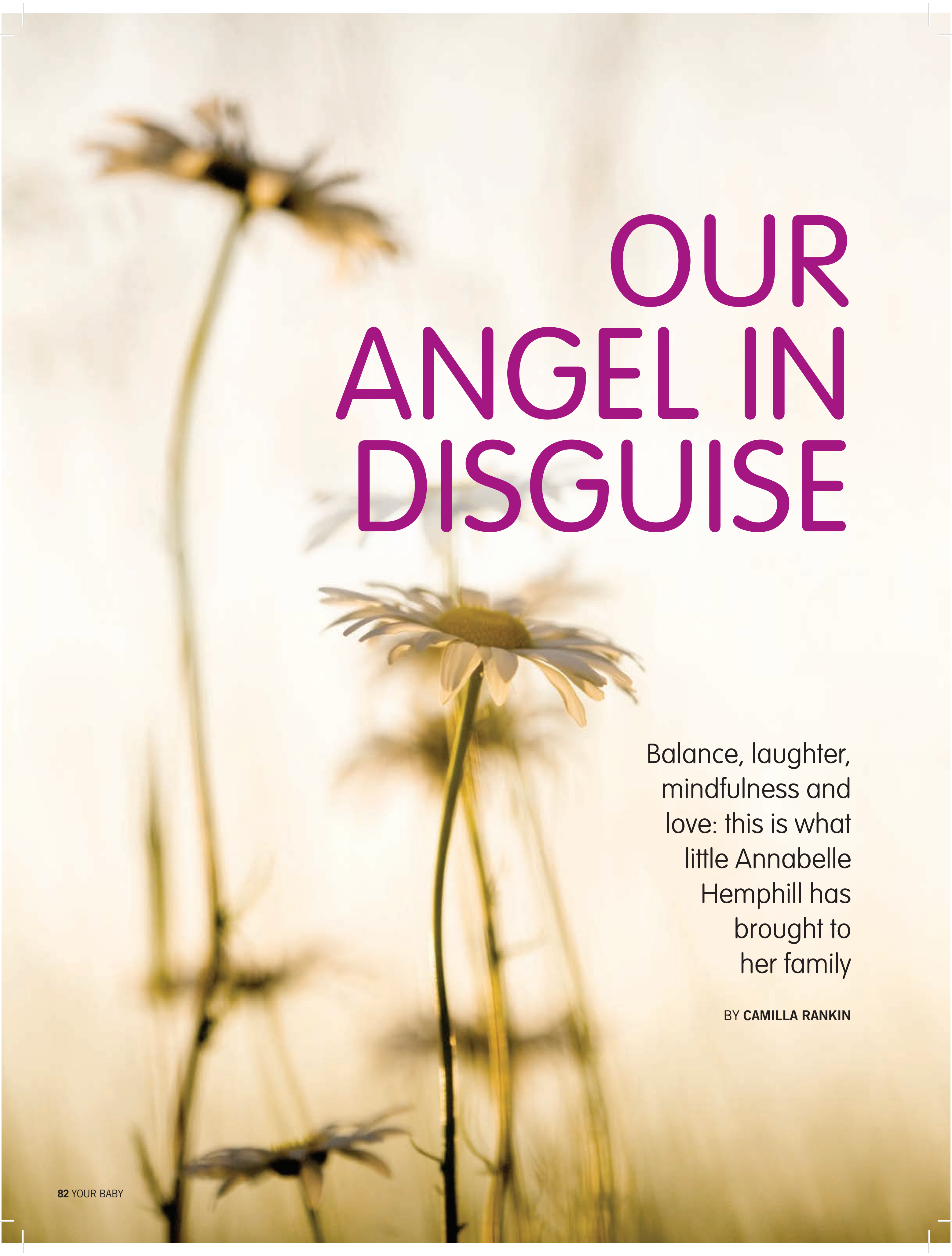

OUR ANGEL IN DISGUISE

Balance, laughter,
mindfulness and
love: this is what
little Annabelle
Hemphill has
brought to
her family

BY **CAMILLA RANKIN**

A unique blessing **After a misdiagnosis of Velo-Cardio-Facial Syndrome, Annabelle was diagnosed with a translocated gene, but her mom wouldn't change anything about her**

Annabelle Hemphill was born with severe cognitive and physical handicaps but the positive impact this energetic little girl has had on her family is amazing. Here is what her mother, Anne, has to say.

Something's amiss

"The first time I saw Annabelle I was completely shocked: she was blonde! Our eldest daughter, Olivia, had been born with very dark hair and I was just so surprised that we could make a baby that looked any different!

"Annabelle was born very calmly via elective C-section, after an uneventful pregnancy. I held her, skin-to-skin, immediately after birth. She tried to latch straight away, but was just not able to get to grips with it. In those hazy moments after birth, I did not think too much of it. But as I looked at her, I could not shake the feeling that she looked a little strange: her eyes were closed, but for me, it was her toes – they were not quite right. I thought I was being silly, so shook the feeling off. It was only later in the maternity ward, when a nurse tried to clear Annabelle's throat that we realised that all was not perfect with Annabelle: she had an internal cleft palate. And so began our journey."

Rude awakening

"At first I pushed aside the feeling that a cleft palate was the least of Annabelle's problems, thinking I was just being paranoid. My husband, Bruce, was being very perky and stoic about everything, so I thought I was being a bit 'doff'. Until the second night, when he just broke down crying and the realisation that our daughter was not absolutely perfect really hit us.

"Those first few days in hospital were a daze. A number of specialists came and assessed Annabelle. One doctor told us that Annabelle had a condition called Velo-Cardio-Facial Syndrome (VCFS). As he described all the things that were 'wrong' with our child, I was bordering on hysteria: she had a hole in her heart, delayed retinal development (which is why her eyes had not opened), she would have major cognitive issues, learning difficulties, the list seemed to go on and on. At one point a speech therapist told me that Annabelle would not be able to say 's' properly and I thought: 'This is ridiculous, she is only three days old, she won't be talking for two years, why are you telling me all this now?'"

One in a million

"I became quite obsessive about finding out exactly what was 'wrong' with Annabelle. I would spend hours searching the internet at work – I became pretty useless; I was a lawyer at an investment bank at that stage. I would be googling away and my boss would come in and ask me what I was doing and, barely lifting my eye from the screen, I would say, 'Just looking something up,' and my boss would respond, 'Okay then, can I get you a cup of tea?'

> "I would spend hours searching the internet at work"

I did manage to track down the doctor in America who was the leading expert on VCFS and I brazenly emailed him descriptions and pictures of Annabelle. He, amazingly, answered immediately to say that Annabelle was not a VCFS child. Eventually I made contact with a genetics clinic in Houston who have the equipment to do fine DNA testing and discovered that Annabelle has a translocated gene –

very simply a gene that for some reason or other during very early development, 'swopped' its position on the DNA chain. It is not an inherited condition, it is a one-of-a-kind developmental 'mishap' and no one understands exactly why or how it happens – it just does and results in a slew of cognitive and physical abnormalities."

Coming to terms

"Annabelle's first year took us through the offices of so many doctors, specialists, genetic researchers and counsellors as well as physio-, speech and occupational therapists. When Annabelle was about four months old she had not yet reached a single milestone – she couldn't lift her head or even smile. An occupational therapist told me not to bother coming anymore as therapies were just a waste of time, she would never be able to do anything. I thought, 'Stuff you, I am going to give Annabelle the best of everything we can,' and we did. So when, on her first birthday, she smiled for the first time, my joy was palpable. That smile was the best thing that has ever happened to me: literally the best day of my life."

Finding balance

"When Annabelle was first born, a friend, who did not have children of his own, came to the hospital and said, 'You are so lucky to have such a special child.' At the time I thought, what a ridiculously stupid thing to say and told him so. I have had to call him since to apologise and tell him how right he is: I would never go back.

"Bruce and I were like ships passing each other in the night before Annabelle, now we are a cohesive unit, we were forced to learn how to really communicate with each other.

"When Annabelle was a year old, I resigned from work. As I left my work on that last day I felt as free as a bird and my being at home has restored a sense of balance to our home. And the laughter… Annabelle has brought so much laughter into our home too: in some situations there really is no other alternative but to laugh. Annabelle hates cars and screams like a banshee when she is in one. Once on the way home from a holiday, I was pulled over for speeding. When I opened the window and the office heard the high-pitched wailing coming from Annabelle, he just looked, nodded and said, 'Ma'am, drive like the wind, drive like the wind to get home, just be careful of the speed trap 10km down the road, but then drive like the wind.'"

Nine years on

"Annabelle is such a loving child, there is not a malicious or unkind bone in her body and in many ways she is easier than my other two children. She can sit, walk, feed herself and she loves TV. We are still struggling with potty training, and parts of her speech are still not great, but as her speech therapist pointed out when Annabelle once told her to 'f-off', she can say her f's brilliantly!

"She has taught me, us, to live in the moment and that you simply can't control everything in life – which for a type-A personality like me, is quite a lesson to learn. It has been an impossibly hard journey and who knows if we are doing it right, but then what parent ever thinks they are getting it all right? And yes, I do often think: 'Can I stop learning this lesson now?'"

In retrospect

"If we had had any indication during our pregnancy that our child would have such handicaps, Bruce and I would have terminated but now, knowing Annabelle, we would not change a thing. Annabelle's first year was a definitely a disaster but once I resigned and she gave us her magic first smile, I realised that having a handicapped child is not the worst thing that can happen to you.

We live in a society fixated on perfection, so when something is not perfect, it feels like it is wrong. But life is not really like that if you are able to see beyond the handicap and learn to see the child. I love how in the Jewish religion, when a handicapped child enters the room, people will stand up in respect. A handicapped child is seen as free of sin, as a person untainted by life: Annabelle is always kind and loving – she is a perpetual Duracell bunny of happiness." ●

All smiles **Annabelle blesses the home with lots of laughs, says Anne**