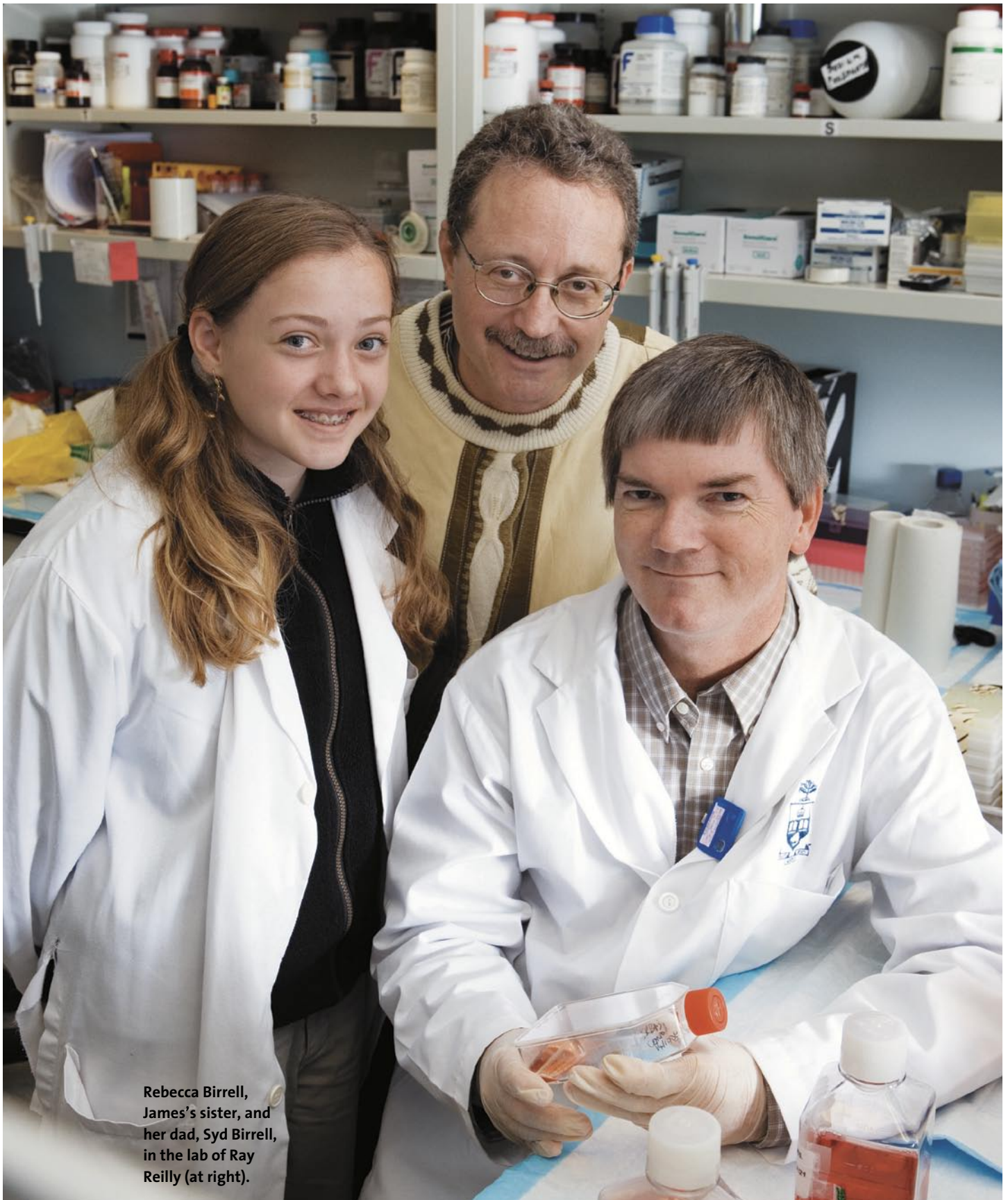




# A Little Boy's Legacy

James Birrell's death at the age of eight was a staggering loss for his family, yet in his short life he succeeded in bringing a human touch to medical research in this country.

BY CHRISTINE LANGLOIS



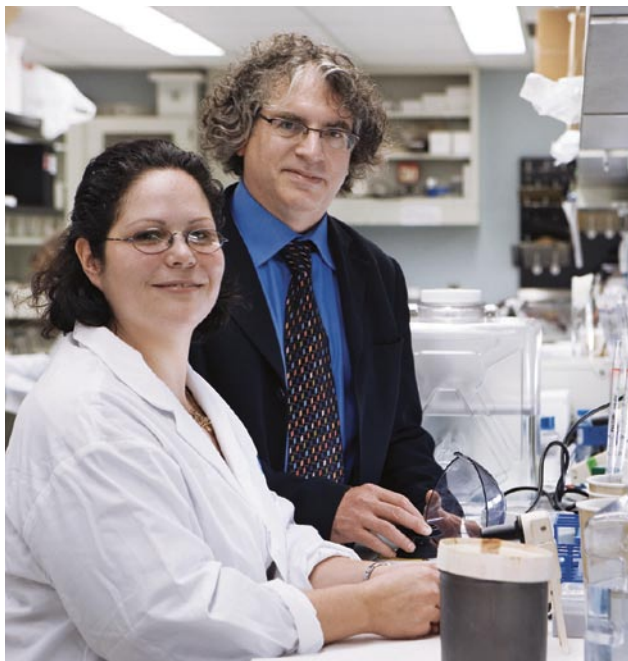
PHOTOGRAPHY: COURTESY OF SYD BIRRELL (THIS PAGE); RAINA KIRN AND WILSON BARRY

Rebecca Birrell,  
James's sister, and  
her dad, Syd Birrell,  
in the lab of Ray  
Reilly (at right).

**W**hen seven-year-old James Birrell looked up at scientist Ray Reilly in his Toronto laboratory and asked him with a soft lisp to show him some cancer cells, Reilly's heart lurched. At the time, the little boy with the dark curls visiting his lab with his dad, Syd, was being treated for a rare form of pediatric cancer called neuroblastoma. The cancer cells he eagerly wanted to see were very similar to the cells that both Reilly and his dad knew were likely to kill him.

But James wasn't thinking what the adults were thinking. He was just excited to stand on a little stool that Reilly provided and peer through the microscope at the wondrous little star-shaped cells piled on top of each other at the bottom of a culture flask. It was the same wide-eyed curiosity that made his nurses and doctors grin as they patiently answered all his questions about the intricacies of IVs and chemo treatments.

Chatty, adventurous James, who loved to talk about trains and astronauts and *Lord of the Rings*, died in December 2001 just after his eighth birthday. But in the five years that he battled his disease, he touched the hearts and so captured the imagination of Canadian cancer researchers that, through a special fund in his name, research into neuroblastoma, which in the past had received little attention, has grown exponentially in Canada. Today many scientists are full of hope for a breakthrough in treatment,



**With a grant from the James Fund, Loen Hansford, seen here with David Kaplan, succeeded in isolating the rare cells that cause neuroblastoma.**

perhaps even someday a cure. James, himself, caught that hope when they started the fund. He told his dad, "With all this experimenting, they'll get it figured out and then all the kids with neuroblastoma will be able to survive."

James could melt the hearts of just about anyone, even the most stoic white-coated researchers. But it was James's parents, Syd and Pam, who made sure these scientists saw the human face of neuroblastoma. The couple decided to share their son's journey in a very personal way to engage as many people as possible in the ultimately doomed battle to save their son. "All along I wanted people to pay attention and not keep their professional distance," says Syd. "Taking a kid through cancer treatment is hell, and I wanted them to somehow identify with us."

A mix-up in James's treatment was what brought him to Reilly's lab.

A compound that James needed for a testing procedure at The Hospital for Sick Children (HSC) hadn't arrived from the lab, where it was to have been mixed. Syd, by then a veteran of his son's cancer treatments, got Reilly on the phone. The nuclear pharmacologist explained that part of the compound was stuck in transit but would arrive shortly. Then, after a few minutes of chatting to Syd about his son's treatment, Reilly did something out of character for a busy cancer researcher. He suggested that Syd bring James to see his laboratory facilities the next time they visited Toronto from their hometown of Peterborough, Ont.

"Despite the fact that we had been doing cancer research for 15 years, James was actually the first cancer patient who had ever stepped foot in our lab," Reilly says now. When he met James, he came face to face for the first time with the cruelty of neuroblastoma, a cancer that spreads tumours along the nervous system to every corner of the body, causing excruciating pain and death in 85 per cent of its victims.

The meeting changed the direction of Reilly's research. Until then, he had focused only on breast cancer. Touched by the inquisitive dying boy, he added research into neuroblastoma to his list of research priorities.

Reilly's decision is significant. Neuroblastoma affects only 800 children a year in North America compared to the 200,000 – mostly women – who are diagnosed with breast cancer. It's hard to convince pharmaceutical

## THE JAMES E-MAILS: NOW IN PRINT

**T**he collection of e-mails that Syd Birrell sent to friends, family and others during his son's battle with neuroblastoma is available at select bookstores as well as online. *Ya Can't Let Cancer Ruin Your Day: The James E-mails*, with a forward written by actor Tom Hanks, was published to help raise awareness and research funds into neuroblastoma, the rare cancer that took James Birrell's life in December 2001. You can order the book from [www.chapters.indigo.ca](http://www.chapters.indigo.ca) or [www.greentrainbooks.com](http://www.greentrainbooks.com).

In another fund-raising effort, Hanks designed *Space Mouse*, a six-foot, 700-pound Mickey Mouse statue. Seventy-five of these statues were auctioned, with the \$15,000 raised going to the James Fund. MDS Nordion donated the money, and the mouse will be placed in the lobby of The Hospital for Sick Children.

companies to fund drug trials, let alone attract researchers to work in the field. But by sharing James's story, Syd and Pam Birrell not only attracted researchers to their cause but also attracted precious research dollars.

The Birrells set up a dedicated research fund after one of their son's doctors remarked that the death rate for neuroblastoma hadn't changed in 40 years because very little money had been spent on finding a cure or even treatments to prolong life. By contrast, children with leukemia had gone from having an 85 per cent chance of death to an 85 per cent chance of survival thanks to money invested in the field. "It seemed outrageous to us that our son would not live because no one had got some money together," says Syd.

At first, the fund was a desperate pitch for money to find help for James. "If sharing the story got us more money and more awareness then that was a chance to save my son's life," says Syd. The family held their first fund-raiser in March 2001 at their Baptist church in Peterborough, where Syd is the choirmaster. The five Birrells – Syd, Pam, James, and his two siblings, Rebecca, then 9, and Ben, 5 – took the stage to the applause of a crowd of 400, mostly friends, colleagues and neighbours. Syd told stories about James on his good days – how he loved to catch frogs and play with his best friend, Cam. And he shared some of the horrors of managing the pain on the bad days. That night they raised \$30,000.

But even though the first donations got fast tracked into research within months – Reilly got one of the first grants – the frantic efforts came too late. After a terrible month of grinding pain, James died at home a week before Christmas. In spite of their grief – or perhaps because of it – Syd and Pam kept raising money for research.

Now, four years later, James's legacy – the James Fund for Research into Neuroblastoma, operated through the HSC Foundation in Toronto – has raised almost \$700,000, which makes it the largest research initiative into neuroblastoma in the country. American actor Tom Hanks is the fund's patron.

No one wants to suggest that because of the James Fund a drop in the death rate is just around the corner, but there has been some clear progress. Recently, for example, the cancer stem cell responsible for neuroblastoma tumours was isolated. Based on that work, senior scientist David Kaplan, who heads the cancer research program at HSC, plans to test existing drugs to see if they will kill those stem cells. "If we find an existing drug that works, maybe we can use it on patients soon," he says.

Risa Torkin, a post-doctoral fellow working with Kaplan, is another scientist who was profoundly touched by James's story. She remembers thinking when the little boy died that "we just didn't work fast enough." At the time, she was studying the disease as part of her doctoral thesis and had no intention of continuing on after she graduated.

But that all changed shortly after James died. She was at a meeting where Syd and Pam were to distribute grant money from the fund. The couple, their grief still clear on their faces, asked the assembled scientists about their research. They also talked about their son and his own course of treatment. "I don't want to sound corny, but it was a very profound moment," she says. "To see these parents sitting there asking questions, knowing that any advances could never help their son. They were so brave. It was unbelievable to me, and so inspiring. I knew then that I couldn't change my focus."

Today, with funding from the James Fund, Torkin is a post-doctoral fellow working both for David Kaplan and a former colleague of his, Barbara Hempstead, who heads up a major research lab at Cornell University in New York City. Torkin is studying a protein that may encourage neuroblastoma cells to metastasize – identifying this protein is a major first step in finding ways to stop it in its tracks. Her American colleagues are impressed by the support she gets from the James Fund founders. "On bad days when nothing is working out, I remember that someone really cares about the work and we might be helping the greater good later," she says.

When they started the fund, the Birrells shared the story of their little boy who loved trains and astronauts, the colour green and the movie *Apollo 13* starring his friend Tom Hanks, in hopes of finding a way to save him. Now they're sharing his story to help researchers save the James Birrells yet to be born.

Reilly, for one, believes the James Fund "will make the difference. It's no longer about what happened to James," he says. "I think the impact of the James Birrell story is to change what has been the story of neuroblastoma in the past to what it could be in the future. The ending to that story hasn't been written yet. Maybe Syd and Pam are actually writing the ending right now." ●

## Put Your Money Where Your Heart Is

How do you choose where to spend your health charity dollars? Follow your heart, says Lisa Hartford, manager of media relations and communications at Imagine Canada. Research conducted by Imagine Canada, a new umbrella agency for charities and nonprofit organizations, shows that we donate for very personal reasons. "Just as the personal story of James Birrell engaged researchers, what we know about donors is that they engage for the very same reasons – because they are compassionate and concerned about a cause."

Compassion is the No. 1 motivator for giving, followed by a personal belief

in the cause and, thirdly, by being personally affected, says Hartford. "I encourage people to look for causes that touch their family and community and to direct their donations to something meaningful to them on a personal level," she adds.

Large charities allow donations to specific funds. The Hospital for Sick Children Foundation, for example, allows you to direct dollars to the James Birrell Fund. United Way has a similar policy. Visit [www.canadahelps.org](http://www.canadahelps.org) for links to more than 80,000 charities registered with the Canada Revenue Agency.