

## JUSTICE

**I**'ll show you a handy trick," says Berni Barry, pulling the zip open on her backpack with her big toe, picking up her iPhone with her foot and using her big toe to turn it off.

This dexterity is impressive but what is most amazing is the realisation that this is just one of many such "tricks" that Barry must do to simply manage her daily life. She was born a "Thalidomide baby".

Barry was born in 1960 with phocomelia major (the medical term for shortened limbs) and has severely shortened arms. She also suffers from hearing and vision impairment, heart disease and has sustained damage to other internal organs, some of which is only just being discovered as she grows older.

Her deformities are the product of what was once spruiked as a wonder drug, an effective treatment of conditions such as anxiety, insomnia and morning sickness, its apparent safety for unborn children being its main claim to fame.

The wonder of Thalidomide turned to horror when more than an estimated 10,000 children were born worldwide with severe malformations to their limbs, facial deformities, hearing loss, damage to internal organs and neurological issues attributed to the drug. And those were just the ones to survive. Many more would succumb to their injuries through foetal death. The mothers of these children need only to have taken one tablet to cause deformities if they did so in the danger period of the first 34-50 days of pregnancy.

Barry's mother had taken two and a half Thalidomide tablets for morning sickness given to her over the pharmacy counter. Although the arrival of the drug into Australia was not officially heralded until August 1960, it had already drifted onto our shores in many forms well before then, with samples arriving in doctors' surgeries, pharmacies and people's homes.

The drug should never have got here.

"The very day it was licensed for use in Australia, Chemie Grünenthal (the German manufacturer) had received over 1000 reports of side effects," says Peter Gordon, the lawyer who settled the class action against Diageo (the company which bought Distillers, the drug's distributors) for Thalidomiders in 2014.

By the end of 1961, Chemie Grünenthal and Distillers had pulled the drug from the market but it wasn't until August 1962, nine months later – the full length of a pregnancy – that the Australian government banned it from sale and finally informed the public.

An estimated 20 per cent of the entire Australian Thalidomide cohort was born during that period. Even once the drug was banned, there was little effort to ensure the public were well-informed.

A letter from the Director-General of the Commonwealth Department of Health to the then Minister for Health, Harrie Wade, gives some insight.

The letter recommends the government make a statement to the press about the dangers of Thalidomide, recognising the reasonable possibility that some households might have had the drug still lurking in their medicine cabinets unaware of its inherent dangers. The handwriting at the bottom of that letter, signed off by Wade on January 9, 1963, notes that any such public statement would "serve no useful purpose".

Those words were likely to ensure that there would continue to be uninformed mothers taking the drug despite the ban.

There are around 150 Thalidomide survivors in Australia out of a total of 3000 worldwide. Many governments have provided compensation to their victims but Australia is not one of them. The drug's distributors, Distillers, agreed in 1974 to pay a yearly sum of compensation to 40 of the identified survivors, and, in 2010, Diageo (the company that bought Distillers) made a subsequent ex gratia payment to the remaining 35 survivors in acknowledgment of their increasingly unmet needs. Eighty-nine other victims were subsequently identified as part of a class action which settled in 2014 against Diageo. Although Thalidomiders are grateful for the compensation, it is nowhere near enough to meet their ongoing needs after coping for a lifetime with severe disabilities.

Spurred by the rapid disappearance of their already limited physical capacity and angered by the government's response, they have begun a fight for justice.

For nine months, Australian officials knew Thalidomide was dangerous, yet didn't tell the public. Now the children born with defects are soon to turn 60, they want justice – and compensation

# FEET FIRST

WORDS

SARAH HENDER

MAIN PHOTOGRAPH

MATT TURNER

Thirty-five of the original Thalidomiders rallied to form Thalidomide Group Australia. TGA successfully pushed for a Senate inquiry, which was held last August, to investigate the role of the government in the catastrophe 50 years on, and to consider the adequacy of compensation and support for survivors. The recommendations were handed down on March 22 this year.

The Senate committee found the Australian government owed a moral obligation to Thalidomide survivors for the failure of the government of the time to act swiftly to recall the drug. The Committee recommended the government provide an official apology and compensation to Australian Thalidomide survivors, with such payments to be adjusted to account for their increasing needs together with the provision of ongoing disability support. It also recommended that the search be widened for those survivors who may not yet have been identified. >



Berni Barry is forced to use her feet in place of hands because of Thalidomide

## JUSTICE

That was five months ago. The survivors' initial jubilation at the inquiry's outcome has died down as they wait for action from the government.

**W**hen Barry was born, her parents didn't know she was alive for three days. When they finally learnt the truth, they were offered a private room, considering their difficult circumstances. Barry's mother refused privacy; her child would not start life separated from mainstream society. That set the course for Barry's life.

The physical challenges have not been the hardest thing to overcome. That has been dealing with people's attitudes.

She recalls what it was like growing up in a world that sought to normalise those people that were born different. With no useful hands, Barry learnt to use her feet to perform daily tasks at home but in the outside world using your feet was not allowed. Children like Barry were fitted with prosthetic limbs thereby ensuring a life of struggle at school.

Barry recalls whipping off her shoes and socks before anyone noticed so she could easily empty out her school bag, something that was nearly impossible without access to her feet, her alternative hands.

"To have to wear artificial limbs, and socks and shoes, was like putting your hands in boxing gloves all day," Barry explains. Her other recollection from school days was her daily confrontation with bullying. She was called a "freak" every day of her school life. At her Year 8 dance, a boy asked her for a dance and, when she accepted, he said, "I get to dance with the ugliest girl in the room."

Home and family got her through, her mother her greatest support. Barry learnt to be self-reliant. Unsurprisingly, she preferred being home with a book than dealing with people.

She strove early for independence. By 20, Barry had moved out of home and worked full-time as a disability support worker, having been rejected from her chosen career of teaching because she wasn't able to hold chalk.

By 25, Barry had bought her own home and had learnt to drive using her feet to steer. She became a single mother at 26, giving birth to a son. Single parenting is hard enough without having to do everything for your baby using just your feet and teeth. Barry recalls that getting her son in and out of a pusher was difficult but that was nothing compared to smelly nappies.

"They were a little too close to my face!" Barry says, laughing.

All the work and effort has been worth it though. Her son is the joy of her life. He is now 22 and, just like his mum wanted to, he is studying to be a teacher.

Barry hasn't let Thalidomide interfere with life's joys. She attends weekly art classes where she paints using her mouth and foot, with several of her paintings requested by friends. She is training an assistance dog to accompany her when she goes walking and she keeps fit at her local gym.

In recent years though, Barry has required help with her personal care and transport. Arthritis is causing havoc to her already limited physical capacity. Arthritis is not uncommon in Thalidomiders, as they are calling upon their bodies to do things they were never designed to do, placing stress on those parts that do work.

Barry stopped driving when she found she couldn't get her foot off the steering wheel. Public transport is not an option, having fallen and broken her nose several times. She needs help to get dressed and al-



though she has always enjoyed cooking, she now gets help with meals as it is difficult for her to lift hot things. She has burnt her breasts several times lifting hot pots and pans off the stove, leading to her decision to have a mastectomy last year.

"It was a risk-reducing choice so I could continue to stay in my home," she says. "I don't want to go into a care facility at my age. I would rather make my own choices."

"We (Thalidomiders) are aware we are looking down the barrel of the gun. We can only push our bodies for so long. I'm fending off the inevitable as long as I can."

**I**t is clear that "fending off the inevitable" is going to take more than the already extreme personal efforts of Barry and her fellow survivors. They need support to do that but to get it, they had to make some noise, not something that comes easily to people who have felt shunned for much of their lives. It was going to take a special person to lead them down that path. That person is Victorian, Lisa McManus. She, too, was born a "Thalidomide baby" on March 3, 1963. As TGA's representative, McManus lobbied 600 politicians to push for the Senate inquiry and gently coaxed survivors to attend and make their submissions about their predicaments.

On the face of it, McManus, 56, of Bendigo, has lived a life that many would envy. She has travelled the world, is university educated with two Masters' degrees, married the love of her life with whom she has two children and enjoyed a satisfying working life as a social worker, grief counsellor

and educator. But at birth, no-one could have predicted such a life for her.

She was born with severely malformed arms with three fingers on each hand, only one on each working, as well as neurological, vascular and internal organ damage.

At McManus's birth, the first sound that her mother, Beryl, heard was the midwife, running and screaming from the room. Beryl was left alone, her legs still in stirrups, knowing only that something had gone terribly wrong. When she finally saw her baby with her deformed arms, she was shocked but the love she felt for her daughter was immediate. That, and the overwhelming guilt which would dominate her life.

Life has had its struggles but McManus can't remember a day when she ever wondered how her disabilities might impact on what seemed to just be the natural progression of life. Though others have.

When McManus announced to her friends and family that she was going to have a baby, there was not the expected reaction of joy and excitement. Instead, she

**“**  
**We can only push our bodies for so long. I'm fending off the inevitable**

Barry at home using a colouring book, left, and getting herself a drink of water; Lisa McManus, below right, was forced to retire early  
Photographs: Matt Turner, Supplied

recalls relatives asking how she would ever be able to carry a baby around. Negativity not being part of McManus's husband's make-up either, Andrew's response was one that reflected their mutual approach to life: "Well, we'll just make sure we have a baby with handles."

Throughout her life, people would ask if she was angry that she had needlessly suffered avoidable injuries. "I always thought I'm supposed to be angry about something but I just didn't feel it," she says. "I was pushing myself to feel something - 'go on, get angry' - but I never did."

But four years ago that changed when, at 52, McManus was forced into early retirement from her role as a TAFE educator in community services, a job she adored and was good at. Her health issues had got to a point where they were seriously impacting on her ability to work.

How was she in this situation? She had to know more about how the Thalidomide catastrophe had happened and the roles that everyone played in it, the manufacturer, the drug distributing company and the Australian government.

Her research led her to discover letters indicating the government's attitude at the time, no better expressed than the comment made by the health minister Harrie Wade that a public statement about Thalidomide "would serve no useful purpose".

That purpose was entirely clear to McManus. And that was when her anger kicked in. "My retirement was the key that unlocked the door that was holding the baggage in the background. Thalidomide didn't have to happen and it certainly didn't have to happen to as many as we know - and the government had done nothing," she says.

When the recommendations were handed down this year, it was a relief for McManus but for her mother it would lift a lifelong burden of guilt and sadness.

"She would say to me that there wasn't a day that went by that the guilt didn't flare up in some way," says McManus.

When she told her 92-year-old mother the good news, her mother let out a long primal howl, releasing a lifetime of pain, repeatedly asking her daughter if it was true, was she sure that her girl and all of the others were going to be looked after? "Yes," McManus told her, "I'm sure."

But McManus can't really be sure. Until the government approves the recommendations, the war is not yet won.

"I'm very aware that we are at the stage now where our bodies are shutting down and there is this huge loss and grief period we are entering into. Some of us are well-entrenched into and some are just entering it," she says.

McManus feels lucky to have her husband Andrew, who is quick to notice when she is having trouble doing something. But she wonders what will happen as he ages and needs care himself. And some survivors have no-one to care for them.

Berni Barry wonders the same thing. All her life she's battled to be independent, but there is a limit.

It's a difficult future, but one that would be improved enormously by federal compensation. Now it remains to be seen whether Canberra finally accepts it has a "moral obligation" to the children of Thalidomide. Fifty years is a long time to wait for justice.