



**POWER OF ACCEPTANCE**  
Rog and Tina Thomas gave Mui (left and inset) a second chance after she was abandoned because of her rare skin condition.

fair. Also, Hong Kong's best-loved sporting event, the World Rugby Sevens Series, has brought Mui into contact with leading players.

#### LOOKING AHEAD

Away from the pitch, Mui works as an education officer and videographer at The Rock Foundation, teaching life skills to adults with special needs. "I'm committed to helping people. It gives me a focus, and I get a salary." Her road to adulthood has been rocky at times, though she admits that connecting online with other HI sufferers – as well as others with personal problems who have been inspired by her story – is rewarding.

"A Frenchman with HI got in touch recently, so we have established a good network. We also heard from a South American woman who had been raped when she was a teenager and – like me – had contemplated killing herself."

Mui says she could never have got as far on her own. "My parents are the coolest kids on the block. I gave a TEDx talk and they were on stage with me. I'm amazed they can go on coping with someone as 'crazy' as me."

"We wrote a book together – *The Girl Behind the Face* – which is about the three of us. It's an inspirational story about courage, forgiveness, resilience and love. We haven't found a publisher yet. I can't be sure what the future holds, but the book means so much to us. I'd like to see it published, to spread the word, and go on helping others." <sup>MI</sup>

For more information, visit [facebook.com/GirlBehindTheFace](https://facebook.com/GirlBehindTheFace), [thegirlbehindtheface.weebly.com](http://thegirlbehindtheface.weebly.com)

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# SKIN DEEP

*Bullying was commonplace for Mui Thomas growing up due to her rare skin condition, but she overcame the dark times by finding success as an inspirational speaker and rugby referee.*

WORDS BY ED PETERS

**S**tricken with harlequin ichthyosis (HI) – a genetic complaint that strips away human skin – Mui Thomas was abandoned by her birth parents in Hong Kong, and later tormented to the point of suicide by cyberbullies at high school.

Yet today, at the age of 24, she is a qualified rugby referee, works full-time at an adult special needs academy, delivers motivational lectures – including a TEDx talk that ended with a standing ovation – and last year won a Spirit of Hong Kong award in recognition of her fortitude.

Mui's odyssey is tied up with her adoptive parents, Rog and Tina, a Welsh-German couple who met her when she was 18 months old while volunteering at a hospital. Their initial concern turned to compassion and plans to emigrate to Australia were ditched. By the time she was three and a half, Mui was Mui Thomas, their legally adopted daughter.

"Being adopted gave me a second chance in life, and my parents have always spurred me on," says Mui. "They've always said, 'Give it a go, don't let others hold you back'. It's a

pretty good philosophy." Mui's early childhood was marked by frequent hospital visits. She still suffers from arthritis, can't sweat, has to avoid sun and strong wind, and takes vitamins and dietary supplements daily as her skin renews itself 14 times faster than an ordinary person's.

#### LEADING A NORMAL LIFE

The challenges of giving her a regular upbringing in a largely Chinese society that looks askance at any sort of deviation from the norm were legion. Stares and scathing comments were commonplace, and once a passer-by spat in Tina's face, accusing her of having burnt her baby. Undaunted, Tina and Rog decided from the outset that Mui would go to school and lead a life like any other child.

But Mui's life took a turn for the worse when she started high school. Like any teenager, she found many situations awkward, which were exacerbated by her diminutive stature and crimson features. Cyberbullies zeroed in, and taunts turned to cruel abuse, reviling her appearance and declaring she didn't deserve to live. Miserable and terrified, Mui responded by withdrawing into

herself. "I was paranoid, insecure and didn't know who I could trust, even if people were being nice to me. At one stage, suicide seemed like the only way out."

Eventually, with her parents' help, and assistance from her school and the police, the bullies were tracked down.

"The difference between online and face-to-face bullying is that the cyberbullies don't see the effect of their actions. I met one who had been exposed, and he shamefacedly said he hadn't realised his comments would hit me so badly," says Mui.

"So when I give talks to schools I urge anyone who is being cyberbullied to find someone they can trust and tell them, and – above all – avoid going down the path I was going to go down." After leaving school, Mui's plans to "sit around and chill" were confronted with her

**"My parents are the coolest kids on the block."**

– Mui Thomas

parents' determination that she was going to do anything but. "My dad's a great rugby fan so he suggested I go down to a local club and see what I could do. At first, I didn't do much more than 'gopher', which was great, but I got bored after a season. Because I couldn't actually play – getting tackled would be too problematic with my skin and brittle bones – I decided to get into refereeing."

Mui found the chance to take part in a team sport and she continues to referee under-12 matches, where she has a reputation for being firm but