

Spotlight on BC

Summit on the Value of Medicines

Arthritis Consumer Experts, together with organizations representing myriad chronic diseases, are holding the "Summit on the Value of Medicines". It is vitally important to get as many people living with illness as possible out to this event. People who depend on medications to live, and live well, must be heard and this is your chance to get prepared to speak out about arthritis treatment and care in British Columbia.

WHAT:

The Summit on the Value of Medicines

WHERE:

Rocky Mountaineer Station,
1755 Cotrell St (at Terminal Ave), Vancouver.
Free parking will be available.

WHEN:

Saturday, February 24th Noon to 5pm

TO REGISTER:

Visit www.theciainc.com,
or call 604-714-5580 by February 15th.
Registration is free.

Participating at the Summit on the Value of Medicines will help to prepare you to attend the Conversation on Health forum coming to your community in 2007.

Please register now. We look forward to seeing you there.

Advocacy

Make your voice heard

— speak out about arthritis treatment and care in Canada

"How can government decision-makers reach effective conclusions without valuable input from all affected? The short answer is, they can't." BEST MEDICINES COALITION

Arthritis Consumer Experts believes that the most important voice in discussions about health care belongs to those most affected by health policy—the person living with chronic disease (or "consumer"). As people living with chronic disease, consumers can provide critically important perspectives in discussions about health policy; yet too often, consumers' voices are not heard.

Think about it. Who has a more intimate understanding of the strengths and weaknesses existing in the health care system than a person who must navigate it daily? Who knows more about the importance of being able to access the very best, most effective medicines? Who knows more about the damage that poorly considered health policy can do to flesh and bone? Who cares more about your quality of life—your ability to work, care for your family, and participate in society? The answer to all of these questions is clear: You do.

Increasingly, government makes decisions based on the financial bottom line, not in the best interests of consumers or based on current "best clinical practice" standards. They routinely make decisions behind closed doors—decisions which directly affect the health and quality of life of consumers.

For these reasons and many others, consumers must work to make sure their voices are heard and that their interests are protected. Arthritis Consumer Experts does this every day,

and we need your help. **Join us—speak out about arthritis treatment and care in Canada.**

As the people most affected by these decisions, people living with disease must look for ways to be heard, and take every opportunity available to advocate for fairness and excellence in health care. You can advocate to government, state your opinions in the media and participate whenever possible in consultation processes with health care decision makers.

This February edition of JointHealth monthly is dedicated to giving you the tools you need to become an arthritis activist. Included is a pull-out "tip sheet" designed to help you write letters to government and the media, and speak effectively to health care decision makers. Also, because we know that facts and numbers serve to support your arguments, we are including two pages of important facts about arthritis treatment and care in Canada, as well as the key messages about medications that we believe that decision-makers need to hear.

We know that government is always looking for solutions that make financial sense, and we believe that creating a health care system that provides the best possible treatment and care to people living with chronic disease makes sense, socially and economically. We hope you will join with us to make sure that the people making the decisions get that message—loud and clear.



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“Every Canadian must be aware of arthritis.”

— Standard #1: Alliance for the Canadian Arthritis Program

At Arthritis Consumer Experts, we believe

that people living with arthritis must play an active role in making every Canadian aware of arthritis – including government and others who help to develop health care policy. People living with arthritis who depend on the health care system to live—and live well—must be heard.

Following is a list of arthritis facts and key messages that will help you speak out at government, to health policy makers and to the public media. **Remember, concrete facts and numbers add power to your arguments.**

Arthritis facts:

- 1 in 5 Canadians have arthritis – 4 million in total.
- 3 out of 5 Canadians with arthritis are under the age of 65.
- Arthritis is a term used to describe over 100 different diseases.
- Researchers do not know what causes any type of arthritis; there are no known cures.
- Only 1.3% of the federal health research budget is dedicated to arthritis, yet arthritis is responsible for approximately 10.3% of the overall cost of health care in Canada.
- Osteoarthritis is the most common type of arthritis – it can affect people of all ages.
- Rheumatoid arthritis, psoriatic arthritis and

ankylosing spondylitis are inflammatory types of the disease; they are deforming, significantly reduce a person’s quality of life, and can be life-threatening.

- Arthritis is the leading cause of long-term disability in Canada, costing the government \$16.4 billion each year.
- Arthritis is the number one reason a person over the age of 65 visits their family physician.
- The chance of developing arthritis increases with age, but more serious types of the disease can strike babies and people in the prime of their lives.
- Only biologic response modifiers stop or delay the devastating bone and joint damage caused by inflammatory arthritis.

Message:

Public insurance coverage for the best medications should be seen as a strategic investment in patient health. Allowing patients to access the most appropriate medications reduces costs elsewhere in the health system.

FACTS:

- Every dollar invested in new medicines saves the health care system seven times that amount in other medical areas (Lichenberg, 2001).

- Early treatment with medications can reduce the short- and long-term costs associated with arthritis. Early treatment can:
 - i. Control aggressive forms of the disease
 - ii. Minimize the need for on-going tests and procedures
 - iii. Reduce the need for hospitalizations and visits to physicians
 - iv. Delay or eliminate the need for some joint replacement surgeries, relieving pressure on our growing waitlists
 - v. Decrease costs associated with intermediate and long term care.
- Spending on medications is associated with improved health outcomes for Canadian citizens (Cremieux et al. 2005).

Message:

Ensuring that effective arthritis treatments are accessible for all Canadians is good for Canada’s economy.

FACTS:

- Arthritis is the leading cause of disability for people over the age of 15.
- Arthritis and musculoskeletal conditions are the leading cause of long-term work disability in Canada and the US, with a yearly cost of \$13.7 billion in Canada.
- In rheumatoid arthritis, reported rates of work disability are remarkably high: 32% to 50% 10 years after onset, and 50% to 90% after 30 years. Studies have shown that work disability starts early in the course of rheumatoid arthritis (Lacaille).
- Treating people with rheumatoid arthritis with biologic response modifiers helps them stay at, or return to, work (Yelin et al. 2003).

Message:

The drug review process in Canada is inefficient and costly, limiting and delaying treatment options for patients across Canada.

FACTS:

- It takes over 700 days for new drugs to be reviewed for use in Canada. This is double the length of time the Federal government has set for itself as acceptable, and significantly longer than it takes in the United States, Britain and Australia.
- The Common Drug Review was established

Spotlight on rheumatoid arthritis

Based on British Columbia (BC) Ministry of Health data, the number of new cases of rheumatoid arthritis in BC per year was 2,422 in the late 1990s. Based on current demographics, the incidence of rheumatoid arthritis is rising; the rate of permanent disability is rising as is the incidence of co-morbidities resulting in death. This alarming trend is due in part to significant delays in access to diagnosis and specialist care, and highly restricted access to the latest treatments targeted at the molecules that promote inflammation and destroys joints and other vital organs such as the lungs, eyes and heart.

By comparison, there were approximately

2,860 new cases of breast cancer in BC in 2006, the incidence rate is now steady and deaths as a result of breast cancer are declining – the latter as a result of the development of new, tumor targeted therapies and timely access to all types of treatments, including specialist care.

Rheumatoid arthritis is as common as breast cancer in British Columbia yet people diagnosed with it are receiving mediocre care for their disease. People with breast cancer in BC are being treated and cured, while people with rheumatoid arthritis are being told they cannot have the best treatments or care available. They are left to languish in the prime of their life, and tragically, to die prematurely.

to “streamline” the drug review process in Canada. It has now become an added step in the review process, inserting itself between the Health Canada review and the provincial formulary reviews, further delaying access to effective medications by 17-24 weeks.

- As of May 2006, 40 drugs have been reviewed by the CDR; 22 of these have not been “recommended for coverage”.

Message:

Reference-based pricing policies are being implemented across Canada to attempt to reduce health care costs, but these policies are denying patients access to physician-prescribed medicines.

FACTS:

- Reference-based pricing is based on the idea that all drugs within a given class of medications (for example, non-steroidal anti-inflammatory drugs) deliver the same benefit for every patient. Under reference based pricing, a drug plan will pay only up to the level of the least expensive medication in the class. If the patient and their physician determine a different medication in that class is needed, the patient has to pay the difference from their own pocket.
- Reference-based pricing limits patient access to medications by forcing them to pay for medications that are not covered on provincial and federal drug formularies.
- Reference-based pricing creates inequity and lack of access based on one’s ability to pay and their province of residence.

Message:

Pharmacare programs from province to province are inequitable; most provinces severely restrict access to breakthrough treatments. All Canadians should have equal access to prescription drug coverage for the best medicines.

FACTS:

- The average time to list medications on provincial drug formularies ranges from 327 days in Nova Scotia to 503 days in BC and 565 days in New Brunswick.
- People with ankylosing spondylitis living in Quebec have provincial insurance coverage for both etanercept (Enbrel®) and infliximab

(Remicade®); those living with the same disease in British Columbia have no provincial insurance coverage for either drug.

- Each of the 13 provincial and territorial drug plans and several federal drug programs have independently defined its own eligibility requirements, levels of coverage, and reimbursement criteria creating inequity across the Canada.
- Currently over 600,000 Atlantic Canadians do not have any drug coverage.
- Research has shown that better health benefits are seen in provinces with higher drug spending (Cremieux et al. 2005).
- Provincial pharmacare programs require patients to “fail” a host of less effective, less expensive medications before providing coverage to the latest, often best, new medications.

Message:

Drug formulary decisions must be based on scientific evidence, clinical expertise, and the health experiences of patients; these decisions must not be based on economics alone.

FACTS:

- The clinical experience of physicians that work directly with patients, and see the benefits of medications, must be included in drug budget decisions.
- Rheumatologists are medical experts at treating arthritis, yet all provincial drug formularies in Canada restrict their ability to prescribe medications for their patients.
- Research shows that financial benefits from wise health care spending are growing in other areas of government budgets but are not being reinvested in health care budgets.

Message:

Patients and members of the public need to be involved in decision-making regarding health policy governing access to medications

FACTS:

- Despite suggestions in both the *Commission on the Future of Health Care in Canada* (Romanow) and *The Health of Canadians – The Federal Role* (Kirby) reports to include the public and patients in health decision-making,

there continues to be a lack of transparency and public inclusion in health care system reform.

- Research has shown that the public wants to be involved in health care decision making and can be a “critical ideal source” of identification of values to guide the health care system. (Abelson and Eyles 2002)
- Consumers and patients can positively influence their own health outcomes if they are actively involved in shared decision-making and provided with quality information and appropriate self-management tools (Abelson)
- Patients, consumers and the public are the only ones able to speak from the perspective of living with disease and the impact of treatments on their quality of life.

Spotlight on BC

Key message:

British Columbia’s PharmaCare program has one of the poorest performing review processes in Canada.

FACTS:

- The backlog of drugs under review in BC has grown from 22 to 60 in just two years.
- British Columbians living with chronic diseases like arthritis are receiving poorer care than other Canadians due to highly restrictive coverage of the best medications.
- BC takes longer than all but one province to make new medications available.
- PharmaCare spends just 7% of BC’s health budget on medications.
- In BC, reference based pricing result in reduced patient choice, forced switching between medications (often from an innovative medicine to a generic) and patients stopping treatment.
- Policies in British Columbia that require patients to “co-pay” for part of a medication’s cost drives up costs by increasing visits to physicians and emergency rooms (Lacaille), and forces the elderly and the poor to stop taking their medications and causes death (Anis).

Become an arthritis activist

This pull-out sheet is designed to be used as a “tool” for people with arthritis, their family members and friends. Included is information about effective ways to speak out on arthritis treatment and care in Canada.

Presenting yourself well, in writing or in person, makes it more likely that government, health care decision makers, and media will listen to what you have to say.

As a person living with illness, you have the right to speak and be heard about the issues that profoundly affect your health care and your life.

You deserve to be heard, and writing and speaking effectively will help to make that happen.

Expressing Your Views to Government and Health Care Decision Makers

It may seem like a small gesture, but writing a letter to an elected official or key decision-maker is one of the most effective ways of communicating the public view. Elected officials need to be continually reminded that their constituents are paying attention to the critical decisions they make.

While a quick, informal e-mail missive may seem easiest, a single handwritten or typed letter will have much more impact.

Here are a few guidelines to keep in mind when preparing your letter:

Composing your letter

1. Prepare your letter in a way that reflects the importance of the issue and your message.
2. In the first paragraph, introduce yourself and state the reason you are writing, and why it is personally relevant to you and your community. Keep the first paragraph to three sentences, at most.

3. In the next paragraph, provide specific details about the issue, and why it's important to you and your community. Remember that facts and numbers help to support your argument.
4. Offer constructive solutions. Once you've outlined the problem, discuss what action you would like to see taken to resolve the issue. Support your proposed solutions with facts and examples, if possible.
5. Try to keep the letter to one page – one and a half, at most – but still allow yourself to make the points that you think are most important to you and your community.
6. If you have more than one issue to raise, send more than one letter – keep each letter focused to one issue if at all possible.
7. Close the letter by restating the action you would like to see taken and when, and thank them “in advance” for taking the action you recommend.

General Tips on Letter Writing to Elected Officials

1. Be respectful, but make your points clearly and very firmly.
2. Prepare your correspondence in a way that does not threaten the security of your elected representative, staff or anyone related to him or her.
3. Do not rant or be abusive.
4. For issues related to the delivery of, or access to, provincial health care, write to your provincial Minister of Health and send copies of the correspondence to your local Member of the Legislative Assembly (“MLA”). You can find your Minister of Health's mailing address on your provincial government's web site.
5. If you are writing about a federal health care issue, write to the federal Minister of Health and send a copy of your letter to your local federal Member of Parliament (“MP”). You can find your local MP's mailing address on the federal government's web site http://canada.gc.ca/directories/direct_e.html
6. Be sure to spell the person's name correctly, and include their official title.
7. Always remember to sign your letter, and below your signature, provide your full occupational title/position, residential address (more important than a post office box number since politicians need to know if you live in their riding), and postal code. Make sure you put your return mailing address on the envelope, as well.
8. NO STAMP is required for correspondence to a Member of Parliament, the Prime Minister or a Senator (Canadian federally elected/appointed officials).
9. A stamp IS REQUIRED for correspondence with a provincial or municipal elected official (MLA, Premier, Councilor/Alderman, or Mayor). A stamp is also required for correspondence with government staff.

Speaking to Government and Health Care Decision Makers

From time to time, people living with arthritis are given the opportunity to address key members of government and other health care decision-makers. It is critically important that members of the arthritis community make the most of these opportunities; as people living with the disease, your voices are vitally important in the fight to get the best possible treatment and care into place for Canadians living with chronic disease.

Here are a few tips for speaking effectively to government:

1. Dress respectfully; a speaker who is sloppily attired is given less attention and respect than one who looks "pulled together" or professional.
2. Speak clearly and with confidence; remember that you possess a vitally important perspective, and you have every right to be heard.
3. Remain calm. Health is often a very difficult, emotional issue to discuss, but avoid shouting and ranting. Know that your facts and messages, supported by your experience with disease, give your words more weight than yelling ever could.
4. Know what you are going to say—do not ramble. Have your key points outlined on a piece of paper if you find this helpful, but do not read or memorize a speech.
5. Introduce yourself, and give a brief outline of your experience with disease – no more than 1 or 2 minutes in length. The purpose of speaking to government is not to tell your story or gain sympathy; rather you are outlining a problem and providing suggestions about concrete solutions. Your disease gets you through the door, but once you are through, you are speaking on behalf of thousands and millions of people like you.
6. Outline the points you are going to make, and then clearly elaborate on each one.
7. Support your arguments with accurate facts and numbers.
8. Be as brief as you can, while still providing all of the necessary information.
9. When you finish speaking, thank your listeners for their attention, invite them to ask you questions, and tell them that you look forward to seeing concrete progress on the issues you have discussed.

Writing a Letter to a Newspaper

1. If you are writing a "letter to the editor" of a newspaper in response to an announcement or news item, do it quickly – the same day or next day is best. Letters that go in three or more days later typically do not get published because the interest in the news item is less.
2. Letters to the editor should not exceed 250 words; as such, your letter needs to be "to the point".
3. Remember that facts and numbers help to support your argument.
4. Send a copy of a letter you write to your elected official to your local, provincial, or national newspaper as well.

At right is a letter that was published in the National Post to use as an example. It was written in response to a story about a woman living in New Brunswick whose expensive arthritis medication is not being covered by her province's drug benefits plan.

<http://www.arthritisconsumerexperts.org/pdfs/natpostnov29.pdf>

Wilhelm's not alone

Re: "My One Hope Was This Drug" November 28.

Sadly, Linda Wilhelm's story is one of over 40,000 stories of Canadians living with severe rheumatoid arthritis fighting to get the medications and health-care services they desperately need to function, let alone live any semblance of quality of life.

Tragically, in Alberta, Prince Edward Island and Ms. Wilhelm's home province, New Brunswick, the fight for access painfully drags on. Neither Enbrel nor Remicade have been placed on the provincial drug benefit plans. The ministers of health in these provinces should hang their heads in shame for allowing this to happen.

Let us hope the Romanow Report brings transparency, accountability and public participation as key ingredients of the "cure" it will prescribe for Canada's chronically ill health-care system. Otherwise, Canadians like Ms. Wilhelm will have witnessed millions of dollars being thrown out the government window rather than paying for drug coverage for catastrophic and chronic illnesses such as rheumatoid arthritis.

Cheryl Koehn, president, Arthritis consumer Experts, member organization, Best Medicines Coalition, Vancouver.

Listening to you

We hope you find this information of use. Please tell us what you think by writing to us or emailing us at info@arthritisconsumerexperts.org. Through your ongoing and active participation, ACE can make its work more relevant to all Canadians living with arthritis.



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Arthritis Consumer Experts

Who we are

Arthritis Consumer Experts (ACE) provides research-based education, advocacy training, advocacy leadership and information to Canadians with arthritis. We help empower people living with all forms of arthritis to take control of their disease and to take action in health care and research decision making. ACE activities are guided by its members and led by people with arthritis, leading medical professionals and the ACE Advisory Board. To learn more about ACE, visit

www.arthritisconsumerexperts.org

Guiding principles and acknowledgement

Guiding Principles

Health care is a human right. Those in health care, especially those who stand to gain from the ill health of others, have a moral responsibility to examine what they do, its long-term consequences and to ensure that all may benefit. The support of this should be shared by government, citizens, and non-profit and for-profit organizations. This is not only equitable, but is the best means to balance the

influence of any specific constituency and a practical necessity. Any profit from our activities is re-invested in our core programs for Canadians with arthritis.

To completely insulate the agenda, the activities and the judgments of our organization from those of organizations supporting our work, we put forth our abiding principles:

- ACE only requests unrestricted grants from private and public organizations to support its core program.
- ACE employees do not receive equity interest or personal "in-kind" support of any kind from any health-related organization.
- ACE discloses all funding sources in all its activities.
- ACE identifies the source of all materials or documents used.
- ACE develops positions on health policy, products or services in collaboration with arthritis consumers, the academic community and health care providers and government free from concern or constraint of other organizations.
- ACE employees do not engage in any personal social activities with supporters.
- ACE does not promote any "brand", product or program on any of its materials or its web site, or during any of its educational programs or activities.

Thanks

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ACE thanks these private and public organizations.

Disclaimer

The material contained in this newsletter is provided for general information only. It should not be relied on to suggest a course of treatment for a particular individual or as a substitute for consultation with qualified health professionals who are familiar with your individual medical needs. Should you have any health care related questions or concerns, you should contact your physician. You should never disregard medical advice or delay in seeking it because of something you have read in this or any newsletter. <


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