Summit on the Value of Medicines
Summary Report and Submission to the Conversation on Health

July 9, 2007
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Executive Summary

On February 24, 2007 more than 310 patients/consumers, health care professionals, chronic disease non-profit association administrators and industry representatives gathered for the Summit on the Value of Medicines in Vancouver.

The purpose of the Summit was to raise awareness and evoke action among all attendees to participate in the Conversation on Health and make their voice heard around the deficits in BC’s PharmaCare drug program.

Through impassioned patient testimonials, compelling evidence from a health economist and clinical frustrations and first-hand experiences from a Vancouver endocrinologist, attendees were informed and encouraged to communicate the same key message to elected officials.

That key message is:

PharmaCare should be seen as a strategic investment in better patient outcomes -- PharmaCare is focused on the cost of medications rather than the value of medications. Access to medications improve health outcomes and generate savings through effective cost utilization.

Attendees were encouraged to take their access to medication stories and relay that with the key message in a variety of mediums...

1. Participate in the Conversation on Health
2. Write the Premier and Minister of Health
3. Contact their MLA and ask to meet with them to discuss access to medications issues.
Section 1: Background

Drug review/approval process:
Drugs are approved for use in Canada through a process called the Common Drug Review (CDR.) Once drugs are approved, it is up to each province to decide whether to add them as a benefit under their respective drug plans.

BC takes longer than just about any other province to make a listing decision, and often that decision is to deny coverage. BC has a parallel process to the CDR called the Therapeutics Initiative (TI.)

As a result of the duplicate system, there exists a backlog of much needed drugs waiting for listing in BC.

The TI does not make public the rationale behind its listing decisions and often does not call on the advice of disease-specific experts and consumers in making the listing decisions.

Formation of Better PharmaCare Coalition:
• Founded in July 1997;
• Formed in response and opposition to Reference-Based Pricing and Therapeutic Substitution policy implemented under the previous NDP governments PharmaCare program;
• Membership is currently comprised of 18 national and provincial health, professional and consumer organizations.

Chronicle of the Better PharmaCare Coalition efforts to date:
The Better PharmaCare Coalition members have worked tirelessly as a group and on behalf of their respective organizations to achieve a more transparent provincial drug program that puts the needs of the patient first.

Examples of BPC activities...
• Hosted an MLA breakfast (then Minister of Health, Colin Hansen, was in attendance)
• Private meetings held with the last three Ministers of Health
• Meeting held in the Premier’s office
• Media conference in February 2005 that generated extensive coverage
• Participated in Premier’s Summit in July 2005, where the Premier, Minister of Health and Deputy Minister heard from BPC members and medical experts on how to improve BC’s PharmaCare program.

After more than 1 ½ years had passed since the Premier’s Summit and with still no tangible improvement to BC’s performance, the BPC members decided to take the issues once again to the public.
Section 2: The Summit on the Value of Medicines planning process.

In November 2006, members from the Better PharmaCare Coalition and a few other interested parties met to discuss combining resources to host a public forum on access to medication issues.

The purpose of the Summit was to inform, educate and motivate individuals to take action through participating in the Premier’s Conversation on Health and making their voice heard about the value that improved access to medications and timely approvals to new medications make in managing their chronic disease(s.)

The Summit was designed for patients, caregivers, health professionals, and other British Columbians concerned about the future of health care and the potentially negative impact of PharmaCare policies.

The planning partners consisted of representatives from the following organizations:

Arthritis Consumer Experts, BC Lung Association, Better PharmaCare Coalition, Canadian Arthritis Patient Alliance, Canadian Diabetes Association (Pacific Division), Canadian Society of Intestinal Research, Heart and Stroke Foundation, BC/Yukon Division, Mood Disorder Association of BC, Osteoporosis Canada, BC Division, Parkinson Society of BC, SmartCare for Western Canadians Living with Chronic Obstructive Pulmonary Disease (COPD), and The Arthritis Society, BC & Yukon Division.

Each planning committee representative agreed to participate on the planning committee, support the Summit financially by making a contribution to offset expenses and to target their own membership base in the marketing and promotion of the event.

In addition, unrestricted educational grants from other organizations were secured to offset additional Summit expenses. These grants were given with no conditions and representatives did not participate in the Summit planning process.
Section 3: Key Messages

Why is the Summit on the Value of Medicines necessary?

Key Message

- PharmaCare should be seen as a strategic investment in better patient outcomes -- PharmaCare is focused on the cost of medications rather than the value of medications. Access to medications improve health outcomes and generate savings through effective cost utilization.

Supporting Messages

1. PharmaCare is limiting treatment options for patients -- Rather than striving for excellence and facilitating the delivery of better treatment options, PharmaCare is fostering mediocrity by limiting treatment options.

2. Patients are being increasingly denied access to new medications.

3. PharmaCare policies are going in the wrong direction. A policy of delay harms patients.

4. The PharmaCare program is deteriorating, increasingly working against patients rather than working for patients.

5. Investment in PharmaCare acts to avoid costs elsewhere in the healthcare system.
Section 4: The Summit on the Value of Medicines

Date: Saturday, February 24, 2007
Time: 1pm to 5pm
Location: Rocky Mountaineer Station, Vancouver, BC

Agenda & Speaker summaries:

Note: To receive hardcopies of individual presentations or to receive a DVD copy of the Summit, please contact Summit Project Manager, Pamela Gole at pgole@telus.net.

1:00 – 1:15 pm
We are all here for the same reason.
Dr. Ron Woznow, PhD

Ron Woznow is the Executive Director of The Arthritis Society, BC and Yukon Division. He is the former CEO of the Canadian Genetic Diseases Network.

Highlights from Dr. Woznow’s opening remarks:
- We all want better and timely access to medications routinely available to most Canadians through a publicly funded system that are denied to us in British Columbia;
- The PharmaCare program in BC should not be focused on cost-containment but focussed on what they can do to enhance health;
- This is the only program left over from the previous NDP government that the Liberals haven’t made more responsive to patient needs;
- Change will happen;
- Need to change how decisions are made as to what is covered – eliminate the secrecy and delays
- People want greater access to medications;
- Why has nothing happened? Access to medications doesn’t rate high on the polling scales.
1:15 – 1:20pm  
*Small steps for a giant change – working with our government to make a difference.*  
**Celine Pitre, Summit moderator**

Celine Pitre is a member of the Consumer Advisory Board of the Arthritis Research Centre of Canada and Principal of Celine Interiors Inc., Vancouver.

**Highlights from Celine’s opening remarks:**
- Today’s audience is made up of patients/consumers, caregivers, physicians, one MLA and industry representatives.
- The Summit is hosted by 12 different associations [referenced in participant package.]
- The goal for today is to provoke a change in which government officials think and act pertaining to PharmaCare policy.

1:20 – 1:30 pm  
*It’s not child’s play: living with juvenile arthritis.*  
**Logan Graham**

Logan Graham is a 12-year old who co-founded the Vancouver-based Children’s Arthritis Foundation when he was 6, proving that “no matter what age you are, you can always make a difference.”

**Highlights from Logan’s presentation:**
- I have had juvenile idiopathic arthritis for 9 years (he is 12 years old.)
- My parents spend $10,000 per year in expenses not covered by the medical system;
- Good medicines help;
- Kids grow – they need the right drugs at the right time. Even a short wait can make a big difference.
- Kids are waiting too long for approvals, too long for a decision on what drugs will go on the drug plan, too long for private health insurers to decide, too long for hospital procedures.
- Waiting for drugs costs more.
- Without the right drugs, kids grow up and cost the health system more.
1:30 – 2:00 pm
*PharmaCare patients at risk: practical solutions to a pressing problem.*
Brian Battison

Brian Battison is the coordinator for the Better PharmaCare Coalition, BC’s largest coalition of national and provincial health, professional and consumer advocacy groups.

**Highlights from Brian’s presentation:**
- Why are PharmaCare patients at risk?
- The PharmaCare mission statement is:

> *To improve the health status of British Columbians by providing reimbursement to ensure reasonable access to and appropriate use of prescription drugs and related benefit services for eligible residents of the province.*

- Who defines what is reasonable access? Who decides what is appropriate use?
- PharmaCare is supposed to provide equal access and equal treatment to the medications we need;
- The Better PharmaCare Coalition did an analysis of the PharmaCare and produced the findings in a 2005 report entitled “Does PharmaCare Pass the Drug Test?” [available at www.betterpharmacare.com]
- Many new drugs are not covered – we need to change that.
- Virtually every disease is negatively affected by PharmaCare delay;
- 91% of drugs are listed in one other province, 65% are listed in at least three other provinces, 52% are listed in at least five other provinces and 26% are listed in at least six other provinces.
- In listing drugs, BC is 9th out of 10 provinces in total listings, 9th out of 10 provinces in full listings and 8th out of 10 provinces in partial listings.
- We need PharmaCare policy makers to shift their thinking.
- Sustainability shouldn’t become an excuse for not trying harder.
- There are practical solutions that could generate $20 to $50 million in projected savings:
  - Make PharmaCare the payer of last resort;
  - Eliminate distribution up charges;
  - Lower generic drug prices – we would save $30 million annually if BC paid the same as Ontario for generic drugs.
- Stop trying to save money at the expense of patient care.
- Stop looking in isolation.
- An investment in PharmaCare saves money elsewhere in the system.
- Hire better and more efficient managers.
- PharmaCare is focussed on the cost, not the value.
- Make sure changes are not at the expense of the patient.
2:00 – 2:10 pm  
**Bankruptcy or begging? One patient’s story.**  
Lynn Macdonald


**Highlights from Lynn’s presentation:**

- All too often, patients on lower incomes must make impossible choices between satisfying fundamental human needs, such as eating, or buying expensive drugs that have not been approved by the BC drug formulary thanks to Reference Based pricing, but are essential to their health.

- **COPD/Spireva case example:**
  - 100% dependent on oxygen [up until Jan 2006];
  - January 2006 put on Spireva – within ONE week, off oxygen completely.
  - Spireva is not covered by PharmaCare and at $67/month it is beyond my means;
  - Now walking daily on a treadmill – if I was still on oxygen, there is no way I would be walking unassisted, but with a walker or scooter.
  - Yet the government of BC would sooner pay several hundred dollars for oxygen, concentrator rental, an OCD device, plus pay for medications that don’t work (approx. $470/month) – rather than approve a $67/month drug which has given me a vastly improved quality of life, better health and more independence.
  - Nine other provinces list Spireva.
  - Without this drug, my quality of life would rapidly degenerate.

- Medications can alleviate sickness, delay symptom progression and manage chronic disease;

- Medications save the health care system a great deal of money if they are used wisely and at the right time.

- Decisions should be patient-centred, taking account of the unique needs and therapeutic outcomes of individual patients;

- Pharmaceuticals should be evaluated, not in isolation, but as an integral part of the health system. They should be assessed in the context of the overall burden of illness and of their impact on direct and indirect illness costs and health sustainability.

- The decision-making process should be open, transparent and accountable and include all relevant stakeholders, including patients/consumers.
2:10 – 2:45 pm

Can we put a price on the value of medicines?
Dr. Pierre Cremieux, PhD

Dr. Pierre Cremieux is the Managing Principal of the Analysis Group in Boston and an Adjunct Professor at the University of Quebec at Montreal. His work on drug cost-effectiveness and the medical/workplace costs of illnesses and the value of medicine has been widely published.

Highlights from Dr. Cremieux’ presentation:

- Debate about whether the government should pay for drugs.
- Drugs have played a role in the decrease in the mortality rate of children since 1970;
- Life expectancy has increased dramatically since 1980 – not only, but largely due to drugs (3 years for men, 2 years for women.)
- Quality of life and length of life – drugs have an impact
- By not providing drugs, you [government] think you are saving money but can we put a value for the added years of life?
- An investment in drugs sees a ROI from reduced hospitalization
- Spend $1 on drugs, save $1.50 elsewhere
- Every time PharmaCare refuses to list a drug, they are spending money, not saving.
- BC stands to gain the most in Canada by increasing access to drugs.
- Concluding remarks:
  - 50% of the gains in life expectancy over the last 50 years has come from drugs;
  - The value in terms of life associated with these pharmaceuticals – the rate of return on drugs is greater than 1:1 (actually +20:1);
  - If you rely on drugs more heavily, you save money;
  - In Canada in 2005 – the average per capita spending on drugs is $65/month (about the cost of cable)
  - The government’s job is to be the patient advocate and get access to the best medicines at the best price.
  - Reason for drug listing decisions should be public knowledge.
2:45 – 2:55 pm

*Every day is a chemistry experiment.*

Rex Moore

Rex Moore is a freelance writer and public speaker who was diagnosed in 1993 with young onset Parkinson’s disease. He is an Executive Member of the Parkinson Society British Columbia’s Board of Directors.

**Highlights from Rex’ presentation:**

- I take 23 pills per day to stickhandle my illness [early onset Parkinson’s] = every day is a chemistry experiment for my body.
- I work with a neurologist to get the right combination for me.
- My family incurs additional expenses ranging from $5000 to $10,000 per year – fortunately my wife’s plan covers most of those additional costs.
- But that is not the case for everyone.
- Good quality drug therapy delays the need for long term care placement.

3:15 – 3:50 pm

*Timely access to the tools we need – a physician’s perspective.*

Dr. Hugh Tildesley, MD

Dr. Tildesley is an endocrinologist at St. Paul’s Hospital in Vancouver and a Clinical Associate Professor in the Department of Medicine at UBC.

**Highlights from Dr. Tildesley’s presentation:**

- All patients should be treated equally.
- There exists a strong incentive to provide new therapies for diabetes treatment – a business case supports it.
- The Common Drug Review (CDR) was supposed to streamline the drug approval process.
- The Therapeutics Initiative (TI – BC’s drug approval agency) is not transparent and are to advise PharmaCare = duplication of the CDR.
- Timeline to get a new drug to the patient - Trials take about 5 years, HMB takes another year, PMPRB 6 mos. To 1 year, the TI review is indeterminate and the PharmaCare listing decision is indeterminate.
- The system is set up for safety and price but forgotten is the customer/patient.
- The CDR has added at least 6 months to the process.
- Less than 50% of the provinces have bought into the process.
- Example: TZD vs. insulin
  - TZD have not been approved by PharmaCare = silo view of costs
  - Increased risk of emergency room visits with insulin patients due to hypoglycaemia.
- When you treat people properly it is in fact cheaper and you have to take all costs into account.
- Special authority forms:
  - Hypoglycaemia developed by some of these drugs that people have to go through to get on the latest drug treatments;
  - However, you don’t need to go through these hurdles if you have a private drug plan or are an MLA/MP.
- New diabetes drugs are coming down within 24 – 36 months:
  - Need to know how to use them; need to be able to individualize care and treatment
  - Need to organize quick approval
  - Need to organize post-release studies.
- I have a dream that one day:
  - Patients will have the right to use the best medicines in a timely manner;
  - Government will fund treatment in an equitable manner;
  - Government will have prompt and transparent processes in deciding on funding;
  - Government will remove excessive paperwork (by physicians for special authority);
  - Patients will have access to treatment without discrimination;
  - Government will understand the need for cooperation with those who treat the disease which is very complicated;
  - Time for refusing drugs which is based or biased on incomplete information is over.

3:50 – 4:00 pm

**Prescriptions, not incisions.**

Jay Fiddler

Jay Fiddler is a founding member of the Consumer Advisory Board of the Arthritis Research Centre of Canada and is currently co-chair of the Consumer Advisory Council of the Canadian Arthritis Network.

**Highlights from Jay’s presentation:**
- I was put on medications two years ago that changed my life.
- I have a form of inflammatory arthritis called Stills Disease – a disease that could have been destructive and disabling is now manageable and given me my life back.
- At age 29, I had to be carried everywhere, constant fevers, non-stop nausea and extreme weight loss.
- After 1 ½ years of searching and suffering, found a rheumatologist who put me on medications, which improved my daily living slightly but the x-rays showed a lot of degeneration. [put on queue for joint replacement surgery]
- Met an expert in my disease, who recommended a new drug that would change my life. However, this drug was not covered by BC’s
formulary or extended health plans and the cost was $12,000 per year = unaffordable for me and my family.

- I was kept on a drug that didn’t work for me but that was covered by PharmaCare and at three times the cost.
- Several surgeries later, I finally was able to get the new drug – not because it was listed on BC’s PharmaCare program but because my husband got a new job and his plan covered it.
- Now I work, I am finishing my PhD, I volunteer on two national committees and I started rock climbing again.
- When you invest in PharmaCare, you invest in your Province and your citizens. I would have been on disability for the rest of my life.
- It is important to challenge the government and important to stay informed.
- I want to see open, transparent and accountable decision-making.
- I want to see innovation and thoughtfulness in health care policy rather than just cost containment.
- If we think drugs are expensive, if we look at long term costs of under-treated or untreated chronic disease, it is going to be a lot more expensive.

4:00 – 4:45 pm
One person can change the world! How to make sure your voice is heard.
Sandy Struss

Sandy is a woman with diabetes who is an inspirational speaker by trade and a tireless patient advocate by choice. She believes everyone has an opportunity to make a difference – and a responsibility to speak up.

Highlights from Sandy’s presentation:

- After hearing all the presentations from today you may be overwhelmed, discouraged (what can I possibly do?), doubtful and jaded. Or you may be keen (how can we come together and be heard?)
- We are all here today because we have a desire to be a part of the bigger picture solution.
- When you are worried for your future, it limits what you feel is possible for yourself [recounting her personal challenge with diabetes and the future she saw for herself.]
- She was put on new insulin called Lantis – it worked.
- For the first time in 16 years, I had the promise of a healthy future that I didn’t think I had.
- The Common Drug Review turned down Lantis citing the cost.
- 1 emergency room visit (ambulance, hospital stay, staff) due to a hypoglaecemic reaction is about the same cost as one year of Lantis.
- NEVER GIVE UP
• This is not just about our lives – this is about the next generation so they aren’t sentenced to 1940’s medications when there are better ones available.
• PharmaCare is a joke. Until each one of us steps up, speaks out and participates in this conversation nothing is going to change.
• One action can be the tipping point [Rosa Parks story shared]
• Persistence – we are going to get a lot of no’s; the ones who don’t give up are going to win.
• Be the change you wish to see in the world [Gandhi.]
• The ripple effect of one person’s actions is immeasurable when you stand for something that is higher than yourself.
• What can you do?
  o Participate in the Conversation on Health
  o Write to the Premier and Minister of Health
  o Write and meet with your MLA
Section 5: Next steps

The Summit Planning Committee in partnership with the Better PharmaCare Coalition will continue to speak with and work with government and elected officials until the following is realized:

- The process by which PharmaCare receives, and acts upon, the advice they receive is changed.

- The rationale behind decisions not to list a drug on the BC provincial formulary is transparent and made available to all stakeholders.

- Consumers in British Columbia have timely access to the right medications for their disease management when they need them.