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THE GLOBE AND MAIL

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OHIP ordered to compensate family whose search for best medical care took them to U.S.

By Lisa Priest
From Saturday's Globe and Mail

Argument to appeal board was that patient faced lower death and complication risk at hands of Phoenix surgeon

Brad Remigis, a healthy 18-year-old working toward a law career, was suddenly experiencing double vision and one eye that would not look left. His diagnosis - a bleeding lesion in his brain stem called a cavernoma - required surgery so complex even Canada's top doctors had performed it only a handful of times. At a consultation, he was told it was "too risky" to operate.

A second bleed prompted a search for the world's best neurosurgeon, which ended with Mr. Remigis on an operating room table in Phoenix. The Ontario Health Insurance Plan refused to pay for his care, saying surgery could have been done in Toronto, with no delay. But for the Remigis family, the issue was expertise: Brad's best chance of survival rested in the hands of one doctor in the United States. So his parents remortgaged their home and cashed in their life savings to pay for the surgery, while friends held fundraisers.

Now, in a landmark decision, Ontario's Health Services Appeal and Review Board has ruled that the superior skill of a surgeon justified treatment in the U.S., and ordered the provincial government to pay all the family's care costs, estimated at \$200,000. The decision has also opened the door to patients with relatively rare conditions to seek out doctors with the most expertise and have that treatment covered by the government.

What the appeal board found, according to lawyer Adrian Nurse who worked the case pro bono, was that in the hands of Arizona doctor Robert Spetzler, Mr. Remigis faced a lower death and complication rate for a complex, high-risk surgery.

"I persuaded the board they should take into consideration the hands of the person actually doing the operation," said Mr. Nurse, a Hamilton-based litigator who worked on the case for more than two years. "The room for error was so small that if there is a problem, his vision may be gone, his breathing may be gone and his heart may stop. ... A life was at stake."

Perry Brodtkin, a health lawyer in private practice who was the sole lawyer for OHIP from 1973 to 1991, said the decision opens the door for other patients with rare conditions to have the care of an expert funded, if they have exhausted all other avenues in Ontario.

"It's the first time I've seen where the board has said you can go to the world expert because you properly prepared and presented your case," Mr. Brodtkin said, noting the decision would not apply to routine procedures.

More broadly, the case suggests Canadians should be savvier before going under the knife, asking doctors how many of a given operation they have performed, and their death and complication rates. It also raises a delicate debate: How many operations does a surgeon have to perform to be considered proficient?

Even Dr. Spetzler, who operated on Mr. Remigis in Phoenix, could not answer that question with certainty.

"How many times do you have to hit a tennis ball to become a superb player?" he said in a telephone interview from Phoenix. "I don't think we can really put a number on it."

On a recent sunny spring afternoon, Marty and Leslee Remigis watched their now 24-year-old son shoot hoops in their Hamilton driveway, having just completed his first year of law school.

It has been a long road back.

After Brad's second bleed, in June of 2005, Toronto neurosurgeon Mike Tymianski did not recommend surgery - but Dr. Spetzler did.

"With each bleed, you have further damage to the brain stem ... some of which is irreversible" Dr. Spetzler said.

"It was very overwhelming," Ms. Remigis said. "The anxiety of not knowing what was going to happen to my son. ... It was like a time bomb waiting to go off."

Friends and family banded together to hold several fundraisers. Marty and Leslee spent hours on the Internet, trying to figure out what to do after receiving the conflicting advice.

"I really was in a panic," Ms. Remigis said.

It wasn't until a third bleed of the cavernous malformation in July, 2005, that another Toronto neurosurgeon, Dr. Chris Wallace, recommended surgery. (Dr. Tymianski was on vacation.)

Marty, a barrel-chested man with a precise nature, asked questions about the two surgeons' experience: He had been told that Drs. Wallace and Tymianski had performed three and six such operations respectively. The family chose to take on the cost of travelling to Phoenix to have Dr. Spetzler, who had at that time performed more than 200 such operations, remove the small mulberry-sized lesion from Brad's brain stem. Though the family declined to say how much the care cost, experts pegged it at about \$200,000.

Neither neurosurgeon testified at the Remigis hearing but Charles Tator, who works with both surgeons at Toronto Western Hospital, did. He did not provide figures to dispute the number of brainstem cavernoma operations Drs. Wallace and Tymianski had completed, but said he believed three was enough to make a surgeon proficient, given their experience in that area of the brain.

Dr. Wallace said he has been happy to do follow up treatment, which the Remigis family described as excellent.

"I have no trouble with a Canadian individual wanting more than the Canadian health care system can provide, but that operation could have easily been done by Dr. Tymianski or myself," he said, adding he thought that together they had done "way more" than nine brain stem cavernoma operations as of 2005.

Ontario Health Ministry spokesman Andrew Morrison said the government is abiding by the decision to reimburse the family for the "rare and unique" operation but could not speculate on what would happen with future cases. Lori Coleman, registrar of the Health Services Appeal and Review Board, declined to comment on the ruling.

As for the patient, Brad Remigis says life is good. At 6 feet 2 inches tall, he looks like the picture of health. He has had two operations on his left eye, which has improved the double vision he sometimes experiences.

The ordeal, he said, has taught him the importance of a champion - like the ones he had in his lawyer and parents. He hopes that by becoming a lawyer, he can help others the same way.

"I want other people," he said "To know to not give up hope."

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