

Newsletter – Spring 2007

Important Patient Update re: Decisions Affecting Access to Nexavar and Sutent Provinces Need to Ignore the Common Drug Review

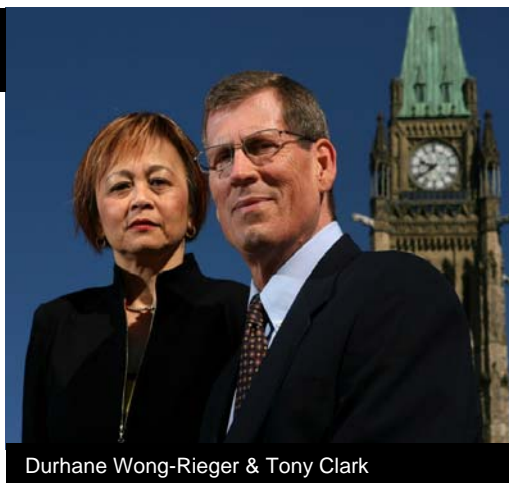
In late February the Common Drug Review (CDR), our national drug review agency, recommended government drug plans across Canada **NOT** cover Nexavar. Nexavar is a proven kidney cancer treatment approved by Health Canada, covered in 13 countries, and by most Canadian private drug plans, and is the first effective treatment for kidney cancer in 10 years.

In early May, the Common Drug Review also recommended that Sutent, another anti-angiogenesis drug for the treatment of kidney cancer, **NOT** be reimbursed by the provinces.

Our governments are obliged to ensure equitable, accountable and transparent access to health care for all Canadians – this was the original intent of CDR. Now, it is critical governments acknowledge that CDR is fundamentally flawed and patients are suffering as a result. **Provincial and territorial governments can decide to cover treatments independent of CDR recommendations, and must uphold their obligation to Canadians by covering these important new treatments** in the battle against kidney cancer.

Canadian Organization for Rare Disorders Newsmakers Breakfast

On April 24, 2007 at the National Press Club across from Parliament Hill, Durhane Wong-Rieger, President of the Canadian Organization for Rare Disorders (CORD), hosted a newsmakers breakfast where she challenged the Canadian government to respond to charges made by patients and families with rare disorders, such as renal cell carcinoma, that they are being unjustly denied potentially life-saving medicines.



Durhane Wong-Rieger & Tony Clark

Mr. Tony Clark, one of the co-founders of Kidney Cancer Canada, also spoke at the breakfast where he stressed the importance of breakthrough treatments for rare disorders by revealing that “I would not be here today without Nexavar, the disease is now stabilized, I am back at work and am enjoying life”. Commenting on the recent CDR recommendation that this drug not be reimbursed, Tony Clark said: “It is devastating that others suffering from Kidney Cancer might not have access to Nexavar”. Various lawmakers and policy influencers attended the breakfast including the Chairman of the Standing Committee on Health, Mr. Rob Merrifield, and Dr. Jo Kennelly, the Director of Policy to the Honourable Tony Clement, Minister of Health.

Contact Us

For more information about joining our volunteer organization, please contact:
Tony Clark, Chair: tonyclark@rogers.com (905) 828-6108
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Join Our Membership List

To stay informed about future meetings and important updates, please ensure that we have your correct email address and telephone number. Email this information to groupkidney@yahoo.com or mail to:
Dale Miron, Membership Manager: 880 Atwater Avenue, Mississauga, ON L5E 1M1



ABOUT OUR ORGANIZATION

The Kidney Cancer Canada support and advocacy group is a newly-formed organization to support patients and families living with kidney cancer across Canada.

Our Mission as the first Canadian-based kidney cancer support group is to increase awareness of kidney cancer and provide timely information to patients and caregivers facing the diagnosis or treatment of kidney cancer. Given recent government decisions that severely impact patient access to important drug treatments, our group has become involved in advocacy and activism to ensure equal access to life-saving new drug therapies. We invite you to join our efforts.

WHAT CAN YOU DO TO HELP?

We strongly encourage you to write a letter to your elected representatives and drug reimbursement officials in your province. To download sample letters and contact information for provincial law-makers and reimbursement authorities, go to:

www.kidneycancerCanada.org

Please take the time to send letters to help secure access to new medicines for Kidney Cancer.

Excerpts from testimony of Dr. Jennifer Knox, Kidney Cancer Specialist, to the House of Commons Standing Committee on Health, April 30, 2007

“The first (drug) that came along with evidence of survival was the drug Nexavar and then soon after that the drug Sutent. Both of these drugs have recently been reviewed by CDR, and, (the CDR) advised that these drugs not be funded in provinces based on their understanding of the data and their cost effectiveness analysis which, I think, is very flawed.”

“There's nobody who treats kidney cancer, or any expert in the world who doesn't believe the drug (Nexavar) had a meaningful impact on the survival of those patients, but it's awfully hard to put a number on it.”

“In oncology circles and the way we think about these things, these drugs are home runs. We're not curing these patients with advanced disease, but this is the biggest thing that's happened in 30 years and it has the potential to really build momentum to understand more and make further progress.”

“I'll end just by saying we're very unusual here in Canada in not embracing these drugs for funding very quickly. As far as I know, Nexavar, which is the first one that came along, is being reimbursed in Austria, France, Germany, Greece, Ireland, Italy, the Netherlands, Sweden, Spain, Switzerland, the United Kingdom, and the U.S.”

“I made this impassioned plea for kidney cancer ...because not only are these very good drugs, they're a first. They're not me-too drugs. They're not just adding a little something to what we've already got for kidney cancer. We're going from nothing to these ones. I think we were all caught a little off guard that this was not found (by the CDR) to be adequately cost effective.”

Kidney Cancer Canada – Our Recent Efforts to Fight for Drug Access

Members of Kidney Cancer Canada have been meeting with lawmakers and policy influencers over the past few weeks to raise awareness of the breakthrough new therapies for kidney cancer, and to point out the serious flaws of the Common Drug Review.

On Parliament Hill, the Standing Committee on Health recently held hearings to examine the status and operations of the Common Drug Review (CDR) which was established by all federal, provincial and territorial governments (with the exception of Quebec), as a single process for reviewing new drugs and providing listing recommendations to participating publicly funded drug plans. Deborah Maskens and Tony Clark have met with various members of the Standing Committee to brief them on the important breakthroughs for the treatment of kidney cancer, and to inform them of the serious mistakes made by the Common Drug Review in their review and recommendations concerning Nexavar and Sutent.

Tony and Deborah have briefed the following members of the Committee: Ms. Bonnie Brown, MP, Ms. Susan Kadis, MP (Co-chair of the Standing Committee), Ms. Penny Priddy MP, Mr. Rob Merrifield, MP (Chair of the Standing Committee), Ms. Colleen Beaumier MP. Additional briefings have been arranged with Ms. Christiane Gagnon MP, and, Dr. Carolyn Bennett has also been briefed on the issues.

Tony Clark also had the opportunity to meet with Mr. Jack Layton, Leader of the NDP, and present him with information about the flawed CDR process.

Over the coming weeks, members of Kidney Cancer Canada will be meeting with reimbursement authorities and lawmakers within the Government of Ontario to present the case that both Nexavar and Sutent should be reimbursed by the Ministry of Health and Long-term Care.

Patient and Caregiver Meetings

Our Last Meeting – April 4, 2007

Thank you Dr. Christopher Chan for being our keynote speaker on: Living Well on One Kidney. Dr. Chan is the Staff Nephrologist at the Toronto General Hospital, and he provided our group, including those who participated via web-cast, valuable information on maintaining optimum kidney health.

Our Next Meeting – September 12, 2007

On September 12, 2007 Kidney Cancer Canada will host its next Patient and Caregiver meeting. Dr. Robert Buckman, Medical Oncologist at Princess Margaret Hospital, will speak on the topic of “Surviving or Thriving after a Kidney Cancer Diagnosis”. Dr. Buckman is a renowned speaker and author of numerous books including *Cancer is a Word Not a Sentence*.

We hope to webcast this meeting to patients who are unable to join us in Toronto.

For further details and to RSVP, please send an email to: groupkidney@yahoo.ca or call Jenn at (416) 930-5212. Meeting details will also be posted at: www.kidneycancer canada.org