Miracles do happen

Young Harry Feller doesn't know it, but he could hold the key to a revolutionary new therapy to cure blindness, writes **Susan Horsburgh.**

PHOTOGRAPHY ● **DAVID HAHN**
STYLING ● **LEDA ROSS**

HAIR AND MAKE-UP BY KIM TAVARES. HARRY WEARS ZARA TOP AND PANTS. DANIEL WEARS ZARA T-SHIRT AND TRENERY SHIRT. HOLLIE WEARS ZARA TOP AND SABA JEANS. OPPOSITE: HARRY WEARS ZARA SHIRT. THESE IMAGES HAVE BEEN RETOUCHED.

After an agonising six-month wait for genetic test results to arrive, Hollie and Daniel Feller were led into a small Melbourne hospital room in February 2014 to learn their little boy's fate. The geneticist didn't need to say a word. "Her hands were shaking holding the piece of paper," recalls Hollie. "Then I knew."

The couple's third child, Harry, had been born deaf less than three years earlier – which was shocking enough – but the latest news came like a body blow: their only son had Usher syndrome, a rare genetic condition that would eventually make him go blind, too.

"You know when you're about to faint and you go all hot and sweaty and prickly?" asks Hollie. "It was just like that. I felt sick. You have a deaf child, you've spent two or three years dealing with it, you're on top of it, you're happy, and then bam! You're hit with a second diagnosis and you're just thrown." Says Daniel, "It's devastating."

The meeting was over in five minutes – because there was neither a cure nor a treatment to talk about. "There was nothing they could do," says 46-year-old Hollie. "There was no support group, no other families they could connect us to." Googling didn't offer any consolation, either. Harry would start losing his peripheral vision by the age of 10 and be legally blind by the end of adolescence, left with only the narrowest tunnel vision.

The Fellers, however, refused to accept it. They scoured the internet, went to an international Usher conference, quizzed experts all over the world and eventually networked their way to researchers in Melbourne, who gave them what they needed most: hope. According to world-leading scientists at the Centre for Eye Research Australia (CERA), Associate Professors Alex Hewitt and Alice Pébay, a revolutionary gene therapy could stop Harry losing his sight – and cure a host of other inherited eye diseases – by repairing the faulty gene that causes his retina cells to degenerate.

ABOVE: Daniel and Hollie Feller with (from top) daughters Tess, 13, and Alice, 10, and son Harry, five.

> "It's going to be down to the wire ... but it's more than hope."

In the genes

Harry had cochlear implants when he was 10 months old, so has learnt to hear, but now the race is on to save his sight. Fortunately for Harry, he's an ideal research candidate because his vision hasn't started deteriorating yet (his glasses are for an astigmatism that has nothing to do with Usher syndrome), which means scientists could potentially stop it. The researchers know how to do it in theory, but need $3 million for a world-first human trial. With the Fellers, they've set up a charitable foundation, Genetic Cures Australia (GCA), to fund the final development and approval of this treatment. "Wouldn't it make you cross, knowing the knowledge and technology to potentially cure your kid is available, but there isn't the financial backing to do it?" asks Dr Hewitt.

The researchers have already taken skin cells from Harry and turned them into stem cells; now they need to do experiments on those to make sure the gene therapy is safe enough for a clinical trial. It is not commercially viable for big pharmaceutical companies to work on treatments for rare diseases, and Australians don't usually get to participate in clinical trials conducted overseas, so not-for-profit GCA aims in the longer term to give local patients access to gene-based therapies here in Australia. That way, says Dr Hewitt, Australians wouldn't need to go abroad for "quack stem-cell therapies".

If the proposed gene therapy works as expected on Harry, researchers would be able to use it to potentially fix any number of inherited eye diseases – and beyond. "You could use it for any disease, basically," says Dr Pébay. "This isn't just about a rare disease that affects no one. The repercussions are major." It could take more than five years before Harry is treated, but the researchers are optimistic. "It's going to be down to the wire with Harry," says Daniel, "but it's much, much more than hope."

Today, at the Fellers' Melbourne Bayside home, Harry plays on the floor with his train set, »

oblivious as his parents talk to *The Weekly* at the kitchen table. He is weary after a sleepless night. At one point, Daniel tries to cajole him into speaking with a cockney accent, but Harry replies, "Too tired". Usher syndrome causes night blindness and Harry takes off the exterior parts of his cochlear implants at bedtime to recharge them, so Hollie sits with him every evening until he falls asleep, worried that her five-year-old is scared without sight or sound.

Not that Harry ever complains. "He's just a really tough kid," says Hollie. "He is so stoic and he doesn't want to be different – so he'll just work it out. He knows that his ears are different, but he says to his middle sister, 'Are you getting your cochlear implants for Christmas this year?' Alice has to go, 'I'm not special enough to get them', and he says, 'I don't want to be special, I want to be normal like everybody else'."

ABOVE: Harry and his sisters, Tess (left) and Alice. They don't have Usher syndrome and the chances of Harry being born with it were one in 650,000.

The only one in Australia

Daniel dreads having to tell Harry about his possible future. "I don't want him to lose his confidence," says the 45-year-old brand consultant. "One day, he's going to say, 'I can't see anymore.' I personally think he'll deal with that, but we just don't know."

For now, though, the gregarious kindergartener has no idea about his Usher syndrome. If it weren't for a newspaper article, his parents probably wouldn't either. In 2013, Daniel read a story about a deaf Melbourne boy with Usher syndrome, Louis Shepard, who was losing his sight and going on a helicopter ride to build up a visual memory bank. The article also mentioned the child's balance issues, which called to mind the Fellers' biggest concern at the time: two-year-old Harry's inability to walk. "I read it," says Daniel, "and thought, 'Oh, God, this is what my son's got'." Yet doctors brushed off the Fellers' requests for genetic testing, using Harry's deafness to explain the walking delay and insisting Usher syndrome was too rare to worry about.

Eventually, though, they relented when the Fellers mentioned they were both of Jewish descent. Usher syndrome, which affects more than 700 Australians, comes in a variety of types, but type 1F (the one Harry has) is caused by a gene associated with Ashkenazi (or Eastern European) Jews. Only about 5000 people in the world are thought to have type 1F, and Harry is the only one currently known in Australia.

> "Hollie sits with him every evening until he falls asleep."

Hollie often ponders the sheer unlikelihood of Harry's existence. Born in the UK, but raised in Australia, she moved back to London in her early 20s and had been there for 10 years when her flatmate offered to set her up on a date. Hollie had no interest in meeting a "nice Jewish boy", but her friend insisted – and they fell in love. "I never went out with Jewish guys and I was like, 'No, no, no'," recalls Hollie. "The chances were one in 650,000 that we would come together and activate [the gene mutation]. Crap, really. But you have to take what you've been given and make the most of it."

Globally, only four in every 100,000 children are born with Usher syndrome. Those with Harry's Usher type 1F are born profoundly deaf with balance problems, and lose their sight from around the age of 10. This has traditionally meant that deaf kids have not been diagnosed with Usher until their early teens, when their sight becomes so restricted they start tripping over things. "How bad is it being 13 anyway [without] dealing with that?" asks Hollie.

This year, Hollie has been educating clinicians so that the syndrome is picked up earlier with genetic testing, and kids and parents can adjust to the diagnosis.

Adamant that no other family should face the same isolation and ignorance that they did, Hollie and Louis' mother, Emily Shepard (who remarkably lives just a few suburbs away), have »

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set up UsherKids Australia, a support group based around a website offering information to parents of newly diagnosed children.

The Fellers also recently launched an awareness campaign, posting photos of train-lover Harry at different railway stations and urging supporters to do the same. Pictures have come in from around the world and, in October, even Prime Minister Malcolm Turnbull got behind the cause, posting a shot of himself boarding a carriage ("Harry is 5 & like me loves trains") on Twitter. Mad Hawks fans, Harry and Louis also ran through the banner at an AFL game in September.

Possible cure

For Hollie, the campaigning has been a positive, productive way to deal with something that she admits has left her occasionally feeling "unhinged". While Daniel is relentlessly upbeat and focused on a speedy scientific solution, Hollie is perhaps more pragmatic, shuttling Harry to his appointments and dealing with the day-to-day needs of Harry and his two sisters, Tess, 13, and 10-year-old Alice. "You don't have any time to think about it … to grieve," says Hollie, who is preparing Harry for his start next year at a mainstream primary school that caters for the hearing-impaired. "I had two other kids to look after, I couldn't just break down in tears if that's what I wanted to do. You just have to keep going, focusing on their learning and development."

Tests show that Harry's language skills are actually better than those of an average five-year-old hearing child, and that is thanks to the work Hollie has put into her son. After he had his cochlear implants, for example, she would show flashcards over and over to one-year-old Harry in his highchair. "He would have to listen to a word thousands of times before the brain picked it up and interpreted it, because with a cochlear implant the brain has to decipher what's background noise and what's speech," she says. "It takes 12 to 18 months before the speech starts to unravel, and in that time you just have to expose them to books and words and pictures. It was absolutely a full-time job."

ABOVE: The Fullers haven't told Harry about what the future may hold, but focus on giving him a full life.

Harry has also benefited from having to keep up with two older siblings. "Alice doesn't take any prisoners," says Hollie. "She will play with Harry and talk and talk, and he has to work it out. If he wants to play with her, he needs to be able to manage her language."

After keeping Harry's diagnosis secret from their daughters for more than two years, Hollie and Daniel finally told them in July, taking them to the CERA lab to reassure them that a cure was possible. "The girls understand that he's going to have a harder road than them and they just love him for who he is," says Hollie. "I don't doubt he will change their lives for the better. They are into causes, they are very humble about what other people have to go through, they're very sensitive towards his and other people's needs, and now they're interested in science."

Although not religious, the family celebrates the festive season as a time of togetherness and thanksgiving, and in January they plan to take the ferry to Tasmania for a campervan trip around the island. The walks, says Hollie, will be like physio for Harry and he'll have the chance to see beautiful scenery. For transport-obsessed Harry, though, it's all about the ride; in preparation, he has been watching YouTube videos on how to empty the campervan toilets.

A cure for Harry's impending blindness might be a few years away, but the Fellers are savouring his childhood and making precious family memories in the meantime, confident science will eventually have the answer. "People have said to me that Harry's is such a sad story, but it's not," says Daniel, "because now Harry has hope he didn't have before. Modern miracles can, and do, happen." **AWW**

For more information about and to make a donation to Genetic Cures Australia, visit geneticcures.com.au.

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