

Premier 'hiding' behind drug review

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Therapies introduced Replagal, an enzyme replacement therapy used to treat Fabry. Mr. Irwin volunteered for clinical trials and noticed a marked improvement almost immediately.

"I was feeling much better and more confident and had good energy with the drug. The quality of my life improved."

Replagal and a competitor's Fabrazyme, were approved by Health Canada in early 2004.

The twice monthly infusions, valued at \$25,000, were supplied free of charge to Mr. Irwin's doctor at Markham Stouffville Hospital by the pharmaceutical company until last February.

Transkaryotic withdrew its complimentary supply when it couldn't get an indication whether the province would include the product in its drug benefits program, an initiative that helps pay for costly drugs outside traditional provincial and private drug plans.

"I was cut off Feb. 16 and I'm now starting to digress to my pre-infusion status," Mr. Irwin said. "I'm getting vertigo attacks, pain is increasing and my whole history with Fabry has been strokes, many strokes. My biggest problem, of course, is that I now have to sit and wait for the next one."

Unwilling to give up hope, Mr. Irwin optimistically began a letter writing and telephone campaign to gain answers to his ample suggestions, including interim federal-provincial bridge funding to make the drug available to victims of Fabry.

"I wrote and called the Premier, (Health) Minister (George) Smitherman, my MP and MPP and got absolutely zero response. The only one who got back to me was (Oak Ridges Conservative MPP) Frank Klees."

Mr. Irwin contends the province continues to dally on funding approvals because Fabry affects a small segment of the community and the price tag is heavy.



GERRY IRWIN: With medication, "I can make use of what time is available," man with Fabry disease said.

"I know for a fact that there are other drugs that cost as much and have been approved by Ontario," he said. "The drug I need is approved and available and the province still plays God."

Mr. Klees concurs. "I believe it's unconscionable that the government is turning their backs on people with Fabry disease," he said. "The government has a moral responsibility to respond to these patients. At what point does the Premier have the right to say yes to one group of patients and no to another?"

KLEES SUPPORTIVE

"This government has collected \$2.8 billion in new health taxes. Where's the money going? It's frustrating. In the House, the government looks at a \$450 million hotel casino in Windsor and in the same afternoon, can't tell Fabry victims if they'll get help. No one can justify that."

Health Ministry spokesperson Dan Strasbourg said Ontario's drug benefit program does consider listing specialty pharmaceuticals based on national common drug reviews.

"The program does help defray the costs of high price drugs in relation to an individual's income," he said. "The (Fabry) drugs are still under common drug review."

During Legislative Assembly

question period April 6, Premier Dalton McGuinty responded to Kitchener-Waterloo MPP Elizabeth Witmer's query whether the Fabry drugs would be funded by the province.

Mr. McGuinty said all provinces and territories have agreed to adhere to a common drug review provided by the Canadian Co-ordinating Office for Health Technology Assessment, an independent national organization that reviews approved pharmaceuticals' effectiveness from a clinical and financial perspective.

"As drug companies come forward and propose that we add an additional drug to the list of those we publicly support, we think it's important to find out whether they are as efficacious as they hold them to be," the Premier said. "We have a common drug review. Again, we have a process. It's not an easy one, but I think it's the appropriate one and the responsible thing to do."

Common drug reviews of Replagal are not promising. The jury is still out on Genzyme Canada's Fabrazyme.

Based on data provided by the Canadian Expert Drug Advisory Committee, the assessment agency recommended Replagal not be listed last November, citing, in part, clinical trial outcomes were not impressive and the per-patient treatment cost is \$239,200 per year, excluding pharmacy markups.

Review of Fabrazyme continues and final recommendations are due within weeks.

"Premier McGuinty is hiding behind the CDR (common drug review)," Mr. Irwin said. "I would love to see everyone with Fabry have access to the drugs. It's important to us and important to the next generation so we can minimize impact on our children."

"If and when funding comes through, I would be delighted. I could then get back to the infusions and make use of what time is available."

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