
Joan Bona (02/2003 – present)

**Newfoundland & Labrador:** Michele Walsh (10/2001 – 06/2002),  
Harold Wells (09/2002 –present)

# Overview

## What Is CAPA?

The Canadian Arthritis Patient Alliance (CAPA) is a national organization for people with arthritis. We also have associate members from across Canada and around the world and most of these individuals do not have arthritis. The single thing that unites us all is that we want to ‘make a difference’ in the fight against arthritis. We create links between Canadians with arthritis. We assist them to become more effective advocates. We seek to improve the quality of life of all people living with arthritis. We support individual members and groups in implementing advocacy activities, including the continuing education of advocates.

## Why do we do it?

We are CAPA members because we want better access to medications for people with arthritis. We want to increase the level of public and political awareness of arthritis. We want better access to health care professionals and we want to increase patient involvement in establishing arthritis research and planning agendas. We also want people to understand that arthritis is not ‘just arthritis’, it is not ‘just aches and pains’ and it is not ‘an older persons disease’. It is a collection of debilitating diseases any one of which can occur from early childhood to very old age.

## How do we do it?

We provide a strong voice and concerted effort to promote the social, economic and environmental well being of people living with arthritis. We communicate with all levels of Government to make positive changes to health policies. We initiate or participate in committees and partnerships with other organizations to assist us in better negotiating on behalf of people living with arthritis, and we talk to our neighbors.

## Where do we meet?

CAPA is not a ‘bricks and mortar’ organization. The Internet connects us and we communicate by email. Information updates are frequent.

# 2002 Strategic Plan

In December of 2001 the CAPA Steering Committee had its first annual meeting to determine a strategic plan. The Steering Committee at that time, was comprised of 9 people with arthritis from across the country in addition to 3 ex-officio TAS representatives. The TAS representatives were TAS National Office staff, Denis Morrice and Lisa Crawford. Gwen Haliburton represented the National Board from October 2001 until the restructuring of the board in March 2002. The Committee went through a formal analysis of CAPA's strengths, weaknesses, opportunities and threats to determine its strategic plan.

## Mission

CAPA is a national organization, which creates links between Canadians with arthritis, assists them to become more effective advocates and seeks to improve the quality of life of all people living with arthritis.

## CAPA's strategic objectives for 2002

- Working with The Arthritis Society to implement our National and Provincial advocacy strategies;
- Supporting individual members and groups in implementing advocacy activities, including the continuing education of advocates;
- Increasing the number of CAPA members and their involvement in arthritis advocacy;
- Increasing public awareness of the devastating effects of arthritis;
- Working with The Arthritis Society to increase funding and support by government and other institutions in order to meet our objectives.

CAPA intends to meet the above objectives by providing a strong voice and concerted effort to promote the social, economic and environmental well-being of people living with arthritis. CAPA members will communicate with all levels of Government to make positive changes to health policies. CAPA will initiate or participate in committees and partnerships with other organizations that will enhance our cause and assist us in better negotiating on behalf of people living with arthritis.

## Our key CAPA/TAS advocacy priorities for 2002 are:

- To increase the level of public & and political awareness of arthritis
- To ensure better access to medications
- To ensure better access to health care professionals
- To increase the involvement of people with arthritis in establishing the arthritis research agenda.

# Public and Political Awareness of Arthritis

Joint Meeting of Canadian Arthritis Patient Alliance (CAPA) Steering Committee and The Arthritis Society (TAS) Advocacy Staff January 27th, 2002

- CAPA Steering Committee presents strategic plan to TAS advocacy staff
- Staff provides feedback to CAPA strategic plan
- Staff and CAPA advocates develop skill sets for media and government relations

Lobby Day on Parliament Hill January 28th, 2002

- CAPA members and TAS staff present Members of Parliament and Members of the Federal Standing Committee on Health Care with The Arthritis Bill of Rights and Responsibilities to increase their awareness of arthritis issues.
- The results of the meetings were an overwhelming success.

Launch of the Canadian Arthritis Bill of Rights and Responsibilities January 29th, 2002

- The Canadian Arthritis Bill of Rights was launched at The National Press Club in Ottawa.
- Several members of the Canadian Arthritis Patient Alliance (CAPA), some Arthritis Society staff, volunteers and donors attended. The news conference went smoothly, with the room filled to the brim.
- The Media Event included a panel presentation provided by the following individuals:
- Media coverage was remarkable with total broadcast reach from radio and television at nearly 9 million and total print impressions at 341,399 putting The Arthritis Society (TAS), CAPA and the Bill of Rights among the top stories in Canadian healthcare news.
- It was a long road, but now Canadians with arthritis have an official platform on which to make their voices heard!

Montreal Conference on Building Consensus for Health Care Reform in  
Canada, sponsored by McGill University February 14-16th

- CAPA member, Ann Qualman, participates.

**Conference Focus:**

Health policy and programs and the reforms underway in each province.

Building the Evidence for Enlightened Drug Policy In Canada Forum,  
Ottawa April 11th

- Lisa Crawford, TAS Manager of Community Development, presents information to approximately 100 stakeholders, government health policy and industry policy representatives on how consumers use evidence.

Appearance before the Romanow Commission on the Future of Health  
Care in Canada, Toronto May 30th

- The Commission warmly receives presentations by Denis Morrice, President & CEO of TAS, and CAPA member, Catherine Hofstetter.
- CBC Radio (French and English), Media-Q Radio of Ottawa and CPAC covers the hearing.
- Catherine is interviewed by CBC Newsworld.

**Presentation Points:**

- Catherine's story of her life with arthritis, highlighted issues that affect all Canadians with the disease.
- Focus on the need for a national pharmacare program.
- Stress the importance of consumer involvement from the time of medication approval through post-marketing surveillance
- Emphasize the tenants of the Canadian Arthritis Bill of Rights, (included as part of TAS's submission.)

Health Charities Conference:  
The Role of Health Charities, Ottawa April 26th-28th

- CAPA steering committee member, Ann Qualman & Lisa Crawford attend

**Meeting Focus:**

Advocacy, with sessions on both government and media relations.

## Canadian Pension Plan (CPP) Review Tribunal, Halifax

June 4th

- CAPA Steering Committee member Linda Wilhelm presents the consumer's perspective
- Dr. Dianne Mosher presents the medical perspective
- Lisa Crawford presents the perspective and policy recommendations of TAS

## National Health Care Forum – Saskatchewan, Co-sponsored by the Romanow Commission and the University of Saskatchewan, Saskatoon

June 10th

- Anne Dooley, CAPA member, attends the forum that is broadcast live and recorded for CPAC.
- During question period Anne comments on-air:
  - i. Uneven access to medications across Canada
  - ii. Potential benefit of the increase in consumer/patient input in health care planning called for by several panel members

## Meeting with Geneviève Tremblay, Special Assistant to Anne McLellan, Ottawa

June 30th

CAPA members Jean Légaré and Ann Qualman along with Denis Morrice meet with Anne McLellan's (Federal Health Minister) Special Assistant Geneviève Tremblay.

### ***Meeting Objective:***

To set the stage for Arthritis Awareness Week (September 9th-13th). Arthritis Awareness week is an effort to link consumers with MP's to increase politician's awareness and political will towards arthritis issues.

### ***Meeting Outcome:***

Learned that the Federal government is no longer sponsoring national action plans/strategies

## Disability Tax Credit Coalition

July

- TAS and CAPA join sixteen major health charities representing millions of Canadians with disabilities that have rallied behind a House of Commons Committee report that calls for immediate changes to the disability tax credit (DTC).

## Bone & Joint Declaration

August

- The Federal Minister of Health, Anne McLellan endorses the declaration of 2000-2010 as Bone & Joint Decade, as a national and international working partnership which will result in more progress toward the reduction of bone and joint disorders in Canada and the rest of the world.

## Arthritis MP Awareness Effort

September

- TAS in partnership with CAPA coordinates Arthritis Awareness Week to increase public awareness & political will towards arthritis care in Canada.

## CRA Meeting with Geneviève Tremblay, Special Assistant to Anne McClellan, Ottawa

September 6th

- CAPA member, Linda Wilhelm, joins members of the CRA executive and others at a meeting with Federal Health Minister, Anne McLellan's Special Assistant, Geneviève Tremblay, requests support for an integrated approach to arthritis care.

## Canadian Pain Summit – “ Understanding, preventing and treating debilitating persistent pain”

November 14th

- CAPA member, Lynn Cooper joins other key stakeholders with an interest in pain and its management in Canada.

### ***Purpose of Summit:***

To solicit the input of interested parties toward the evolution of the Canadian Pain Network.

# Better Access to Medications

## Canadians for Best Medicines Coalition Meeting (Aylmer, Québec)

January 24–27th

- Many CAPA members and Denis Morrice, TAS CEO, attend

### **Key Message:**

The Canadian drug review and approval system needs:

- i. Timely access to drugs through an efficient drug review system
- ii. Post-approval surveillance of prescription drugs
- iii. Public participation

## CBC Television Interview – High Cost of Medication

May 29th

- CAPA member Jean Légaré from Quebec is interviewed by CBC television for CBC News and Newsworld, “Canada Now”, with Ian Hanomansing.

## Coxib Consensus Conference, Vancouver

June 19th

- Arthritis Consumer Experts (ACE), the Arthritis Research Centre of Canada (ARC) and The Arthritis Society, BC & Yukon Division co-convene the Coxib Consensus Conference. Denis Morrice and CAPA members are in attendance.

### **Conference objectives:**

- i. Review the health policy and scientific evidence base on coxibs published to date.
- ii. Prepare a majority consensus statement on access guidelines that appropriately meet the needs of British Columbians.
- iii. Provide the public with emerging safety information on this therapeutic class in consumer-friendly language.
- iv. Ensure that the principles of the majority consensus process are respected and supported.

## Provincial Formularies & Private Payers Course, Toronto

July 11th

- Three CAPA members and three TAS staff from across the country attend.

### ***Meeting Objective:***

Presentation of various technical materials and strategy objectives for public and private formularies.

### ***Meeting Outcome:***

Materials and information to augment the advocacy facilitator guide are obtained.

## Health Canada Working Group on Health Promotion related to Natural Health Products and Complementary and Alternative Health Care

July 20th

- CAPA member, Michele Walsh is a member of this year-long working group.

# Better Access to Health Care Professionals

## CRA Executive Committee meeting in Montreal

April 6th

- Ann Qualman is invited to make a presentation on CAPA

### ***Meeting Objective:***

Discuss strategy for promoting integrated care teams of family physician, rheumatologist, orthopedic surgeon, nurse practitioner, physiotherapist and occupational therapists, social worker.

## Meeting with Ian Green, Deputy Minister of Health, Health Canada July 5th

- Denis Morrice on behalf of TAS and CAPA, along with members of the orthopaedic care community meet with Ian Green as a follow-up on the Canada In Motion initiative.

### ***Key issues:***

- i. Waitlists for surgeries
- ii. Need for Federal Government to sign declaration for Bone & Joint Decade

# Patient Involvement in Establishing the Arthritis Research Agenda

Knowledge Translation Workshop—Consumer Briefing, Ottawa January 30th

- CAPA member, Ann Qualman, with others in the Cochrane Musculoskeletal Group (CMSG) organize the briefing
- CAPA members Anne Dooley, Anne Lyddiatt, Dennis Jeanes and TAS CEO, Denis Morrice, participate

**Workshop Objective:**

Provide information to enable full participation of consumers in the Knowledge Translation Workshop.

Knowledge Translation Workshop, Sponsored by Institute of Musculoskeletal Health and Arthritis (IMHA), Canadian Institute of Health Research, Ottawa January 31st

- The workshop is sponsored by the Institute of Musculoskeletal Health and Arthritis (IMHA) for consumers and clinicians in its six health specialty areas. Dennis Jeanes, Ann Qualman, Anne Dooley, Jim Davies and Anne Lyddiatt are the arthritis consumer participants.

**Workshop Objective:**

Identify research needed to enable better transfer of knowledge acquired in Cochrane reviews to clinicians and consumers.

National Conference on Appropriate Use of Placebos in Clinical Trials, sponsored jointly by Health Canada and CIHR, Ottawa March 22nd -23rd

- CAPA member, Anne Dooley, participates as a consumer stakeholder

**Conference objectives:**

- i. Obtain stakeholder input
- ii. Provide forum for discussion and debate
- iii. Further stakeholder understanding of different perspectives on placebo use
- iv. Work toward developing Canadian consensus on what constitutes appropriate placebo use in clinical trials on human subjects.

## Canadian Rheumatology Association (CRA) Media Release on Access to Biologics

April 3rd

- The CRA and members of CAPA participate in a joint media initiative

### **Objectives:**

- i. Increase awareness of the need for access to biologic medications for patients who most need these drugs.
- ii. Increase awareness of the cost of biologic medications, plus the economic and ethical considerations of access to these drugs.

## 2002 Arthritis Society Research Review Panels

April 4th – 9th

- Six CAPA members participate as panel members on the 2002 Arthritis Society Research Review Panels.
- A consumer mentor/apprentice model is incorporated based on level of experience for each consumer.
- Considerable reading materials were reviewed by each of the consumers prior to the review panels.
- The role of the consumer is to review the research operating grant applications (for his/her assigned panel) and to attend the meetings to provide a consumer perspective on the submitted applications; ie, what arthritis research is relevant to the consumers needs, etc.

The participants include:

**Immunology Panel:** George McKeil (CAN\* member-mentor) & Linda Wilhelm (apprentice)

**Bone/Joint/ Cartilage Panel:** Dr. Gordon Gray (biochemist-mentor) & Helen Klassen (apprentice)

**Epidemiology/Health Services Panel :** Ian Rollo (CAN\*member-mentor) & Lynn Cooper (apprentice)

\* CAN - Canadian Arthritis Network, Consumer Advisory Board members

## Speaking for Ourselves Workshop: Consumer Participation in Research, Toronto

April 19th

- Presenters included CAPA members Anne Dooley, Catherine Hofstetter, Helen Klassen and Cheryl Koehn. 28 CAPA members from across Canada participate.

### **Meeting Objectives:**

- i. Provide participants with interactive overview of medical and osteoarthritis (OA) research in Canada.
- ii. Increase knowledge of current trends in osteoarthritis research from the perspective of: Clinician/scientist Industry.

## OA (Osteoarthritis) Consensus Conference, Toronto

April 20—21st

- Among presenters are CAPA members, Ann Qualman and Liza Lorenzetti
- CAPA member, Helen Klassen participates in a media event which highlights what current research is indicating: *Canadians with lower income and education levels have limited access to joint replacement surgery*
- 20 CAPA members participate in the conference

### **Conference Objective:**

Bring together for the first time, leading arthritis researchers from several countries and Canada's leading arthritis research organizations, The Arthritis Society (TAS), the Canadian Arthritis Network (CAN), the Canadian Institutes of Health Research - Institute of Musculoskeletal Health and Arthritis (IMHA) to create a national osteoarthritis research strategy.

## Towards a National System of Oversight for the Governance of Research Involving Humans, Conference sponsored by Health Canada, Vancouver

June 17th

- CAPA members, Anne Dooley, Cheryl Koehn and two others attend
- Consumers make a case for:
  - i. Transparency, consistency and reliability of oversight on behalf of human subjects involved in clinical trials.
  - ii. Consumer participation on hospital ethics review boards.

### **Meeting Objective:**

Consultation with stakeholders to help develop a framework for a system of oversight that promotes socially beneficial research, protects the rights and well-being of research participants and enhances public trust.

### **Meeting outcome:**

A direct result of this and the March Placebo conference is the CAPA project to introduce qualified consumers onto Ethics Review Boards.

## Health Canada – Office of Consumer and Public Involvement (OCAPI) Ottawa

July 16th

- Sylvie Cantin, Director of the Office of Consumer and Public Involvement for Health Products and Food Branch of Health Canada, invites Ann Qualman to meet with her to explore areas of mutual interest.

### **Meeting Outcomes:**

- i. OCAPI approaches CAPA regarding the need for a consumer representative on a Product Monograph and Appropriate Dispute Resolution committee.
- ii. Ann forwards the FDA advisory committee models for OCAPI's consideration. OCAPI expresses interest and will be doing further research on these models.

## Health Canada's Advisory Committee on Governance of Research Involving Humans

August

- CAPA member, Anne Dooley, is a member of this committee that will work together for one year.

## The Clinical Research Process in Canada Consultation

August

- Former Minister of Health, Monique Bégin and Senator Judy Erola interview CAPA members Jean Légaré, Anne Dooley, Ann Qualman and others in connection with their research sponsored by Health Canada and Industry Canada on the subject of ethical research.

## Canadian Arthritis Network (CAN) Annual Meeting, Calgary September 26-29th

- All members of the CAN Consumer Advisory Committee (CAC) are members of CAPA: Co-Chairs George McKiel and Cheryl Koehn and members, Liza Lorenzetti, Ian Rollo, Claire Cadieux and Catherine Hofstetter.
- CAPA Research Co-Chairs Anne Dooley and Ann Qualman attended along with Lisa Crawford of TAS
- September 29th Denis Morrice, Anne, Ann, Cheryl, Catherine and Lisa attend Steering Committee meeting of The alliance for the Canadian Arthritis Program (ACAP) and four other major arthritis stakeholder organizations, the purpose of which is to develop the vision for the arthritis research strategy in Canada. Denis chairs meeting.
- Ann Qualman, Anne Dooley, Cheryl Koehn and Catherine Hofstetter, with Lisa Crawford providing staff support, form a consumer working group within the Steering Committee.

## Arthritis News Research Feature

October

In collaboration with TAS, CAPA and the Cochrane Musculoskeletal Group (CMSG) arrangements are made with Arthritis News for a feature article in each issue reporting Cochrane evidence-based information about different arthritis therapies. Anne Dooley is working with CMSG on this and was featured in the Fall issue.

## Speaking For Ourselves Forum: The Patient of 2010, Sponsored by The Charles E. Frosst Foundation, Ottawa

November 8th

- Ann Qualman from CAPA and Lisa Crawford from TAS attend.

### ***Forum Objectives:***

- i. Analyze consumer involvement in research and health policy with particular emphasis on informed and engaged consumers
- ii. Examine the questions:
  - How do you get the perspectives of ordinary people who live with disease?
  - What can be done to ensure that consumers will speak up?
  - Do consumers need training to make a valuable contribution?
  - How are informed consumers created?

# The Year Ahead: New Structure and Program Plans

## CAPA Executive Committee

Every organization evolves as it matures and CAPA is no exception. As we head into our second year, we are pleased to announce that the CAPA Steering Committee has elected an executive, as provided for in the CAPA constitution. The Executive Committee of CAPA reports to the Steering Committee and will meet as often as required, usually by teleconference, to assist the planning, monitoring and day-to-day functioning of CAPA.

## The Executive Committee consists of:

- The President of CAPA
- The 2 Vice-Presidents
- The Secretary-Treasurer (The Arthritis Society national staff person- responsible for advocacy as exofficio member)
- The President and CEO of The Arthritis Society (exofficio member).

The Executive Committee is accountable to the Steering Committee for the day-to-day operation of CAPA. The Steering Committee is accountable to CAPA members.

## The Executive Committee for 2003

President : Ann Qualman

Vice President : Anne Dooley

Vice President : Helen Klassen

Secretary-Treasurer : Lisa Crawford (ex-officio)

President/CEO TAS: Denis Morrice (ex-officio)

# 2003 Strategic Plan

In December of 2002 the CAPA Steering Committee reviewed the year's accomplishments and refined their strategic plan for 2003.

We anticipate many opportunities in 2003 to participate and make a difference in our key priority areas and we will be calling on members, associate members and other supporters. But don't wait for an invitation. We invite you to contact any of us at any time with your suggestions. Please see the CAPA Steering Committee contact list attached.

The Mission and Strategic Objectives are the same as those mentioned in the report for 2002.

## CAPA Strategic Priorities for 2003:

- To increase the level of public & political awareness of arthritis
- To ensure better access to medications
- To ensure better access to health care professionals
- To increase patient involvement in establishing the arthritis research agenda
- To support people disabled with arthritis in their efforts to obtain services and other assistance they require

## CAPA Sub-Committees and Chairs for 2003:

Sub Committee	Co-chair	Co-Chair
Access to Medications	Linda Wilhelm	Jean Légaré
Access to Professionals	Ann Qualman	Linda Wilhelm
Education/Advocacy Training	Sue Kapilik	
Elections	Harold Wells	Linda Wilhelm
Research	Anne Dooley	Jean Légaré
Disability	Colleen Maloney	
Pain issues	Lynn Cooper	Colleen Maloney
Member Outreach/ Communications	Colleen Maloney	Anne Dooley
External Relations	Executive Committee	

# Sub Committee Objectives for 2003

## Access to Medications

### Members:

- Linda Wilhelm, Co-chair
- Jean Légaré, Co-chair
- Harold Wells

### Objectives for 2003:

1. Continued collaboration with The Best Medicines Coalition to support their mission and objectives.
2. A concerted effort to push government to act on The Romanow Commission recommendations for catastrophic illness drug coverage and that the biologics for Rheumatoid Arthritis be placed in this category.
3. Identify CAPA members in provinces needing access to medications. Provide support to assist them to mobilize and choose a key contact person for the steering committee to work with. Member Outreach/Communications sub-committee to assist Access to Medications.
4. Continued push for consumer involvement in discussions on The Common Drug Review Initiatives.
5. Continued vigilance for opportunities for consumer participation with regard to issues involving access to medications.
6. Continued push for implementation of a consumer-driven Post Market Surveillance Program focused on biologic response modifier medications.

# Access to healthcare professionals

## Members

- Ann Qualman, Co-chair
- Linda Wilhelm, Co-chair
- Anne Dooley

## Objectives for 2003:

1. To participate and present to the Canadian Rheumatology Association (CRA) AGM and thus make CAPA better known to Rheumatologists so that future collaboration is possible.
2. To actively engage approximately three CAPA members in each of the committees of ACAP so that people with arthritis are part of the decisions that will be made to promote access to care.
3. To explore possible areas of collaboration with the Arthritis Health Professionals Association (AHPA).
4. To explore possible areas of collaboration with the Canadian Orthopaedic Association and Foundation (COA and COF).
5. To identify other CAPA members and associate members interested in this issue, particularly those who are making headway on this issue in their provinces.

# Education/Advocacy Training

## Members

- Susan Kapilik, Co-chair
- Lynn Cooper
- Colleen Maloney
- Ida Tjosvold

## Objectives for 2003

1. Continue the process of providing information to educate the general public, federal and provincial representatives, agencies and NGOs about issues relating to CAPA's strategic plan and the benefits of working together.
2. Obtain advocacy training and provide training/dissemination of materials based on updated National Train the Trainer Materials as required. Be available as a resource to those conducting Division advocacy training.
3. Encourage the development and networking of a Continuing Education Credit (CEC) Arthritis Course for Family Physicians and the Three Minute MSK exam for Physicians.
4. Liaise with and support the Alliance for the Canadian Arthritis Program – (ACAP) Education Development Committee.
5. Continue to push for consumer participation at the table in matters relating to Knowledge Translation by supporting and working with the Research sub-committee.

# Elections

## Members:

- Harold Wells, Co-chair
- Linda Wilhelm, Co-chair
- Ann Qualman

## Objectives for 2003:

1. To work with TAS to develop and support a provincial and federal lobbying strategy.
2. To provide leadership to CAPA in lobbying in support of CAPA's priorities.  
(This will involve liaising with other CAPA committees and TAS).
3. To evaluate the results of these efforts so that CAPA can show our organizational effectiveness and improve our approach.

# Research

## Members:

- Anne Dooley, Co-chair
- Jean Légaré, Co-chair
- Lynn Cooper

## Objectives for 2003:

1. To continue to push for consumer involvement and participation at the table in matters relating to:
  - clinical research planning, process, trends, strategies and priorities, including Health Canada policies and practices.
  - knowledge translation
  - governance of research involving humans and ethics review boards.
2. To encourage consumer participation and cooperation with other consumer groups (e.g. Consumer Advisory Council) and major fund raising organizations (e.g. IMHA, CAN and TAS) in planning projects to accomplish research oriented goals in all areas of investigation.
3. To have CAPA representation on the planning committee for the future RA Inflammation and Auto immune Conference.

# Disability Issues

## Members:

- Colleen Maloney, Co-chair
- Mel Comeau

## Objectives for 2003

1. To contribute to the Disability Tax Credit (DTC) consultation process, monitor communication stemming from the process and provide timely feedback.
2. To become involved in a joint senior level advisory group comprised of senior level government officials, advocacy groups, representatives of organizations of professional groups of medical practitioners who complete Form T2201 and individuals.
3. To actively provide input/consultation regarding ongoing DTC issues to The Federal Government's Standing Committee on Human Resources Development and the Status of Persons with Disabilities.
4. To continue/develop links with advocacy groups, individuals, and members of The Standing Committee on Human Resources Development and the Status of Persons with Disabilities.
5. To encourage CAPA members and non-member stakeholders to participate in the above objectives.

# Pain Issues

## Members

- Lynn Cooper, Co-chair
- Colleen Maloney, Co-chair

## Objectives for 2003

1. To increase awareness and understanding of the pain issues associated with arthritis and arthritis related diseases. Specifically, pain should not be accepted as just part of the disease resulting in its under treatment or lack of treatment. Types of pain addressed would be long-term and pre/post operative pain involved with joint replacement.

2. To research the attitudes and understanding of health professionals, regarding arthritis pain issues and treatment. To research the existence of treatment modalities specific to arthritis care and/or the adaptation possibilities for existing pain treatment methods to arthritis pain.
3. To establish and further develop links with health professionals and consumer groups such as the Canadian Pain Society, Canadian Pain Network, and the Canadian Pain Coalition.
4. To seek out and capitalize on advocacy opportunities.

## Member outreach/Communications

### Members:

- Anne Dooley (communications), Co-chair
- Colleen Maloney (member outreach), Co-chair
- Lynn Cooper
- Jean Légaré

### Objectives for 2003

1. To continue to encourage regular activity reports for CAPA SC meetings, and to support the development of an e-newsletter for distribution to the CAPA membership.
2. To encourage active participation of CAPA members, by:
  - Developing channels of communication that encourage two-way information exchange between CAPA committees and strategic planning.
  - Designing and implementing a system of gathering and disseminating statistical information about CAPA projects and activities with the assistance of interested CAPA members across Canada.
3. To work with all committees as required to facilitate our mutual committee goals of better communication, increased recruitment and volunteer development.

# External relations (Executive Committee)

## Members

- Ann Qualman, President
- Anne Dooley, Vice President

## Objectives for 2003:

1. To partner with other arthritis organizations in the Alliance for the Canadian Arthritis Program – ACAP, formerly known as Canadian Arthritis Plan.
2. To support the further development of the Bone and Joint Decade initiative in Canada.
3. To ensure that CAPA has active links with each major arthritis related organization.

## CAPA Steering Committee – Contact List

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	Province	Email
Colleen Maloney	British Columbia	<a href="mailto:azmony@shaw.ca">azmony@shaw.ca</a>
Helen Klassen	British Columbia	<a href="mailto:hklassen@telus.net">hklassen@telus.net</a>
Ida Tjosvold	Alberta	<a href="mailto:itjosvold@shaw.ca">itjosvold@shaw.ca</a>
Anne Dooley	Saskatchewan	<a href="mailto:annemd@shaw.ca">annemd@shaw.ca</a>
Susan Kapilik	Manitoba	<a href="mailto:skapilik@mb.arthritis.ca">skapilik@mb.arthritis.ca</a>
Lynn Cooper	Ontario	<a href="mailto:LKCooperBES@rogers.com">LKCooperBES@rogers.com</a>
Ann Qualman	Quebec	<a href="mailto:aqualman@cyberus.ca">aqualman@cyberus.ca</a>
Jean Légaré	Quebec	<a href="mailto:jlégaré@sympatico.ca">jlégaré@sympatico.ca</a>
Linda Wilhem	New Brunswick	<a href="mailto:helm@nb.sympatico.ca">helm@nb.sympatico.ca</a>
Joan Bona	Nova Scotia	<a href="mailto:bona.loujo@ns.sympatico.ca">bona.loujo@ns.sympatico.ca</a>
Vacant	PEI	
Harold Wells	Newfoundland & Labrador	<a href="mailto:harold.wells@nf.sympatico.ca">harold.wells@nf.sympatico.ca</a>
Denis Morrice *	TAS- National	<a href="mailto:dmorrice@arthritis.ca">dmorrice@arthritis.ca</a>
Lisa Crawford *	TAS - National	<a href="mailto:lcrawford@arthritis.ca">lcrawford@arthritis.ca</a>

\* *ex-officio members*

# Canadian Arthritis Patient Alliance Constitution

## I. Nature of the organization

The Canadian Arthritis Patient Alliance (CAPA) is a voluntary organization, a self-governing entity of and for Canadians with arthritis. It is a virtual organization located at [www.arthritis.ca](http://www.arthritis.ca). Material and staff support for CAPA is provided by The Arthritis Society (TAS). The organization was first established in August 2001.

For purposes of communication, CAPA members must have e-mail capacity as normally, CAPA will communicate with members electronically. If resources permit, CAPA will take advantage of situations that bring together arthritis advocates, such as the Arthritis and Rheumatism International meeting in Edmonton in August 2001, in order to hold face-to-face meetings of members.

## II. CAPA – Mission

CAPA is a national organization, which creates links between Canadians with arthritis, assists them to become more effective advocates and seeks to improve the quality of life of all people living with arthritis.

## III. CAPA-TAS relationship

CAPA will conduct its affairs in close partnership\* with TAS.

*\* Partnership (definition): a relationship resembling a legal partnership and usually involving close cooperation between parties having specified and joint rights and responsibilities*

## IV. Members

### **Definition**

Members of CAPA are Canadians with arthritis. Others wishing to support arthritis advocacy through CAPA will be designated Associate Members.

### **Roles and Responsibilities**

Both Members and Associate Members may be elected or appointed to serve on CAPA committees. However, nominations and voting to elect members to the Steering Committee as well as voting on other items requiring member approval, such as the annual report and advocacy priorities, will be by Members only (Canadians with arthritis).

Individual members of CAPA must take personal responsibility for their advocacy positions. They can mention their membership with CAPA for purposes of arthritis advocacy but cannot claim to speak on behalf of CAPA or represent it unless authorized by the Steering Committee. The Steering Committee can rescind an individual's membership in CAPA.

## V. Steering Committee

### ***Roles, Responsibilities and Functions of the Steering Committee***

The Steering Committee is responsible for managing the affairs of CAPA.

Its specific responsibilities include:

- Guiding CAPA in fulfilling its mission, goals and objectives
- Overseeing activities associated with CAPA
- Enhancing the organization's national profile
- Responding to advocacy priorities and other needs of CAPA members
- Spearheading and coordinating national arthritis advocacy initiatives in collaboration with The Arthritis Society (TAS)
- Assisting provincial or local advocacy, particularly initiatives with multi -province potential
- Building alliances with other stakeholders in support of CAPA goals and objectives.

The Steering Committee procedures will include:

- Establishment of committees as needed to achieve CAPA objectives
- Development of an annual business plan, including a budget
- Dissemination of Committee minutes, reports and other matters of interest to CAPA members by e-mail
- Regular meetings. The Steering Committee will meet in person at least once per year
- Participation in stakeholder meetings that relate to key advocacy priorities
- Monthly teleconferences. Quorum will be a simple majority of the members including at least one TAS representative.

## VI. Composition of the Steering Committee

***The Steering Committee will consist of 10-14 members:***

- i. 6 Steering Committee Members elected by CAPA regular members
- ii. Up to 5 Steering Committee Members appointed by the elected Steering Committee Members
- iii. 3 appointed TAS Staff/Board representatives
  - The TAS national staff person responsible for advocacy
  - The TAS Executive Director, or his or her representative
  - A representative of the TAS National Board

### ***Eligibility and Selection of Steering Committee Members***

Steering Committee elections will be held annually by electronic ballot. Every other year in September, the CAPA Steering Committee will call for nominations to form its Steering Committee. The CAPA Steering Committee is formed in three ways:

1. A call for nominations within the membership will be followed by an electronic election of the entire membership. Six individuals from different provinces who receive the highest popular vote will be elected to the CAPA Steering Committee
2. The elected 6 CAPA Steering Committee Members will thereafter, appoint up to 5 members based on attaining provincial representation on the committee and enabling the committee to better represent Canadians with arthritis.
3. TAS will appoint 3 ex-officio members

CAPA Steering Committee Members missing 3 teleconferences in a row or 5 teleconferences a year would be asked to evaluate his/her availability to work on the CAPA Steering Committee.

Note, if a CAPA Steering Committee Member resigns, the CAPA Steering Committee will call upon the membership for nominations and thereafter, the Steering Committee will appoint a replacement.

No CAPA representative may serve more than six consecutive years on the Steering Committee.

## VII. The Executive Committee

### ***Roles and Responsibilities***

The Executive Committee of CAPA reports to the Steering Committee. The Executive Committee will be elected by the Steering Committee. The Executive Committee meets as often as required, usually by teleconference, to assist the planning, monitoring and day-to-day functioning of CAPA. The presence of at least one TAS representative and two non-TAS members is required for a meeting of the Executive.

### ***Composition***

- The Executive Committee consists of:
- The President of CAPA
- The 2 Vice-Presidents
- The Secretary-Treasurer  
(*the TAS national staff persons responsible for advocacy - ex officio member*)
- The President and CEO of The Arthritis Society (*ex officio member*).

### ***Accountability***

The Executive Committee is accountable to the Steering Committee and the TAS National Board for the day-to-day operation of CAPA.

The Steering Committee is accountable to CAPA members and to TAS.

For reasons of accountability and to ensure consistent messages, only the members of the Executive Committee can speak for the committee and only the Steering Committee as a whole can issue or respond to communications in the name of CAPA.

## VIII. Health Care Advisory Committee

### ***Role and Responsibilities***

Representatives of the medical, research and health care professions will be invited by the Steering Committee to serve on the Health Care Advisory Committee. The Committee will receive the annual report of CAPA and the reports of the Steering Committee and may be consulted individually or as a group by the CAPA Executive Committee, Steering Committee and sub-committees. A purpose of the consultation will be to help ensure that CAPA initiatives are grounded in the reality of health care in Canada. Advice will also be sought on strategies for joint advocacy between CAPA and the professions represented.

### ***Composition***

The Committee will be comprised of approximately 5 people: a representative Rheumatologist, Orthopaedic Surgeon, Researcher in arthritis, Physiotherapist, Occupational Therapist, etc. The individuals invited will be acknowledged experts in their fields.