

Mothers CHANGING THE WORLD BECAUSE OF THEIR *children*

These mothers did everything they could to help their own children. But they didn't stop there – they went on to help many others too.





Gabi Lowe

The Jenna Lowe Trust raises organ donor awareness
www.jennalowe.org

Jen started to have the most basic thing taken away from her – the ability to breathe. Which meant she couldn't run, she couldn't dance, then she couldn't walk down the passage. In the end, I had to wash her hair, dress her, lift her mostly, pick up anything she needed. She couldn't even bend down. And yet she was filled with gratitude for the time she had. And gracious, dignified, and strong. When you can't lean to the future, you have to value *now*. We learnt from that, and still try to live it.

Losing a child is any mother's greatest dread; there can be no worse pain. But she taught me so much. When we defend ourselves against pain, we also defend ourselves against joy – you don't let joy and meaning in.

I think the only reason our family can actually get up and try to find a way forward is because none of us has any regrets. We've had the gift of unconditional love. A lot of people go a lifetime without that. I'd still have my child back tomorrow, but I appreciate what I had. I fought tooth and nail to change it, but in the end I couldn't.

A terminal diagnosis can tear a family apart. We got a psychologist involved, doing weekly meditations as a family so we knew where everyone was emotionally.

Initially I carried on working while finding my way through the research and the Medicines Control Council, fundraising for the medication, finding global expertise, bringing it into the country – all this in itself a full-time job. And Jen lost more and more physical ability every day. She was completely dependent on me. How that must

GABI LOWE: I WOKE UP AND I JUST KNEW THAT JEN WAS SAYING, 'I'VE INVITED THE NATION TO MY 21ST.' WHAT ARE YOU GOING TO DO?'

have felt for Kristi, her sister. She knew she was loved and supported – we always held her in our circle as a family – but if one child is very ill, the other has to sacrifice a lot.

Then Jen was listed for transplant so I had to stop working, which meant financial stress in addition to everything else. And we had to fight to increase the numbers of organ donors in the country. There was a 287% increase in sign-ups.

And then, miraculously, Jen got a match. The whole family moved to Joburg in four hours. And Jen went in for her surgery. The transplant was successful, and she was doing relatively well, even though she had kidney failure. But then things started to go wrong. She went between ICU and an isolation ward for six months. I was at Milpark Hospital 16 to 18 hours a day. And then she died.

There were many days I couldn't get out of bed. The grief has been horrific. But three and a half weeks before her 21st birthday, I woke up and I just knew that she was saying, 'Hey, what *are* you doing? I've invited the whole nation to my 21st. What are you going to do?'

Our grief is very private. But in terms of the work that Jen started, I don't have a choice. I don't get to hide. I could have walked away, but I would be dishonouring Jen if I didn't find the courage to get up every day and live a meaningful life. I've always believed that looking something in the eye is the better way. If you don't, you'll have to look at it sometime. I'm driven to make a difference, to care for every person I can care for. I know about pulmonary arterial hypertension, bringing drugs into the country, about fighting for people with rare diseases, and about making sure your family survives something this horrific. I don't get to walk away without sharing that knowledge.

We had a lot of time to talk. I knew all the things Jen was going to do when she came out of hospital, and this is

exactly the new mandate of the Jenna Lowe Trust: to promote pulmonary arterial hypertension awareness, to help other families, to help get the medication into the country, to continue to raise the number of organ donors. Jen's greatest wish was that Groote Schuur would start a lung transplant unit so I'm starting to lobby for awareness. There are a lot of lung disease patients whose only hope is a lung transplant.

The Jenna Lowe Trust Relate bracelets (Relate is a partner) sold 4000 in two weeks, and the money has already been put to good use.

There were all sorts of things Jen was going to do. This generation of youngsters is cause-driven and we have to let them teach us, lead us. Jen led the way. We followed. We're not Jen, but we will do her work.



NOMASONTO MKHONZA: 'I'LL NEVER ALLOW ANY CHILD WITH DISABILITY TO BE COMPROMISED.'

Nomasonto Mkhonza

DICAG – Disabled Children Action Group
www.dicag.co.za

Katlego was my first-born and she looked so... I don't want to say normal... so okay.

But by six months she should have been starting to sit on her own. And her hands were always in a fist, even though I encouraged her to open them. I took her back to the hospital for a check-up but they said she may just be a late developer. When Katlego was a year old, I went to visit my cousin, a nursing sister. She arranged for me to see a paediatrician, who asked about her medical history. When Katlego was born she was very jaundiced and had a blood transfusion. The paed said that during the blood transfusion, my child had been brain damaged. I felt so miserable that I cut my holiday short. When I told my

parents, they couldn't accept it – 'But she looks so well,' they said. I went for a second opinion and was sent to Bara, where the doctor confirmed the diagnosis of brain damage, and said there was nothing they could do. I don't want to remember that day.

They directed me to a clinic where I came across other parents and children in a similar position. I knew nothing about disability. Some of the children were 15, 20 and could do nothing for themselves. I thought, 'Is this what I'm going to go through?' Yoh, I had a terrible day. But, thank God, I came across a woman who was driving a motorised wheelchair. I asked her about it, and she told me about a parental support organisation, DICAG. At a DICAG meeting, I met parents who were going through the same challenges. Some of them had been abandoned by their husbands because their children were disabled.

We cried together, sharing experiences. They kept me going. DICAG keeps you informed as a parent, encouraging you not to compromise your child, helping you understand your child's rights. I was so grateful that I joined the organisation and am now the programme manager.

As a quad, my daughter doesn't have the function of her hands or legs; she relies on the next person for everything. I asked the MEC for help, but there was no funding. Katlego's principal at Muriel Brand, Dr Leon Stander, helped write a letter to the education department, explaining her potential. I hold that man in the highest esteem; if only all educators in special schools had the same heart. But again, funding was a problem. I told them my child had a right to learn. Then the minister invited us to a Christmas party for women and children with disabilities. We explained the predicament, and two weeks later, a post was advertised for a state-funded personal assistant for my daughter.

If I hadn't been empowered by DICAG, I'd never have been able to fight the way I did. And my daughter has done so well. She's studying journalism and has started her own publication. She's also assisting children with disabilities, and their parents, through the Living Able Foundation, which she started. My other daughter is also doing well – she is in her third year of industrial engineering.

I'm very grateful to my late dad and mum. Support starts with your family, then your neighbours, then the community.

As DICAG programme manager, every child with a disability is my priority, and disabled children are still being neglected. As parents, we have to support one another as it's just not easy – and in truth, the social grant hardly even meets you halfway.

Disability is my life. God has given me this, so I have to finish it.

LisaAnn Haynes

Closing the Gap education centre
www.closingthegap.co.za

My youngest son, Bradley, had had cerebellitis as a toddler, and experienced learning challenges. By the time he hit Grade 5, teachers said that he'd never get a matric, and that I should move him to a technical school. I was a teacher myself, but was so frustrated I quit teaching to take a course in life coaching. I started coaching adolescents, motivating them to stay at school. I was interested in what they need to stay and succeed. Through coaching, the parents of two Grade 11 learners asked me to home school their kids. I was horrified by the idea, but I looked into it. I knew there must be another way to educate these kids, so I made an 18-month commitment to get these two through matric. Part of my motivation was to come up with a way of helping Bradley too.

Word spread and within a month, there was a third learner. By the end of the year, I had 16. My poor husband would get out of the shower in the morning and there'd be 16 teenagers in the lounge! We were basically living in our bedroom, and we had two young children. I took the plunge and rented the house next door.

The first two students matriculated in 2008 and Closing the Gap (CTG) grew phenomenally, by word of mouth. We expanded to another house in 2015 and opened our first independent centre at the start of this year. We now have 189 students, from Grade 4 to 12. Some are off-the-wall bright and were bored or rebellious at school. Some have a learning problem. Some have been ill, missing chunks of school.

Don't ever tell me a child can't. Anyone can flourish if they identify their strength. I believe your spirit rebels in an environment that's not right for you. So I do take naughty

kids. But if they can't be part of their solution, it won't work.

There's no uniform. And no homework, but we check weekly that key concepts are understood. Tutors work with groups of three, tailoring learning.

My office is called the Black Pearl, after the pirate ship. Steve Jobs talks about the pirates, the crazy ones, the misfits, as the ones who will change the world. That's us.

My perception is that God has given me the wisdom to help these kids, but I don't push religion. And two years ago, I met the goal that set me on this path: Bradley finished matric with a university entrance pass.

Caro Smit

South Africans
Against Drunk Driving
www.sadd.org.za

Chas was a brilliant guitarist in a band called Plush. They won the Battle of the Bands in 2002, beating 500 bands, including Freshly-ground. On tour in 2005, Chas, then 23, had just played at an alcohol-free gig when, as a sober pedestrian, he was killed by a driver who'd been drinking at an office party.

Our whole family was devastated. His death was like the death of a child for the adults, and a sibling for the cousins, and as with our immediate family, many of them had to be treated for depression.

When he was killed, part of me died, and part of my future too. No wedding, no grandchildren.





CARO SMIT, WITH CHAS AND HER HUSBAND MIKE.

Apart from being devastated and very depressed, I was furious. How dare his life have been taken so thoughtlessly! The terrible thing was that very few people thought about Chas. The feeling was, 'It could've been me who'd drunk that amount and driven, so I feel sorry for her.'

I felt deeply that I needed to fight to protect people from drunk drivers. And I decided that fighting back appropriately was the only thing that would help me cope with Chas's death. So I founded South Africans Against Drunk Driving (SADD) in January 2006, four months after his death.

This was extremely difficult at first. I was consumed with grief, and every time I talked about his death or why I was starting SADD I was plunged into the scene of Chas lying smashed in the road, knocked out of his shoes, with rivers of blood from the back of his head running across the street and down the gutters, while the paramedics worked on him, and we stood by. These flashbacks lasted three years.

In addition, I experienced resistance from the community and friends; they thought I should forgive and forget and that I was out to get Chas's killer, while I felt I was trying to save other families from going through unnecessary pain and suffering.

But I knew I couldn't live with my conscience if I did nothing, especially as I had the expertise to deal with alcohol misuse and drunk driving issues – I'd worked in alcohol and drug counselling and education. My family was very supportive, and Mike sponsored the running costs for years.

Initially I was working much too hard, for 10–15 hours a day, but it meant I had something constructive to do, rather than just weeping when I couldn't sleep. And I didn't have to think about my poor dead child.

It was very hard not to expect the worst when my other children, Guy and Philli, went out. Mike and I were in a total panic until they got home. They were very patient.

The work I'm most proud of is standardising units of alcohol and creating awareness. And it's been great to receive recognition; in 2006 I won a local road safety award, and in 2012 we were awarded the Prince Michael of Kent International Road Safety Award. The WHO has also acknowledged our work. This month, sign up on www.alcofreefeb.co.za for AlcoFreeFeb™ and pay R100 for the month, or R50 for a 10-day challenge. The money raised helps minimise the harmful effects of alcohol abuse on our community.

I try to help as many other victims in South Africa as possible. Each time someone dies, part of me is traumatised, but it also empowers me to know I can support and help others.

Karen Moss

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STEPS steps.org.za

My son, Alex, was born with two clubfeet, both turned over and inwards. Back then, in 2003, they performed surgery on the baby to rectify their feet at just a few months old. I wasn't happy with that option so I started researching online. I found an article on the Ponseti method, which involves gentle manipulation of the foot, and minimal, non-invasive surgery.

We went to Iowa, US to meet Dr Ponseti. The entire process took 16 days. We were the first South Africans he'd treated, so he told me I had to take it further.

KAREN MOSS WITH HER SON ALEX.



In 2005, I started STEPS, a non-profit focused on the eradication of clubfoot, to raise money and organise training. Sixty-seven doctors came to our first training seminar with three international doctors. It is now the treatment of choice in South Africa. There's no miraculous cure, but with the Ponseti method you can get a plantigrade, functional foot, with good mobility and strength.

Since 2013, we've been running a clinic support programme in most main centres, which we expanded in 2015 to reach patients in outlying clinics. The challenges are distance, language barriers, and children being brought in late, as some mothers don't know that clubfoot can be treated. To date, STEPS has trained 264 doctors, clinicians and orthotists in four countries. I also designed an education programme, Ponseti for Parents, used in clinics, and wrote a bedtime story, *My Clever Night-Night Shoes*, for children who sleep in a brace.

My son is proud to be the reason that STEPS exists. His feet will never be exactly like other children's, but they are very close.

I want every child to go to a clinic early enough to be helped. If you leave it too late, it becomes a disability.



TINA BOTHA IN THE GARDEN OF HER GUESTHOUSE, FLEUR DE SOLEIL (SUNFLOWER).

Tina Botha

The Sunflower Fund
www.sunflowerfund.org.za

Chris was diagnosed with acute lymphoblastic leukaemia in 1997, at 14. Six months of chemo and radiation followed, then he had the first of his bone marrow transplants, in 1998. A year later, a routine blood test showed that he'd relapsed. So he underwent another six months of chemo, and we frantically searched for a matching donor. This was when I founded The Sunflower Fund. Chris had a second transplant, only to relapse again the following year. He had a third transplant in August 2000. But on 10 September, he passed away.

The most difficult thing was the fact that Chris suffered for over three years.

When Chris was sick, Jason was 12 months old, Tarryn was 11. People always said they didn't know how I found the strength to cope. But I feel that any mother would do the same. I had incredible support from friends and strangers. Every day that Chris was in hospital, someone would drop off a meal and a salad.

Chris spent much of his illness in isolation, which was very tough. This was before cellphones and the internet – it would've been amazing if he'd had email and WhatsApp and all that. We didn't have enough money to recruit bone marrow donors, so we'd chat for hours about what could be done. He came up with the idea of a Bandana Day. He even drew a little cartoon – he'd been offered a scholarship at the Red and Yellow School.

Chris never saw Bandana Day happen. After he passed away, some people thought I'd move on, but I couldn't, because we hadn't achieved what we were trying to do – to build a bone marrow registry and educate South Africans. In 2003, three years after we lost him, we had the first Bandana Day. It's been incredibly successful: people buy the bandanas, which raises money, but it also creates awareness, so they register.

It's an incredible campaign, born out of Chris's concept. At the moment, we have a registry of 70 000. There's more information on the website (above), and to register, the toll-free number is 0800 121082. I urge people to become donors – it saves lives.

I don't think any mother could imagine anything worse than losing a child. You do get on with life because you have to, because you have other children who need you. But you never ever get over the loss. Putting my energy into The Sunflower Fund has definitely helped me. I've been very good at getting help; I see a fantastic psychologist from time to time; you can't help others if you're not coping.

I've been doing this for 17 years and the job's not done. But I realised that I've always put myself last. So I've taken a step back, and running this guesthouse, Fleur de Soleil, is my backup retirement plan. Now that I'm able to look back, I guess what we've done *is* amazing. I'll always be involved, I'm the founder-patron. Whenever I meet people, I talk about it. I can't help it; it's in my blood.

Louise Zietsman

House Elpidos for schizophrenic and bipolar people



My son Paul was brilliant at school. As he began high school, he aced every test, had many friends. The occasional mood swing was nothing out of the ordinary for a 15-year-old boy. At least that's what I thought. But by his 16th birthday, he'd withdraw to his room, was flunking exams and feared being around people. I took him to a psychologist who said he had a social phobia. Nonsense, I thought. I took him to another psychologist who said he was depressed. I then started to believe he was just being naughty and doing it for attention. Years of psychological assessments racked up large bills for me, a single mum, but it all amounted to nothing.

When he was at varsity, I moved in with him after he refused to go back to class. Then he started hallucinating, and doctors sent him to rehab for the marijuana he was smoking! He was eventually diagnosed with paranoid schizophrenia. He'd get psychotic, thinking the government was plotting against him. We couldn't watch TV without him thinking they were talking about us. He switched night and day; I'd work a full day and come home only to chat to him through the night. Schizophrenic people have to be around others like them. Isolation within the family isn't sustainable.

With this in mind, I started House Elpidos (Greek for 'hope'), a home for schizophrenic and bipolar people, four years ago. Recently, we expanded to accommodate 30 people between the ages of 20 and 50.

It works well for him. Here, they aren't treated like patients. They play pool and watch movies, and food and laundry is taken care of. They are so supportive of one another. ♣