

LIFE



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Autumn-winter trends from Milan Fashion Week

> LUXURY C7



Tray chic
How table-side service is staging a comeback

> FOOD & WINE C6

Instant charmer
A peek inside the creative world of Tom Dixon



> TECHNOLOGY & DESIGN C8

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Running up and down the field at Sunday rugby matches with a whistle around her neck, Mui Thomas is a pretty special referee – the world’s first rugby umpire living with Harlequin ichthyosis, a rare congenital skin disorder.

In fact, the 22-year-old’s life has been something of a marvel. Harlequin ichthyosis causes babies to be born with large plates of very thick, hard skin covering much of their body. The inflexible patches of skin can distort facial features, affect the child’s ability to regulate body temperature, and their ability to fight infections as the skin cracks and splits apart.

Initially, doctors did not expect her to survive but under the care of her adoptive parents, Tina and Rog Thomas, Mui has thrived.

Mui came into the Thomases’ lives unexpectedly in 1994. “We were saving to emigrate to Australia before starting a birth family,” says Rog, a freelance writer and writing coach. In the meantime, the couple decided to do some volunteer work, and signed up for a weekend fostering programme run by the Social Welfare Department, which aimed to prepare local children for overseas adoption.

That’s when they met Mui, then 18 months old, who had been abandoned at birth. Tina, then teaching at a learning centre, began spending a few hours with her at the Duchess of Kent hospital every other day.

But “because she had so many trust issues it took more than six months before she could come home with us,” Tina recalls. “At the beginning of each hospital visit Mui would scream, rip off her skin and tear out her hair. There would be blood everywhere. It got progressively worse, lasting up to 40 minutes.” Yet once the toddler stopped crying, she became inseparable from Tina.

Eventually, the Thomases figured out that Mui was angry because Tina had left at the end of each visit.

“When she was in pain and bleeding, she wouldn’t cry,” Tina recalls. “She would just lie there because she had learned from experience that her tears did not bring her the immediate attention ordinary babies get.”

Despite the emotional upheavals, the Thomases began having Mui home for weekend visits. As the couple began to get more involved with Mui, several friends and medical professionals advised them to walk away. But when she was moved from the hospital to an institution that was entirely inappropriate for her needs, the Thomases decided they had to

step forward to adopt the child.

Having faced some dark times growing up in Germany and suffering a nervous breakdown at the age of 19 as a result, Tina says she was determined “to be of help to people in need”. Those experiences gave Tina the strength and resolve to cope with initial months of bloody rejection from Mui and the years of health issues.

The severity of Mui’s condition became apparent to the Thomases only gradually. Her skin could break open easily and was prone to infection. And because the skin was so tightly stretched across her body, her lungs did not develop properly when she was little. “At one point, the doctor told us they were using the last antibiotic available,” says Tina. “We were told bluntly that she was not expected to live,” Rog adds. It was only when Mui was about 12 that they began to think she might have a future. To their knowledge, she is the fourth oldest surviving person with Harlequin ichthyosis.

Each time Mui pulled through, she was breaking new

ground medically. Knowledge on how to treat the condition is limited, and Tina credits Chinese University paediatrics professor Anthony Nelson and his team at the Prince of Wales Hospital for keeping Mui alive.

(Throughout her life, Mui must take twice-daily baths during which she must scrub off the hard upper layers of skin that have built up, and then apply cream throughout the day. Her calorie intake rivals that of an international athlete because her body grows as much skin overnight as an ordinary person produces in a fortnight.)

Growing up was an emotionally harrowing time as Mui was in and out of hospital, with Tina and Rog expecting the worst each time. “It was very much a roller-coaster ride,” says Tina. “We could plan nothing.”

And yet, they got on with their daily lives, having fun and giving Mui a normal childhood. “We’ve never hidden Mui away as some people suggested. We always took her with us everywhere. I always pushed her forward to say hello and made sure she interacted with people,” says Tina.

Passers-by sometimes had extreme reactions when they encountered Mui in the streets. “People would scream, run away, hide their children’s eyes, invite friends to come stare and follow us,” says Rog.

Once an elderly woman spat



I wanted to be like everyone else. I wanted to look perfect and fit in

MUI THOMAS

in his wife’s face and accused her of burning Mui. However, Tina controlled her reaction and walked on. “I didn’t want Mui to feel frightened by what happened. I wanted to help her to focus on the positive and not let other people ruin her day,” she says.

In their neighbourhood of Sai Kung, the couple made an effort to introduce Mui and explain her condition, which helped them get to know more residents and their daughter to gain confidence. “People were quite accommodating once I made the bond,” Tina says.

Residents and local shopkeepers would often offer Mui little presents when she was a child. That’s why Sai Kung has been like a safe haven for her.

“It’s a strong community and that helps with feeling more comfortable with myself,” Mui says. “Everybody knows me here so I don’t have to worry about being the odd one out.”

All the same, people can be very cruel and Mui went through a particularly rough patch during her secondary school years when she faced discrimination and bullying, both online and off. At the time, the teenager reacted by denying to herself that she had a skin disorder.

“I wanted to be like everyone else. I wanted to look perfect and fit in.”

As a result, her skincare routine went downhill and she became more confrontational at home, although her

parents saw through her facade. Struggling to cope with a spate of cyberbullying, she handed her mum a note saying she wanted to kill herself. (Cruel instant messages urging her to commit suicide made her distrustful of everyone at her school, and the police were eventually brought in to trace the bully.)

“The terrible thing was that because of the internet, the bullying came into our home,” says Tina.

Of the severe 10-month ordeal, Mui says: “It is still hanging over me. The internet is such a big part of life. The fear of being cyberbullied is never far from my mind.”

Mui’s experience with cyberbullying led the Thomases to chronicle their story in a book, *The Girl Behind the Face*, which also covers Tina’s background (“to give everything a context and a foundation”, Rog says). “I feel that regardless of what happened to you, you can help yourself best by helping other people,” says Tina.

The family has also launched a Facebook page under that name to share updates, publicise the project and, hopefully, attract a publisher that could give some marketing muscle to their book.

Mui has also begun sharing her story through talks at international schools alongside her parents.

She now works as an education officer at The Rock Foundation, an organisation that helps young people with special needs, and on Saturdays, she volunteers with Sailability, a charity that offers sailing experiences for people with limited physical abilities.

Mui, who acquired her dad’s love for rugby, was also keen to get into the sport. Since her condition made playing in a contact sport unfeasible, Tina and Rog encouraged Mui to make herself useful at the local

rugby club. Mui started off helping the DeA Tigers’ coaching coordinator every Sunday with scoring, timing and other odd jobs. But as much as she enjoyed that, Mui wanted to do more. So she trained to be a referee. “I like that I’m judged as an individual and not by my skin disorder.”

The Thomases are grateful for the support from different quarters. A staunch supporter is Sir David Tang, who funded their trip to a medical conference in Seattle, where Mui was able to meet another girl with Harlequin ichthyosis.

When she was 12, friends organised fundraisers to send the Thomas family on a trip to Disneyland and Universal Studios in Los Angeles. “All our expenses were paid, including hotels and transport by limo,” says Rog. “Support came from across Hong Kong: hotels, companies and individuals – one couple donated their honeymoon savings.”

A bubbly and articulate young woman, Mui has also met a number of celebrities through Tang, including former British prime minister Tony Blair, motivational speaker Nick Vujicic and supermodel Kate Moss, with whom she shared a daily irritant – they both get stared at in the street.

Many would regard the Thomases’ story as inspirational but they don’t see themselves as particularly unusual. For them, the difficulties associated with Mui’s skin disorder are just part of life.

“We get up in the morning and make breakfast like anyone else,” says Tina. Rog says: “We hope that when people notice our daughter running on a rugby field they won’t regard her as someone with a visible difference, they’ll simply see her as a rugby referee.”



Mui Thomas with her adoptive parents Rog and Tina Thomas (far left); Mui poses for *Young Post* as a student; refereeing a junior rugby match (top). Portrait: Nora Tam