

Amazing Brace Article in MacLean's – January 23, 2008

Why aren't parents told about a Montreal invention used around the world to treat scoliosis?



"Welcome to a lifetime of pain" was the dramatic greeting I got six years ago when I typed just one word into my search engine. Last spring, as I sat in a hotel room after a dinner my 22-year-old son Jay could hardly sit through because of pain, I realized just how accurate those words had been.

It all started innocently enough in 2001 when Jay, then 16, complained of a sore back. His back looked fine to me, but I took him to the pediatrician just to be sure. **"Your son has scoliosis, and now it's too late,"** the doctor told me, going on to explain that scoliosis, a sideways curvature of the spine, if caught while a child is still growing, can be treated with a brace to reduce the curve, or a surgically implanted rod to straighten the spine.

We were referred to the Hospital For Sick Children in Toronto, where Jay was diagnosed with adolescent idiopathic (of no known cause) scoliosis, or AIS, the most common type of curvature of the spine. "If you ask me three times, I'll do surgery," the doctor then said to my son.

Confused, I asked him what he meant. *"I wasn't talking to you,"* the surgeon scolded. Intimidated, not a common trait of mine, I backed down. Even though my son was still a minor, I apparently had no say in the matter. When we left the hospital, my teenager said casually, *"Well, I guess I'll have fusion."* The surgeon had succeeded in making spinal fusion sound like a trip to the park.

I soon found out that nothing could be further from the truth. Spinal fusion, introduced in 1911, is still one of the most dangerous surgeries performed today.

Complications are surprisingly common and can include fusion failure, infections, numbness, and, more rarely, paralysis! even, as with any major surgery, death.

"Successful" surgeries have their own issues, mainly chronic pain, and eventually more operations. Medical professionals may call it the gold standard in scoliosis surgery, but except in cases where it is absolutely necessary (serious spinal curves can lead to heart and lung problems), I couldn't find anything golden about spinal fusion.

I was relieved when surgery wasn't recommended for Jay after all. Following the visit to Sick Kids, we received a letter from the pediatric surgeon we had seen: *"No treatment warranted at this time,"* it said, though *"lower posterior fusion may be necessary in the*

future due to pain or progression of curvature." How could there be no treatment warranted, I wondered. **Were we supposed to do nothing until surgery was needed?**



I was writing for the National Post then and had managed to snag an interview with actress Isabella Rossellini, in town for the Toronto International Film Festival. Since time with her was limited, I cut to the chase. *"I've read you have scoliosis. My son has it too,"* I blurted out.

A startled Rossellini sternly replied, **"Don't ever let him get the surgery."** She went on to explain she'd had spinal fusion and had been in pain ever since. The few minutes we spent together, she talked emotionally about her scoliosis, while her handlers flailed. This discussion wasn't exactly what they'd had in mind. As she was being dragged away, her parting words were, *"Remember, no surgery."*

Increasingly concerned, I sought out Dr. Walter Bobechko, a highly respected Canadian scoliosis surgeon who had relocated years earlier to practice in Dallas, Texas (he has since died). Through a mutual friend, he agreed to see Jay while he was visiting in Toronto. After his examination, the expert echoed Rossellini's advice: *"Don't ever let anyone do surgery on your son."* He said that since Jay's curves were under 40 degrees, and more importantly, since he was a male (curves are more likely to increase in females), he was at low risk for progression. *"He's one of the lucky ones,"* I was told.

But Jay didn't feel lucky. Although some scoliosis sufferers have no pain, his back pain was progressing relentlessly. Painkillers would often now appear on his bedside table when he was home from university. *"My back is killing me, Ma,"* he would tell me, but it would be almost three years before he would admit that the pain was constant and almost intolerable. He had been trying to keep it from me so I wouldn't worry. ***"This is seriously affecting my quality of life,"*** he finally confessed. His doctor's solution had been to prescribe ever-more-powerful pain medications, medications that in spite of their devastating side effects weren't solving the pain issues. In the prime of his life, my son was almost disabled from back pain. I was devastated.

I frantically searched for a solution, only to discover that the conventional treatment options in Canada are confusing, antiquated and controversial, even though AIS affects up to three per cent of the adolescent population, with one per cent going on to need treatment. It is one of the leading orthopaedic problems in children and tends to run in families. Mild curves under 25 degrees are virtually ignored in this country, except for a "wait and watch" policy. Beyond that, treatment options get downright scary.

The traditional braces that are prescribed look like something from an ancient torture chamber. The TLSO (Boston-style brace) and the Charleston (nighttime) brace consist of a hard shell that extends from under the arms to the hips. The Milwaukee brace, used since the 1940s, is even worse: metal rods jut out from neck to waist. These

were the braces my son was too late for? It is hardly surprising that many teens refuse to wear these ungodly contraptions, prompting one surgeon to tell me, "**We're getting away from bracing kids in Canada altogether, and going straight from 'wait and watch' to surgery.**" The more I found out about scoliosis, the more frightened I became.

Online forums at the National Scoliosis Foundation's website (NSF is a patient-driven, non-profit organization out of Boston; no such foundation exists in Canada) only added to my angst! Heart-wrenching stories were written by young people struggling to cope with the disabling pain of scoliosis.

One teen, describing a constant state of mental fog from her prescribed narcotic drugs, and desperately seeking an alternative, begged for help; a young store manager described pain so excruciating he was forced to periodically collapse on the backroom floor of his workplace to try to get relief. He feared he would be fired or be forced to quit! There were complaints about doctors who wouldn't take his pain seriously who said scoliosis didn't cause pain. We'd heard that one before. Some older, more resigned scoliosis sufferers offered words of encouragement to the distressed teens, even as they themselves talked about years of constant, daily pain, operations, re-operations, and eventual disability. Good Lord, maybe my son really was headed for a lifetime of pain.

Heartbroken, I hopped a plane to California where Jay was then living so I could try to help. An appointment with another top scoliosis surgeon, this one in L.A., turned up nothing new. Jay didn't need surgery yet, we were told, and he shouldn't be having so much pain. Here we go again, I thought as I caught Jay's frustrated gaze. I was overwhelmed by the hopelessness of his situation.

In my hotel room that night, after the dinner Jay could hardly sit through because of the pain, I began surfing "chronic pain management." I couldn't believe it had come to this, but there seemed to be no other solution. A pain clinic in Los Angeles popped up, touting a flexible scoliosis brace for children and adults! "***A brace for adults?***" I was surprised to learn that the brace had been invented at Sainte-Justine's Hospital in Montreal. Why had I never heard of it?



The next morning I called Sainte-Justine's and got through to one of the inventors, Dr. Charles Hilaire Rivard, a research scientist, orthopaedic surgeon and former head of surgery at the Université de Montréal.

"Will your brace help my son?" I asked desperately, after telling him Jay's story. "Yes, it will," he replied confidently. The brace, called **SpineCor**, an elaborate system of elastic bands, applied with the use of software designed for each individual curve, had been created for 10- to 16-year- old children with AIS and was now being used on adults to relieve back pain.

Since Jay was living in California, Rivard recommended one of several California chiropractors who had been trained in fitting the brace. "He's scientific, and he won't overcharge you," Rivard promised. I was hopeful, but Jay, who had tried everything from acupuncture to physiotherapy, Thai massage, vibrating chairs, yoga, Pilates, and even Dr. Ho's massage therapy (I gave it to him one Christmas), was skeptical. After all, I had discovered the brace on the Internet. *"If I end up looking like Quasimodo . . ."* he threatened.

Yet desperate for pain relief, he decided to try it, and on April Fool's Day, 2007, was fitted with the brace to the tune of US \$3,500. On April 2, the fool flew back to Toronto with her fingers crossed.

Within a couple of days, a disbelieving Jay reported that his daily back pain was subsiding dramatically. And after a couple of weeks, **the chronic pain that he had suffered for years was virtually gone!** The brace was retraining his muscles, and in doing so, correcting painful postural problems caused by the asymmetry of his spine. My son was finally pain free for the first time in six years. I was elated, but miffed. Why hadn't I heard about this great Canadian invention that had helped my son so much? I went to Sainte-Justine's in Montreal to find out.



"Maybe the reason you've never heard of the brace [used in Quebec since 1993] is because they don't want to use it in the rest of Canada," Dr. Rivard told me bluntly. **The SpineCor brace is used in 18 countries, including England, France, Germany, Australia, Spain, Switzerland and the U.S., but not in "English" Canada.** Ten thousand children have been treated with the brace; it is distributed out of the U.K. worldwide. "No one in Canada wanted it," an exasperated Rivard said.

A \$12-million grant from the Quebec government in 1992 enabled Rivard to get the brace off the ground, and to begin research on the development of new instrumentation to be used in the place of fusion. The intellectual property rights for the brace are owned by Sainte-Justine's.

Rivard credits his colleague Dr. Christine Collaird for coming up with the idea for the brace that, he says, *"is keeping kids out of surgery."* Collaird, a pediatric orthopaedic surgeon who studied the biomechanics of the spine for 10 years and spent another four years developing SpineCor, said, *"Unlike traditional braces, there is no muscle atrophy, and no side effects."* Rivard added that the *"dynamic SpineCor uses the muscles. It's like being in physiotherapy 24/7."*

The brace has been used on adults for only about two years, the goal being pain relief not straightening since the spine is mature. "No one thought it would help adults," said Collaird. Still, Rivard admits that the brace doesn't work for everyone. He continues to use the Milwaukee brace on children when the SpineCor won't hold a large curve, and says that when a growing child gets beyond a 50-degree scoliosis curve, surgery becomes almost unavoidable. *"Every time I fuse a child, I feel bad,"* the Montreal doctor told me as his eyes welled up.

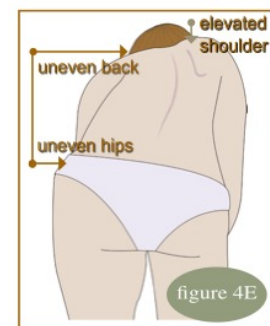
"It's been so long and so difficult," Collaird confided, as she rushed toward him with tissues. *"Tell people I just want to help kids,"* Rivard said. *"I know it's a complicated brace, but it works. Why aren't the others using it?"*

Back in "English" Canada, I contacted Dr. Ben Alman, head of the orthopaedic division, and AIS specialist, at the Hospital for Sick Children, to find out why the hospital doesn't use the Quebec brace. *"The reason SpineCor isn't used here is not because it is good or bad,"* Alman told me. *"It's a financial issue. OHIP [Ontario's health insurance plan] doesn't cover it."* Hard braces are covered *"at least partially,"* he said. Are parents really not being told about this brace because of the cost? Alman added, *"Part of the problem is that the brace is too new to know for certain long-term results."*

But the Canadian brace is not *"too new"* for two of the most prestigious children's orthopaedic hospitals in the U.S. The SpineCor is used at the renowned Shriners Hospital for Children in Erie, Penn., and at the famous Johns Hopkins Hospital in Baltimore, Md. Dr. Paul Sponseller at Johns Hopkins believes that the SpineCor brace *"works for smaller curves, in patients who are very diligent about wear."*

Although Sponseller also said that some patients do not respond to any kind of bracing, he added, *"I have had some noticeable successes as well, preventing surgery in patients who may well have needed it."* Dr. James Sanders is the former chief of staff at Shriners and is now professor and chief of pediatric orthopaedics at Strong Memorial Hospital in Rochester, N.Y. *"While I do like the theories of the SpineCor,"* he said, *"it needs good testing to know if it is any more than just a nice-sounding theory."* Both Sanders and Alman refer to studies now under way to determine if any of the braces currently in use really work.

Some experts believe the best chance of avoiding surgery is in diagnosing curves early. In the U.S., school screenings are done in many states. Girls are generally screened in the fifth and eighth grade, and boys in the eighth or ninth grade. The method used is the Adams forward-bending test: the child bends over to a 90-degree angle while the examiner, standing behind, compares both sides of the back, looking for asymmetry, like a protruding shoulder blade. When the child stands up straight, the screener can also check for unequal shoulders, or an uneven waist. If a problem is noted, the child is referred to a doctor. Canada has no such screenings in public schools.



Adam's Test for Scoliosis
taken from *Parent's Guide to Scoliosis*

Many doctors think school screening is a waste of time, since they don't believe there is an effective conservative treatment for scoliosis. Rivard disagrees. *"I believe finding curves earlier, while they're smaller and treatable, will keep some children out of surgery."* **According to Rivard, fewer fusions are done in Europe due to their rehabilitative approach to scoliosis.** *"In Europe, the first line of defense for scoliosis is rehabilitative therapy. In Canada and the US, the first referral is to a surgeon,"* he says.

At Sick Kids Hospital, Dr. Alman told me that scoliosis patients with curves too small for traditional treatment (under 25 to 30 degrees) are now routinely referred to the hospital's on-staff physiotherapist but not for any active treatment! *"Mainly to wait and watch and keep an eye on things,"* he said.



Joseph P. O'Brien
President of the National
Scoliosis Foundation

Joe O'Brien, president of the National Scoliosis Foundation, is appalled at that. *"I've never understood the logic of 'wait and watch,' "* he told me indignantly. Also a supporter of school screening, O'Brien, who had his first scoliosis surgery at the age of 16, and four subsequent surgeries, said, *"The only operation I regret was the first! It created all the problems that made the following surgeries necessary."*

O'Brien has three children with scoliosis and has managed to keep them all out of surgery: one using the SpineCor. Asked about the Quebec brace, he said, *"It did what it was supposed to do hold the curve and prevent surgery."*

SpineCor also did what it was supposed to do for Valerie Goulet, a second-year journalism student at Université de Montréal who was fitted with the brace at the age of 15 due to a painful 25-degree curve. She wore it the recommended 21 hours a day for 18 months, and said, *"I didn't mind at all. I even had a boyfriend."* Before being fitted with the SpineCor, Goulet had been told she might eventually need surgery. *"And that I must wear a hard brace,"* she said. *"I cried and cried."* Long out of the brace, her curve is stable at only 12 degrees (anything under 10 degrees is so mild it's not even considered scoliosis). *"I am so thankful that I met Dr. Rivard,"* she said.

In the course of my research for this story, I made several unannounced visits to the busy Sainte-Justine's spine clinic, randomly speaking with parents and patients, some in treatment, some in follow-up. Those I spoke with were grateful and had nothing but praise for the Quebec doctors. All were success stories. I also met 13-year-old Esme Tremblay from Ottawa, who might not be as lucky. Her worried parents, Michael and Ruth, told me that although their daughter's curves were discovered three years ago, when they measured under 20 degrees, nothing was done until they advanced enough for a cumbersome hard brace, a brace Esme, like most youngsters, found too uncomfortable to wear.

With Esme's curves now measuring more than 50 degrees, Ruth, who recently discovered SpineCor on the Internet, said, *"We're getting in the game really late, so I'm not sure the*

