

It could also happen to you

It's a preventable condition that cuts across all socioeconomic groups – even one glass of wine counts as 'drinking while pregnant'

Tracey Hawthorne

The baby's withdrawal symptoms were terrible," says Loretta*, a 55-year-old manager of a Cape Town children's home, recalling a period 16 years ago when she fostered a two-week-old infant removed from her mother after she was discovered alone in a house with alcohol in her bottle.

Loretta was running a safe home for vulnerable children in the Cape Flats suburb of Bishop Lavis at the time. She says: "I knew what to expect because I had read up on the effects of alcohol on babies, but I was shocked by how severe it was. The baby screamed and screamed and screamed, and her body went

into convulsions."

These were, at least, signs of life – the infant was discovered by a neighbour, who thought the child was dead. At Cape Town's Karl Bremer Hospital, the baby was found to have high levels of alcohol in her blood, and spent two weeks there.

The effects of foetal alcohol spectrum disorder (FASD) aren't always obvious at birth – many children with FASD show no physical signs – and often, behavioural and learning problems are not noticed until the child is old enough to go to school. But Loretta knew that the baby, whom they called Clio*, was going to face challenges: the mother was a known alcoholic, and her two previous children had already been put into foster care.

"Clio did have all the physical features of foetal alcohol syndrome [FAS]," Loretta recalls, referring to the characteristic smallness of stature, small head and distinctive facial features of children affected by this form of the disorder, which is the most severe on a spectrum of physical and neurobehavioural symptoms.

As Clio grew older, the differences between her and other children her

age became more apparent, and by the time she was three years old she displayed behavioural problems. Even at that stage, when children are known for throwing spectacular temper tantrums, Clio was markedly out of control. "She would pull out clumps of my hair and kick me," says Loretta. "And she was unnaturally strong – sometimes I would have to use my whole body weight just to get her into the car, for instance."

One of these car trips was to the genetics clinic at Tygerberg Hospital, where Clio underwent the battery of tests required to accurately diagnose FASD. Armed with the diagnosis, Loretta took action. "I took her to a psychologist for an educational evaluation – if she was going to struggle at school, I wanted to help her," she says. "The doctor assessed her and told me that he thought Clio would never reach high school."

Loretta wasn't deterred, however, and from the time Clio began school, she took the little girl for remedial lessons.

Clio's story is one of the few about children with FASD that has a happy ending: a well-adjusted 16-year-old, today she is in grade 10 at a mainstream government school,

and has a brown belt in karate, and has just started taking piano lessons. "Perhaps the only clue that she doesn't cope as easily as the other kids with her schoolwork is that she sleeps every afternoon when she gets home from school," says Loretta. "The mental effort exhausts her."

Loretta, who officially adopted Clio in 2003, is house-mother in her children's home to 11 kids aged six to 17, many of whom show the signs and symptoms of FASD.

There's a yawning gap in support structures for these children and their caregivers. As the country with the highest rate of FASD in the world, and by quite a large margin – the department of health estimates the average prevalence of FAS in South Africa at 6%, although studies done by nongovernmental organisation the Foundation for Alcohol Related Research (FARR) show the prevalence of FASD is as high as 25% in some areas – we should be on top of what some refer to as "South Africa's other epidemic".

But FARR chief executive Leana Olivier says that only the Western and Northern Cape governments have shown an interest in developing intervention strategies. On a national level, she says awareness is very low.

In the absence of useful government intervention, FARR, the leading source of research and information on FASD and FAS in South Africa, has implemented its own evidence-based interventions. It provides parents, guardians and educators in the most affected areas with assistance and counselling.

Interventions of these kinds for

adults with FASD are extremely rare, as evidenced by a biological family member of Clio. "From as soon as she was old enough to understand, I explained Clio's background and circumstances to her," says Loretta. This included the information that Clio has two brothers, both older than her. Nothing is known of one, but the other is also affected by FASD and struggles in adulthood with alcoholism. He, sadly, is one of the millions of South Africans paying a lifelong penalty for something he himself didn't do.

And there's another very important issue about FASD that Olivier is at pains to point out: the disorder can affect anyone, regardless of race, income, family history, background or culture. "It's imperative to include all the socioeconomic groups in our thinking and awareness programmes, as many people still believe the myth that FASD only manifests in the lower socioeconomic groups," she says.

For more information about FASD, research on the condition and programmes and interventions, visit www.farrsa.org.za phone 021 686 2646 or email info@farrsa.org.za FASFacts can be contacted on 023 342 7000 or visit www.fasfacts.org.za * Names have been changed to protect personal privacy.

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Be the woman who makes it happen

Be healthy. Encourage those you know to give their unborn babies the
Be strong. best chance in life by avoiding alcohol and maintaining a
Live well. balanced diet when pregnant and breast-feeding.

With the help of organisations such as the Distell Foundation, FARR, the Foundation for Alcohol Related Research, diagnosis and researches Fetal Alcohol Spectrum Disorder (FASD). FARR is a non-profit organisation that aims to prevent FASD.

FASD is caused by drinking during pregnancy. It impedes children in their learning and their socialisation as it affects their intellectual and behavioural development. It can also affect their organs. FASD is preventable but irreversible. The child who has FASD has its growth and opportunities stunted for life.

As a woman you power to help prevent FASD. Use your power! Persuade every pregnant woman not to drink pregnant.

The Distell Foundation is a proud supporter of FARR, a world-leader in its field.

