JointHealth™ monthly
Arthritis research, education and advocacy news : September 2008

Every month is arthritis month

For people who live with arthritis, every month is arthritis month. Every day is arthritis day. Every minute can be filled with excruciating pain, devastating disability, and debilitating fatigue. The effects of arthritis can impact on every area of the life of a person with the disease.

September is National Arthritis Month in Canada, and it is time to take action. For far too long, arthritis has been a misunderstood or overlooked disease—the "poor cousin" in terms of public awareness and government attention to other serious chronic diseases, like diabetes, HIV and cancer.

> *"Change is coming, and now is the time to make sure that the voice of arthritis is heard from people with disease from coast to coast."*

Each month, ACE receives story after heart wrenching story of the impact of arthritis on the lives of people across Canada and around the world. We are so grateful to receive these stories; we learn from them and they are an inspiration to each member of the ACE team and the motivation for everything we do.

Today, we are asking you to share your stories with your elected representative as well; in a letter, a phone call, a personal visit to a constituency or legislative office. Do not be afraid that your experience is not important or that you will not be heard—your story, in your own words, is one of the most powerful tools we have to generate change at the government level. Remember that elected officials work for each of us; their job is to protect our human rights and make health policy that meets our needs—fairly, equitably, and in a timely and respectful manner.

Elected representatives across the country are starting to take notice of arthritis issues; in meeting after meeting, arthritis groups and individuals with disease are speaking face-to-face with those people elected to represent our interests, and they have heard the story of arthritis loud and clear. Change is coming, and now is the time to make sure that the voice of arthritis is heard from people with disease from coast to coast.

This past spring, BC MLA Scott Fraser spoke in the BC legislature about arthritis and the role that governments can play in creating a world where each person with arthritis is treated fairly. In his statement, Mr. Fraser outlined the extent of the arthritis crisis in BC and concluded: *"Here is what we need to do: British Columbians must be made aware of arthritis. We need education. All relevant health professionals must be able to perform standardized age-appropriate screening assessment. They need education. Every British Columbian must have timely and equal access to appropriate treatments and medication. We as legislators definitely have a role to play in ensuring that all of this happens."*

Statements and commitments like this come only when the true story of arthritis is told. The human costs of arthritis are impossible to ignore when a real person tells a true story.

Contact information for all elected representatives in Canada can be found at http://www.jointhealth.org/takingaction.cfm

JointHealth Monthly is available in print and online in English and français.

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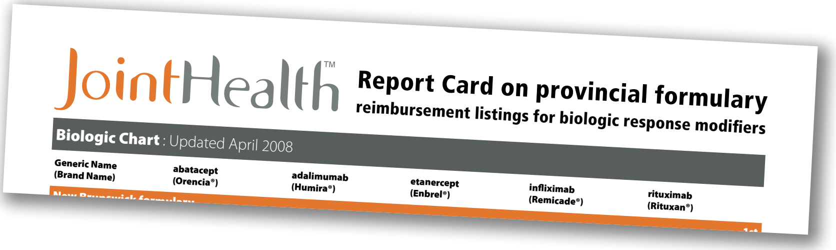
ACE does not promote any "brand", product or program on any of its materials or its web site, or during any of its educational programs or activities.

The ACE campaign to end discrimination against people with arthritis



JointHealth™ **Report Card on provincial formulary**
reimbursement listings for biologic response modifiers

Biologic Chart : Updated April 2008

Generic Name (Brand Name)	abatacept (Orencia®)	adalimumab (Humira®)	etanercept (Enbrel®)	infliximab (Remicade®)	rituximab (Rituxan®)

Last year, the September/October issue of JointHealth™ monthly presented the first ever JointHealth™ Report Card on Provincial Formulary Listings for Biologic Response Modifiers. With that first report card, ACE launched a campaign to inform governments in every province and territory across Canada about the importance of listing medically necessary gold-standard medications for inflammatory arthritis.

This campaign has brought evidence-based information about arthritis treatment, in lay language, to elected representatives and other health care decision-makers from coast to coast. In letters, emails, and face-to-face meetings, ACE has provided the information necessary to help governments make good decisions about medications for people who live with arthritis.

In this issue of JointHealth™ monthly, Arthritis Consumer Experts is proud to be able to present a report on the journey to win back the health care rights of Canadians with arthritis.

The road travelled

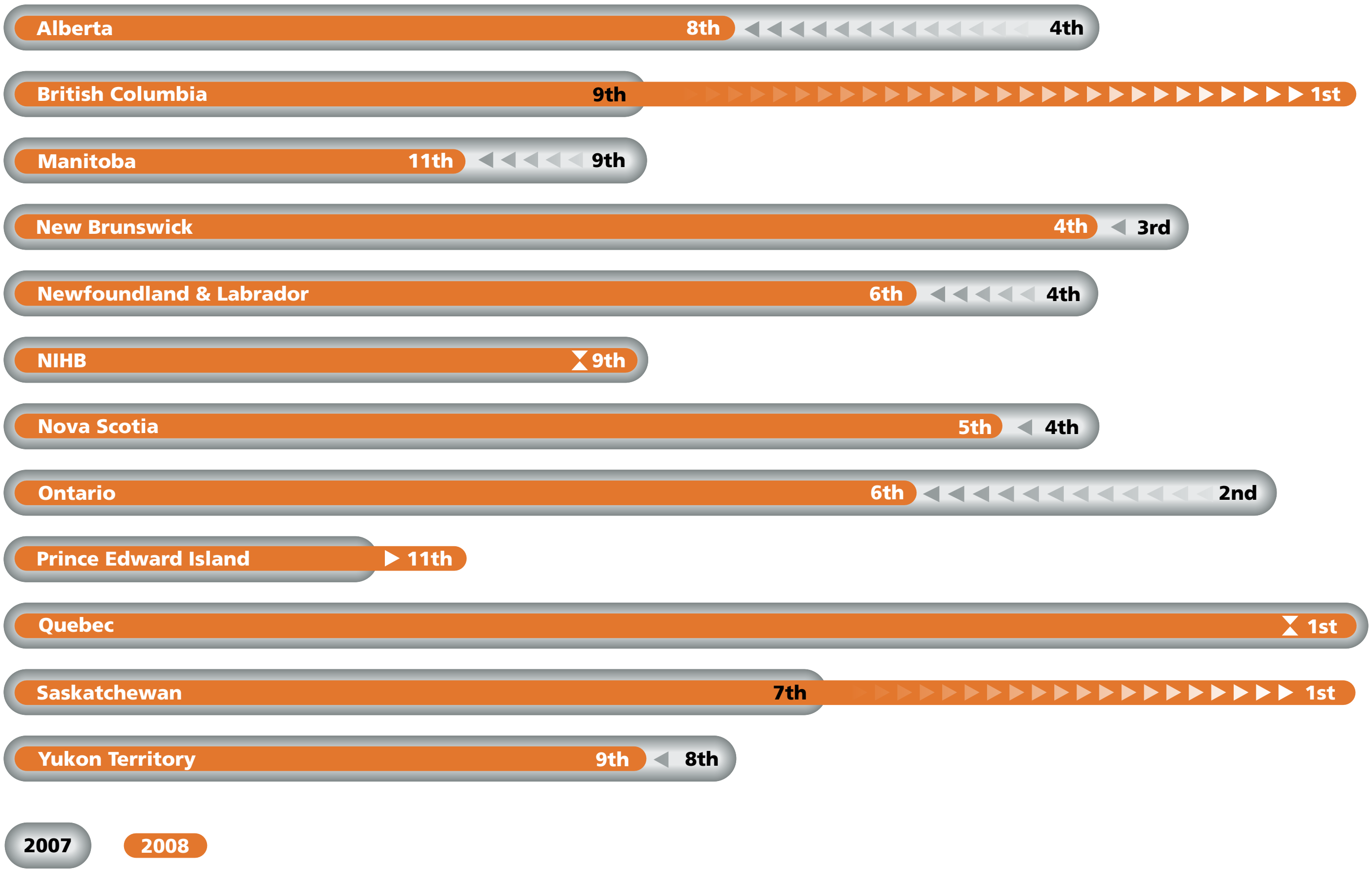
As we look back over the past year, ACE is thrilled to be able to say that great strides have been made towards the day when people who are diagnosed with inflammatory forms of arthritis who need it will have public reimbursement coverage for the medications their doctors prescribe—in every province, for every form of arthritis, regardless of ability to pay.

Since the publication of the first JointHealth™ report card:

- Governments in provinces across Canada have made 26 positive formulary listing decisions for biologic response modifiers
- Three provinces—BC, Saskatchewan, and Quebec—now list every approved biologic for rheumatoid arthritis, ankylosing spondylitis, and psoriatic arthritis
- Nine provinces and territories have made at least some progress in biologic listings
- Thousands more people across the country have coverage for medications they need.

While significant progress has been made, a tremendous amount of work remains to be done. Forty-seven listings on nine publically funded benefit plans need to occur to ensure equality in treatment for people living with inflammatory arthritis.

Remarkably, the largest province in the country – Ontario – has not listed abatacept (Orencia®) for rheumatoid arthritis, adalimumab (Humira®) for ankylosing spondylitis, or infliximab (Remicade®) for psoriatic arthritis. In addition, rituximab (Rituxan®) is listed in a manner that



is inconsistent with the scientific evidence and compared to certain provinces. This means that people with inflammatory arthritis in Ontario are being discriminated against, as they are not being provided coverage for the full range of treatment options. On the other hand, people in British Columbia, Saskatchewan and Quebec are able to obtain coverage on their public drug plans for these and all other approved biologics. And while provinces like British Columbia and Saskatchewan have risen in the rankings, others like Ontario and Alberta – the richest province in the country with an estimated $8.5 billion dollar budget surplus – have dropped significantly. In other words, while many provinces are progressing steadily, people in other provinces are being left behind.

As you can see, some provinces have made noticeable gains; today, Saskatchewan and BC are tied for first place in the country, while last October they were seventh and ninth respectively. Sadly, other provinces like Ontario and Alberta have plummeted in our rankings, from first to sixth and fourth to eighth, respectively. People in these provinces are being left behind, and ACE will continue to make these provinces a focus of our work in the coming months.

The road ahead

With forty-seven listings remaining incomplete across the country, significant work remains to be done. People in the lowest-performing provinces, including Ontario, Alberta, the Yukon, Manitoba, and Prince Edward Island, as well as people covered under the Non-Insured Health Benefit (NIHB) are still facing treatment discrimination when it comes to reimbursement coverage for biologic response modifers. This means that a person with disease in one province will have coverage for a medication they need, and someone in another province with the same disease will be left in the cold.

This year, ACE will be working to inform and engage the elected representatives, policy advisors, and other health care decision-makers in these lowest-ranking provinces. As a community, we need these people to understand arthritis, and the facts around reimbursement coverage for medically necessary medications.

Through media work, letter-writing campaigns, and face-to-face meetings with decision-makers across the country, ACE will be telling the true story of arthritis, and we need your help. Please write to your elected representative, and tell him or her that you are watching to see how your government treats people with arthritis. You can find contact information for your elected representative at http://www.jointhealth.org/actioncentre-tellapolitician.cfm.

ACE Year in Review

Arthritis is a vastly misunderstood group of diseases. Time and time again, we hear from people with arthritis who are told, by employers, friends, and even family members, that arthritis is just a minor disease that naturally goes along with growing older. Arthritis Consumer Experts is committed to telling the true story of arthritis, and has undertaken a campaign to raise public and government awareness of the real human, social, and financial costs of the disease.

Since November 2007, ACE held two press conferences drawing attention to the discrimination against arthritis; disseminated nine major press releases, covering a range of topics including the Report Card, the burden of arthritis on aboriginal populations and discrimination against people with arthritis in Alberta, Saskatchewan and Ontario, gaining unprecedented print, television and radio news media coverage of arthritis issues championed at the "grassroots" level. As it should, ACE's work gave voice to the real life concerns of people living with arthritis from across the country.

But much more work remains to be done. Arthritis Consumer Experts remains committed to the day when no person with arthritis will have to hear someone say "arthritis isn't such a big deal". This year we have seen positive steps toward that goal, and with the help of our community members and partners, the voice of arthritis will continue to be heard.

Over the past year, countless individuals and organizations have supported the work ACE has been doing through donations of time, expertise, money, and moral support. People with arthritis, clinicians, researchers, and public figures across Canada and around the world have joined with us to speak out on arthritis issues. Here are just a few examples:

- Hugh O'Reilly, a noted human rights lawyer, participated in our press conference on discrimination in Saskatchewan, which was held in November 2007, and the press conference launching the report card in January. Hugh believes that discrimination against people with arthritis must be eliminated, and that there is a strong case to be made that restrictive medication formulary listing practices constitute a human rights violation.
- Dr. John Esdaile, Scientific Director of the Arthritis Research Centre of Canada, accompanied ACE to Ottawa in January 2008 to help us launch the report card. Dr Esdaile spoke powerfully at the press conference and in newspaper and radio interviews, and was a key participant in our meetings on Parliament Hill.
- Dr. Heather McDonald-Blumer, a Toronto rheumatologist, participated in our May 2008 press conference in Toronto drawing attention to Ontario's discriminatory medication listing practices. Dr. McDonald-Blumer spoke passionately about the benefits of biologics and said that as a physician, when she learns that a patient in Ontario does not have private insurance, she feels very anxious about that patient's chances for recovery.
- Sue Borwick, vice-president of the Canadian Arthritis Patients' Alliance (CAPA) joined us in Toronto, and reinforced the message that people with arthritis deserve to be treated respectfully, and have equal coverage for necessary medications.
- Ken Mulholland of the Canadian Spondylitis Association spoke out in numerous ACE press releases supporting our advocacy work this year related to ankylosing spondylitis and psoriatic arthritis.
- Dr. Kam Shojania, a Clinical Assistant Professor in the Faculty of Medicine and Head and Director of Continuing Medical Education, Division of Rheumatology at UBC, provided clinical expertise and advice.

Sincere thanks go out to these individuals and everyone who have worked with or supported ACE over the past year to ensure that people with arthritis are afforded the same level of health care as those living with other diseases.

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.jointhealth.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

ACE thanks the Arthritis Research Centre of Canada (ARC) for its scientific review of JointHealth™.

Acknowledgement

Over the past 12 months, ACE received unrestricted grants-in-aid from: Abbott Laboratories Ltd., Amgen Canada / Wyeth Pharmaceuticals, Bristol-Myers Squibb Canada, GlaxoSmithKline, Hoffman-La Roche Canada Ltd., Merck Frosst Canada, Pfizer Canada, Schering-Plough Canada, and UCB Pharma Canada Inc. ACE also receives unsolicited donations from its community members (people with arthritis) across Canada.

ACE thanks these private and public organizations and individuals.

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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