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**Her disease is rare
- but the province's
refusal to pay for her
life-saving drugs isn't**

CHRISTINA BLIZZARD » PAGES 4-5



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QUEEN'S PARK

The high cost of creating new drugs

Why do new drugs cost so much?

How do some patients get "compassionate" funding from the drug manufacturer?

I put those questions to John Haslam — general manager of Alexion, the company that developed and manufactures Soliris. Here are his responses.

"There are several patients in Canada who are part of the clinical trials," Haslam said. "The clinical trials ended at a certain point and they're continued on compassionate therapy."

"We honour those patients until the point at which long-term funding can be provided or a solution can be provided at that point."

Health Canada approved the safety and efficacy of Soliris in March 2013.

Forty other countries have approved it and made the drug available.

Quebec funds it under its Exceptional Access program.

Why do new drugs — especially those for rare diseases cost so much?

"We're often pioneering into a disease where there has never been a treatment, never been anything to help these patients," Haslam said.

There are fewer than 100 aHUS patients across Canada.

"The complexity of conducting clinical trials is very significant," he said. "It cost almost \$1 billion and 15 years to get that first drug approval."

Haslam said Alexion is more than willing to work with the provinces to find a way to make Soliris available to Canadian patients.

— Christina Blizzard

HOW CAN THEY

Toni Vernon's disease is rare, but unfortunately, the province's response — refusing to pay for her much-needed drugs — isn't



The drug Soliris could help Toni Vernon — who has a rare kidney disease — live a more normal life. But the provincial government says it won't pay for the medication, which costs \$500,000 a year per patient.



CHRISTINA BLIZZARD
Queen's Park

It's a date carved in Toni Vernon's brain forever. July 5, 2012.

She was rushed to Sunnybrook hospital with complete kidney failure.

"They had to put me on dialysis within 20 minutes," she recalled.

The illness came out of the blue. The only warning something was wrong were flu-like symptoms.

Then came the devastating diagnosis: Vernon, 59, had atypical Hemolytic Uremic Syndrome (aHUS), an extremely rare, life-threatening genetic disease that threatens the body's vital organs.

Once she was diagnosed, her doctor applied for funding for the drug that's most effective in treating it — Soliris.

"She warned me the chances were going to be slim that I would qualify and they would deny me — and they did," Vernon said.

It's estimated 95% of patients who apply for provincial compassionate funding have their application rejected.

Like many drugs used to treat rare diseases, Soliris is very expensive at \$500,000 per patient, per year. Her doctor was able to stabi-

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NOT UNDERSTAND?

“We don’t look at a surgery and say, ‘Oh, my gosh, that’s a really delicate heart surgery and it’s going to cost more than if I just went in and did ordinary bypass surgery, so I guess you’re just going to be too expensive for me.”

— Durrhane Wong-Rieger

lize her and she now controls the disease with plasma treatment and three four-hour dialysis treatments a week.

“The scary part of this disease is that they don’t know if it will come back,” she said.

Her specialists don’t know why it happened. Bouts of aHUS are triggered by different factors in different patients.

Vernon, who’s married with four grown children, once worked as a realtor. She can’t go out on showings anymore. Her husband, also a realtor, does that for her while she helps with the computer work at home.

Dialysis wipes her out physically.

“There are days when I just can’t function,” she said.

She’s hoping for a transplant but, in an ironic twist of fate, the transplant doctor won’t perform the operation because chances of kidney failure happening again are high.

“He said the only way to ensure I get a transplant would be for me to be on Soliris,” she said. “I was devastated because we knew the chance of me getting Soliris is next to impossible. The cost makes it impossible.

“Even if we ended up pooling all our resources, it would only be good for a year and then after that what happens?” she wondered. “I can’t understand how the government can look at this and not understand.”

What makes this even more infuriating for aHUS patients is that Soliris is funded in

certain cases for the disease paroxysmal nocturnal hemoglobinuria (PNH).

Durrhane Wong-Rieger of the Canadian Organization for Rare Disorders said that, even then, PNH patients must have had one “life-threatening event” before qualifying for funding.

“What if you don’t survive your life-threatening event?” she asked. “Can we not just take patients who we know are at risk and know would benefit from the drug? Why do we have to wait until they’ve actually been at death’s door before we decide that we might try to save them?”



WONG-RIEGER
Rare disorders

The nature of aHUS makes it difficult for patients to get compassionate funding because they don’t have life-threatening events in the same way PNH patients do. “Their quality of life just deteriorates to the point where they spend all their time getting therapy, but we don’t consider that a significant-enough event to fund them,” Wong-Rieger said.

These patients don’t add significantly to the cost of health care, she said.

“We don’t look at a surgery and say, ‘Oh, my gosh, that’s a really delicate heart surgery and it’s going to cost more than if I just went in and did ordinary bypass surgery, so I guess you’re just going to be too expensive for me,’” she said.

Kimberley Tran of the Canadian Health Policy Institute (CHPI) said figures show drug costs are a small part



ANTONELLA ARTUSO/TORONTOSUN FILES

Health Minister Eric Hoskins says his ministry is reviewing Soliris.

of health-care spending.

The CHPI used data from the Patented Medicines Prices Review Board (PMPRB) and the Canadian Institute for Health Information (CIHI). According to the PMPRB, all spending on patented drugs or “new” medicines totalled \$13.6 billion across Canada in 2013. New drugs accounted for only 6.5% of the \$210.4 billion reported by CIHI for all health spending across Canada during the same year — or \$386.82 per capita.

“In fact, spending on patented drugs has actually become more affordable as a percentage of GDP over time, falling from 0.83% in 2004 to 0.72% in 2013,” Tran said.

“Per capita spending on patented drugs grew by only 2.1% over the entire period from the end of 2008 to the end of 2013. By comparison, per capita spending on all other health

care (excluding patented drugs) grew by 16.7% during the same five-year period,” she said.

“By these measures, it is hard to believe the argument that the economic burden of spending on new medicines is unaffordable. Nonetheless, governments are increasingly restricting access to the most innovative drugs anyway,” Tran said. Tory critic Michael Harris said the approval system needs to change.

“The current policy doesn’t address what the expectations are of Ontarians when it comes to coverage of these drugs for these rare diseases. It’s just sad when you open up the paper every day and there’s someone begging for their life,” Harris said.

“It’s not the health-care system that Ontarians expect to see in their province, especially when they’ve been

asked to pay more,” he said. Health Minister Eric Hoskins, a doctor himself, said the ministry is reviewing Soliris.

“This is a drug that has had the attention of the ministry for some time,” Hoskins said. “We have a process in place nationally through the Pan Canadian Pharmaceutical Alliance.”

It’s a national process, made across all provinces and all territories, although Quebec funds Soliris on compassionate grounds.

“When Soliris for aHUS was brought to our attention, we reviewed the information that was available from the manufacturer that was provided to us nationally and the national committee decided there was not sufficient clinical evidence to demonstrate that, unlike other conditions, in aHUS it was effective,” Hoskins said.

“We have what I believe is a very effective, appropriate and non-political process that’s done nationally now that makes this determination and it’s done by scientists and clinicians and experts that really understand the importance of doing it based on evidence and good science,” he said.

That’s not much comfort for Toni Vernon and other aHUS patients. The only science they know is that, without Soliris, their lives are on hold. With it, they have a chance of living healthy lives.



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