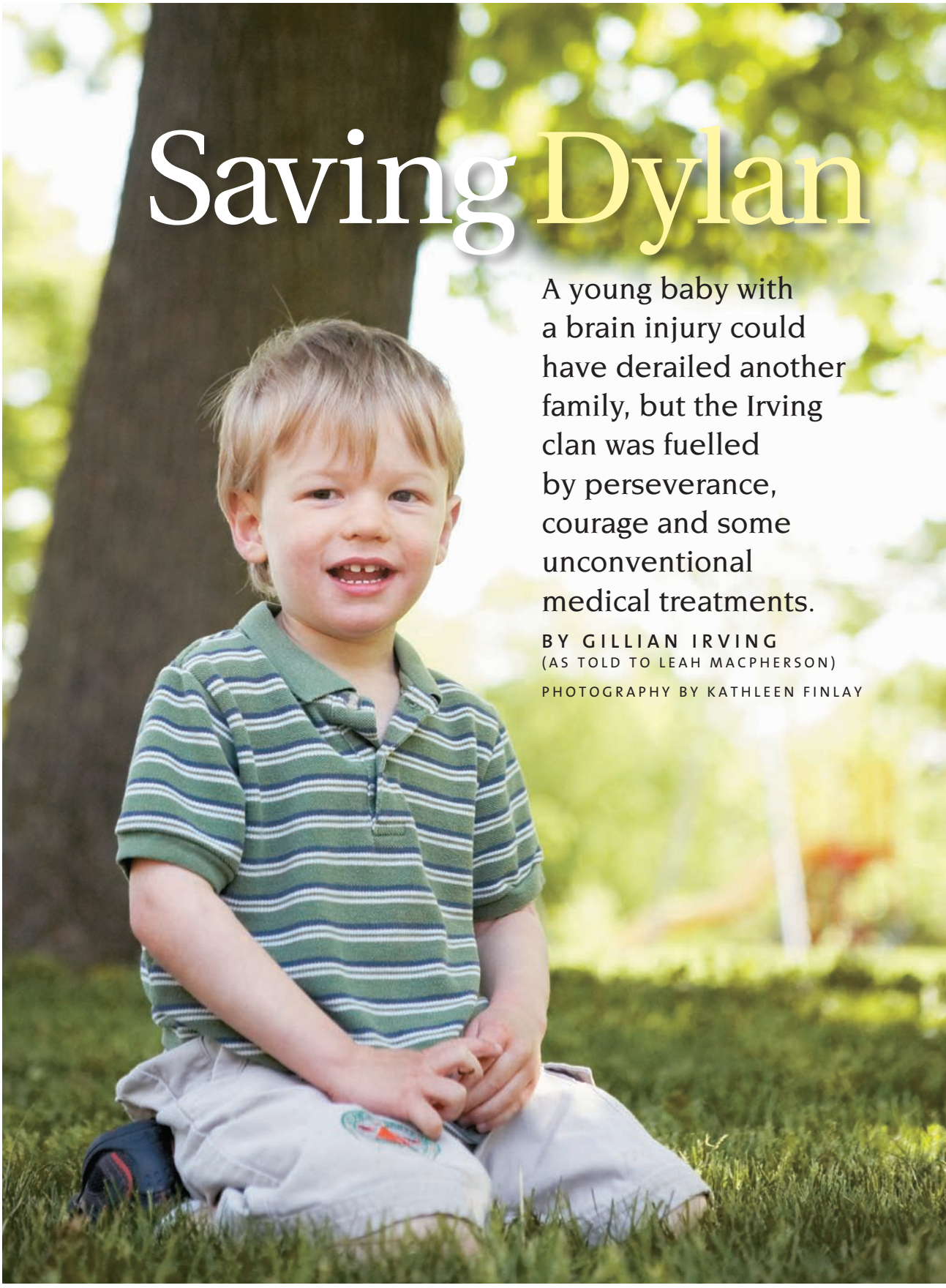

Saving Dylan

A young baby with a brain injury could have derailed another family, but the Irving clan was fuelled by perseverance, courage and some unconventional medical treatments.

BY GILLIAN IRVING
(AS TOLD TO LEAH MACPHERSON)

PHOTOGRAPHY BY KATHLEEN FINLAY

The neurologist's words jolted through me like a seismic wave: "Part of your son's brain is missing," he told my husband, Jonathan, and me as we stood in a consultation room at the Hospital for Sick Children in Toronto. It was clear from the MRI images the doctor showed us that something was very wrong: curly bits of brain matter filled the entire screen except for the black void in the lower left part of the scan. It was shocking to hear those cold, impersonal words about Dylan, our tiny three-month-old infant.

The numbing disbelief quickly gave way to a disturbing question: How could this have happened when I'd had such an uneventful pregnancy and delivered what appeared to be a perfectly normal baby?

The mystery of Dylan's injuries would remain unsolved for weeks, but eventually we learned that before he was born, Dylan fell victim to an infection caused by a common parasite called *Toxoplasma gondii*. I had somehow ingested this parasite and unknowingly passed it on to him.

Only weeks before this hospital meeting, we were a healthy, happy family, blissfully unaware of the heartbreak that lay ahead. Jonathan and I had always wanted a big family, and we were overjoyed when our third child was born in Toronto in October 2004. Five weeks premature, Dylan was, nevertheless, a hale and hearty six pounds two ounces at birth. We were able to join Jonathan and Dylan's older siblings – Aidan, 4, and Ella, 2½ – at home just 24 hours later. With a newborn, a toddler and a preschooler, our house was a place of happy chaos.

By six weeks, Dylan had been to all of his well-baby checkups and had reached all of his early growth milestones. But while no one else suspected that anything was wrong, ▶

I began to sense that something wasn't quite right with Dylan. As a doting mother, I eagerly anticipated that first baby smile and longer periods of wakefulness. At first, I attributed his lack of response and sleepiness to prematurity: surely once Dylan caught up to other babies his age, he'd be giving us big, gummy grins and be more aware of his surroundings.

Instead, as the weeks passed, we began to notice other unusual behaviour. Dylan's eyes seemed to be roving and rolling in an irregular way. Just before the holidays, we took him to a party, eager to show off our new little man. He happened to be very wakeful that evening, making these erratic eye movements unmistakable. I could tell that other guests noticed his eyes but felt awkward about mentioning it. A knot formed in my stomach, and after we put Dylan to bed that night, I couldn't sleep. There was now no doubt in my mind that something was wrong with my son. During the dark watches of that night, I had a terrible epiphany: he wasn't smiling at us because he couldn't see us.

Jonathan and I marched into our family doctor's office the next morning. I was adamant when I told her, "My baby can't see." The doctor took our concerns seriously; the fact that she couldn't get Dylan's eyes to fix on a light – something that even newborns can do – convinced her to probe further, and she immediately ordered a full assessment. The tests confirmed our suspicions: Dylan could see very little, if anything. I held Dylan close and tried to quell the rising panic. In that moment, I had a chilling premonition: what if his lack of sight was the tip of the iceberg, a symptom of some greater problem?

The period between Christmas and New Year's passed in an anxiety-filled fog. We were back at Sick Kids ▶

TOXOPLASMOSIS PREVENTION

At any one time, one-third to one-half of all people are chronically infected with *Toxoplasma gondii*, the parasite that causes toxoplasmosis, says Dr. Rima McLeod, a professor at the University of Chicago and an expert in toxoplasmosis treatment and research. For the most part, though, our immune system keeps the parasite in check so we never develop visible signs or symptoms of disease, and some of us are blissfully unaware that we ever carried the parasite, she says.

It's a different story for women who are pregnant. If exposed to the parasite before pregnancy, a mother's immune system protects her and her baby when she does get pregnant. However, acquiring *Toxoplasma gondii* for the first time during a pregnancy is dangerous because the fetus's immature immune system is less able to mount a protective defence against the disease. The fetus may develop serious complications, such as eye diseases, hearing loss and cognitive or motor abnormalities.

Felines – both domestic and wild cats – carry *Toxoplasma gondii*. When a cat eats meat or something else containing the parasite, oocysts (highly infectious forms of the parasite) are formed in the cat's intestine and are eliminated with the feces. These oocysts contain highly infectious sporozoites that can remain in soil for up to a year and in water for at least six months. People who eat fruit or vegetables that have come in contact with contaminated soil, or meat from animals (cows, sheep, pigs, etc.) contaminated with oocysts, can become infected.

Toxoplasmosis can be detected with a blood test that checks for antibodies to the parasite. In countries like France, national screening programs test all pregnant women monthly. If the parasite is detected, treatment begins immediately to eliminate the active form of the parasite.

According to the *Canadian Medical Association Journal*, up to 1,400 cases of congenital toxoplasmosis are reported in this country every year. Since this is considered a relatively low incidence, screening for the disease is not a part of routine prenatal or newborn care in Canada. Instead, increased awareness and education about the risk factors of the disease is widely considered the most effective method of prevention.

If you are pregnant, take the following precautionary measures.

- **Avoid raw or cured meats.**
- **Use hot, soapy water to thoroughly wash anything that comes in contact with raw meat, including cutting boards, knives, other utensils – and your hands.**
- **Cook meat until there's no trace of pink, the juices run clear and the meat reaches an internal temperature of 71 C (161 F), or well done.**
- **Wash all fruit and veggies thoroughly under running water or use a vegetable wash (Canadian brands such as Nature Clean and Echo Clean are widely available in natural food stores), particularly if you're planning to eat the food raw.**
- **Avoid raw goat's milk products, including goat cheese.**
- **Garden with gloves: (have you ever seen the neighbour's kitty use a flowerbed as a latrine?).**
- **Wash your hands thoroughly with soap and water after working outdoors in soil or sand; cover your children's sandbox to keep felines out.**
- **At home, have someone else clean and dispose of the contents of the cat's litter box.**

In my darkest moments of despair, when I didn't think I could be brave and strong for another moment, there was a beacon of hope.

the first week of January 2005 for a battery of CAT scans, MRIs, eye exams and blood tests. The news was both (relatively) good and bad: Dylan still had some undamaged retina, so he might have some useful vision. The MRI results we saw during that fateful consultation were the bad news: most of Dylan's left occipital lobe and part of his parietal lobe – the parts of the brain that control important functions like vision and language development – were missing. We finally knew what was wrong with Dylan.

As for what to expect in the future, we were told that because Dylan was so young, the implications of his brain injuries were difficult to determine. In addition to limited vision, Dylan might never walk or talk. He would likely be severely cognitively disabled.

The news was staggering. And it raised so many more questions: How would we cope? How would it impact our other children? How could I ever go back to work? How would we pay for treatments Dylan might require? Would we ever do "normal" things again, like take a family vacation? The enormity of the news was overwhelming – the course of our lives had been forever altered.

But just as devastating was learning how Dylan had acquired these injuries. Using the telltale calcifications on Dylan's brain, his eye damage and results from blood tests on both Dylan and me, doctors determined that his problems were due to an in utero infection caused by a common parasite (see "Toxoplasmosis Prevention," page 76). The doctors hypothesized that I had been exposed to the parasite for the first time during pregnancy, perhaps through a slice of medium-rare meat or an unwashed piece of fruit. I was appalled. I'd had two other healthy pregnancies and never took unnecessary risks. But something had gotten past me. I struggled not to blame myself, but I felt like I had failed my son.

While parts of our family life went on as usual – getting the other kids off to preschool, organizing birthday parties, tending to scraped knees and loose teeth – the next six months passed in a blur of blood tests, pill grinding and trips to the hospital. The drugs Dylan was taking to help eradicate the infection and prevent further damage can have toxic effects, so doctors had to monitor his immune system regularly. Several times I was at the hospital five times a week.

Jonathan came with me when he could, but as the family breadwinner, most of the time he had to work. As supportive as our family and friends were, most of them had jobs and other responsibilities, too. So, more often than not, I spent long hours alone with Dylan at Sick Kids. I came to dread those visits – the sterile corridors, the agonizing, four-hour stretches in the waiting room and the clenched, fear-filled faces of the other families.

The constant pressure was dragging me down. By spring I had hit a new low, sunk deep in misery. Some days I didn't want to get out of bed. I couldn't stop crying. I was drowning in tears, choking on helplessness. I got up every day and went through the motions of life – shuttling the kids around, making lunches, caring for Dylan – but I felt so helpless and so hopeless.

One morning, in an effort to allay the boredom of the waiting room, I wandered into the Sick Kids library. I wanted something – anything – to take my mind off things. I literally pulled the first book that I touched off the shelf. Ironically, it was called *What to Do* ▶

About Your Brain Injured Child by Glenn Doman. The book was based on a therapy program at the Institutes for the Achievement of Human Potential in Philadelphia, a nonprofit educational organization. I started reading it and for the first time I didn't want the nurse to call Dylan's name.

Based on the premise that you can train other parts of the brain to compensate for an injury – essentially rewire it – the book was full of practical ideas for an intensive therapy program of auditory, tactile, visual and physical stimulation. I knew nothing about the book or the institute, but it just felt right to me. In my darkest moments of despair, when I didn't think I could be brave and strong for another moment, there was a beacon of hope. In a heartbeat, I felt like I went from powerless to powerful: we had finally found something that we could do to help Dylan.

A few months later, Jonathan and I went to the Institutes for the Achievement of Human Potential for evaluation, training and lectures based on the book. The doctors there designed a therapy program just for Dylan based on his unique abilities and injuries. Since then, we've been back three times to update the program. We have converted one bedroom in our house into a therapy room (Dylan gets therapy six hours a day, seven days a week). It's filled with ramps and gym equipment, projectors, flash cards, a massage table and audio stimulators. There's even a custom-designed apparatus that suspends Dylan from the ceiling like an acrobat to help improve his balance, equilibrium and leg strength.

Dylan needs other monitoring, too. He eats a healthy balanced diet with no sugars or refined foods, and we record such things as the number of steps he takes. (This information will help shape the next stages of his therapy.)

To do all this, we have a team of more than 20 volunteers – family, friends and neighbours take time out of their busy lives to help. Organizing all the schedules and the ongoing training of volunteers is time consuming, but Dylan's amazing progress has kept everyone motivated and gives me the stamina to keep it all going.

Our family has made many sacrifices for Dylan. Because I do therapy with him every day, I was unable to go back to work as a marketing consultant, creating an added financial strain on our household. We have spent thousands upon thousands of dollars on trips to consult with specialists, therapy equipment and extra child care for our other children. If not for the extraordinary generosity of Dylan's grandparents, I don't know how we would have raised the necessary funds.

Today, Dylan has come further than we or any of his doctors would ever have imagined during those bleak early days. In many ways, he's a typical toddler. He loves music, trucks and balls, and playing with his older brother and sister. His vision is limited, but he can recognize things like people and pictures. He walks, runs and even talks, although mostly in single words and couplets. Happy and full of laughter, he begs for hugs and kisses and melts in my arms when I pick him up.

Having seen him come so far, I have an unwavering faith that anything is possible. Our goal is to continue with Dylan's therapy until he catches up with his peers; we want him to go to public school just like any other kid. The higher we aim for Dylan, the higher he'll climb. This is our little boy, the one doctors said would probably never walk or talk. The heart-wrenching irony of Dylan's first complete sentence sends a surge of hope and joy through my heart: "I see you." ●