

Good Health

THALIDOMIDE? WHAT'S ALL THE FUSS?

IT'S 50 years since Thalidomide was first prescribed to pregnant women suffering from morning sickness. It was then found that the drug caused serious birth defects: 500 babies suffered varying degrees of disability as a result. Here, three generations of women tell their story. June Hornsby, 71, has six children with her husband Len, 76. Their daughter Mandy was born in 1962 with no arms. She says:

THE whole time I was pregnant with Mandy, I felt uneasy. For some reason I had a feeling the baby might have Down's syndrome but my mother told me not to be silly.

In those days — the early Sixties — there wasn't much you could do about it anyway. There were no scans to pick up abnormalities and certainly no question of termination.

I took Thalidomide regularly during the pregnancy. My GP prescribed it, not for morning

By TRICIA WELCH

sickness, but as a sedative because I was having trouble sleeping. We didn't ask questions in those days, we just did exactly what our doctors told us to do. Towards the end of my pregnancy the GP told me to stop taking the drug as there might be problems with it. But we didn't know what.

I went into a natural labour and Mandy was born quite quickly. The doctors took her from me before I could even see her. I was terrified. Then a doctor came to tell me that her arms were badly deformed and they wouldn't allow me to see her until my husband Len arrived.

The nurses brought this little baby into us and she was beautiful. The fact that she had no arms didn't bother us. After all that fuss we were just relieved that she was alive and healthy.

Then the problems started. A paediatrician advised us that Mandy was going to be 'a cabbage' and that it would be better if we left her at the hospital and forgot about her. We were horrified and insisted we took her home. We later found out that there were more than 500 Thalidomide children in the UK and many of them were given up by their parents.

I can understand why. There was a lot of pressure from the doctors, who never gave us one bit of hope. They said she would never marry or have children, and might not walk for years, if at all. They were completely wrong, but at the time we didn't know that.

Luckily, I was already an experienced mother and couldn't see that dealing with Mandy would be that much different from looking after my other children. We brought Mandy home and, lying her on the floor, unwrapped all her clothes so that her four older siblings could take a good look. From that moment on they just accepted her as one of them.

It was Mandy who taught me that her legs and feet were going to become her arms and hands. When she was just a few months old she used her feet to play with a newspaper and her toes started to behave like fingers.

AT NINE months old, she was holding a pencil with her feet and scribbling away like any other baby. She was walking not long afterwards.

Len and I realised very early on that, for Mandy's sake, we were going to have to make her do as much as possible for herself. The worst thing we could have done was to do everything for her.

It was very tough, and often emotionally draining. When she was six we decided she had to go to the toilet on her own. She was crying for us to come and pull her pants up and I said: 'No, you have to do it yourself.'

I left her, had a cry myself, and eventually she managed to get her pants up using her teeth.

We often felt as if we were in a running battle with the authorities and the medical profession. They were insistent that Mandy had to wear shoes, whereas I knew that would be a disaster — her feet were her hands.

When she was about three they gave her false arms, horrible plastic ones, but Mandy hated them and didn't wear them for long. That was about the only treatment she was offered.

Luckily, she had no internal problems such as organ malformation, as many of the other children had.

I tried not to waste time feeling guilty, instead we concentrated on helping Mandy. We were told that she had to go to a special school but I said no — over my dead body.

I found a local primary school where the lovely headmistress made sure she was treated like everyone else and Mandy blossomed.

Then there was the battle to get



Using her feet as hands: Baby Mandy

compensation and set up the Thalidomide Trust, established by the parents in 1973 with funds from Distillers, the company which marketed the drug. The idea was that the victims would always have somewhere to go for financial help.

I never blamed our GP even though after Mandy was born and the scandal broke, he did try to deny that he'd given me the drug. If I hadn't found the prescription with his handwriting on, Mandy would have got nothing.

Mandy was always incredibly brave and determined. She wanted to learn to ride a bike like the other children, so Len held on to the back while she pedalled and she told him when to let go. She went over the top a few times but eventually learned how to steady the handlebars using her chin and she was off. Sheer will-power drove her on.

Mandy is now a wonderful wife and a terrific mother to her two girls. For her own sake I wish she had arms, but I wouldn't have her any other way. We hardly think about her being Thalidomide. We are just so proud of her.

MANDY, 46, lives in Essex with her husband Wayne, 46, who cares for her. They have two children, Nicola, 26, and Marie, 22. Mandy says:

ONE of the most frightening moments of my life was watching my own daughter have her 13-week pregnancy scan. There had been a few cases of babies born to Thalidomide adults who also had physical defects, although this has never been definitely linked to the drug. I couldn't see why that couldn't happen to grandchildren, as well. I would never have forgiven myself if Nicola's baby had been deformed.

I sat there shaking, praying the child would have arms, and suddenly I saw some. It was an overwhelming relief but it made me realise how guilty my own mother must have felt.

She was incredibly brave to keep me. She used to receive anonymous letters saying I should have been put down at birth. Some Thalidomides spent their entire childhood in institutions.

Years ago, when I was seven or eight, I met a Thalidomide girl who asked me what home was. When my mother explained it to her, she asked if she could come back with us. My mother did ask if she could come for the odd weekend, but the carers said no.

Both my mother and I were upset and never forgot that moment. It was so unbearably sad to think that just because she didn't have limbs, she was denied parents to love her.

I have my mother to thank for my independent spirit. She was determined I would be as normal as any other child. They fought to get me into a mainstream school and I can never remember being bullied or treated differently — except for the fact that my chair was higher than the

It was the drug that left hundreds of babies cruelly disabled. Fifty years after Thalidomide's launch, three generations of a truly inspirational family reveal how they've refused to let it wreck their lives

SCOPE FEATURES/TONY WARD

other children's to allow me to use my feet on the desk. If anyone ever said I couldn't do something, it would spur me on. I played sports and went ice skating.

The only thing I could never do was climb ropes. Dad was brilliant at inventing gadgets for me, such as a hook to help me pull up my jeans using my mouth. But I have always resisted too many disabled gadgets — using my feet and legs has kept me fit and healthy.

I had horrid little plastic arms as a child which frightened my friends, so I rarely used those. When I was about 11, I was given arms which were powered by gas cylinders worn around my belt.

One day I was out shopping with mum when one of the canisters

developed a leak. There was a loud hissing sound and steam coming out from under my arm. It was so embarrassing and frightening that I hardly ever wore them after that.

Otherwise, I had a very happy childhood. Mum sat me down when I was 11 and explained about Thalidomide and how it had affected me. I never blamed her for a minute. People didn't know about drug side-effects in those days.

I was thrilled when I passed my driving test at 17. It was real independence for me.

Wayne and I were married when I was 19 and five months' pregnant. He chatted me up, not knowing I didn't have arms because I had a jacket around my shoulders, and



Independent spirit: Mandy, left, with her mother June and eldest daughter Nicola

allocated as and when individuals need funds.

This means you have to account for every penny you ask for. That can be humiliating, especially after all the other battles you have to fight.

Like many Thalidomide people, my body is showing signs of wear and tear at a relatively early age.

My legs and feet have to do about ten times the work they were designed to do and I have the beginnings of arthritis. I take anti-inflammatories, which help, but I certainly can't walk as far as I used to.

At 13 stone, I am quite overweight and around five years ago I developed Type 2 diabetes. I also take tablets for high blood pressure, probably because of being overweight.

Three years ago I had a very bad fall in the garden and, for the first time, couldn't get myself up. Luckily, Wayne was there to help. After that he took early retirement from being a builder to be with me.

Although some Thalidomide people have died early, these were mainly the ones with serious internal damage such as organ malformation.

I have worked as a receptionist and a beautician, and I'm now a medium. My life has been a battle to prove wrong those people who said I would be 'a cabbage'. I think I have done that and more.

NICOLA ROBINSON, 26, is Mandy's eldest daughter and is married to Kevin, 28. They live in Essex with their three children, Callum, ten, Dylan, five, and Danny, two.

THE first time I ever really saw my mum worried about anything was when I was pregnant with Callum. She sat me down and explained she was worried Thalidomide might have been passed through to me and on to my baby, and I had to be prepared for that.

The thought had never crossed my mind. In any case, my reaction was if the baby wasn't perfect, I would cope. After all, Mum is the perfect example of how being disabled doesn't mean you can't have a good life.

As a child, I never thought of Mum as being different to other mums, except that she was, of course, better. My sister Marie and I always went to school with our hair beautifully styled by mum in plaits and ponytails, our clothes perfectly pressed and washed.

My mum was so determined we wouldn't be her carers that she went too far the other way and spoiled us by waiting on us constantly. It was a real shock when I left home and had to learn to look after myself.

I can't remember being teased because of Mum, but someone must have said something to me, because, when I was about seven or eight, Mum asked me if she could come in and give my school a talk.

She brought in two identical dolls and explained that they were both normal, just that one had no arms. Then she asked everyone to take off their shoes and pick things up with their feet. She even got a couple of them cracking eggs with their toes. My friends loved it and were so impressed that she was my mum.

Mum and Dad gave us such a happy childhood. On top of that, Mum taught us that with determination and effort, no problem is insurmountable. I never once heard her complain.

Sometimes, when I hear people moaning about silly little problems, I do have to stop myself from telling them to count their blessings.

Mum is a great role model and an inspiration to us all. I wouldn't change a thing about her.

caesarean, but I knew that would be a disaster because I would have been unable to use my legs and feet for a while.

They also said I couldn't breastfeed or look after the baby without help, so I used to get up early, pick Nicola up with my feet, breastfeed her and have her dressed by the time the nurses came in.

From an early age, the children knew to put their arms up and cling around my neck. We worked our way around any problems.

The worst part of being Thalidomide is the struggle with bureaucracy. I received a lump sum from the Thalidomide Trust which I used to buy a house, and there are annual payments. The remainder is

I fought to have a natural birth. The doctors were insisting on a