

## Brave 2-year-old survives rare surgeries to remove tumour

<http://www.health24.com/News/brave-2-year-old-survives-rare-surgeries-to-remove-tumour-20160815>

Nicela Naude smiles broadly as the camera takes a picture of her and her mother, Madeleine. The 2-year-old girl is holding onto her mother's shirt and her eyes are sparkling with excitement. Looking at this image, it's difficult to imagine she has been through more suffering than most people endure in a lifetime.

### Syndrome often leads to death

Nicela has Klippel-Trenaunay syndrome, a rare disorder that affects the blood and lymphatic vessels, soft tissues and bones. She was born with a large tumour on her chest, with her left arm twisted, enlarged and almost completely non-functional.

At birth she was given a few weeks to live, but against all odds, this little fighter survived two complicated and dangerous surgeries – one three months after she was born, and the second one earlier this month.

Klippel-Trenaunay syndrome affects about 1 in 100 000 babies. Complications include a type of skin infection called cellulitis, swelling caused by a build-up of fluid (lymphoedema), and internal bleeding from abnormal blood vessels. A recent study from the [University of Pittsburgh](#) found the syndrome can often lead to death due to serious complications.



### Two complicated surgeries

In June 2015, little Nicela underwent her first surgery to remove the tumour. "This was a substantial growth on her left upper body which extended around her back to her spine, says Dr Frank Graewe, a plastic and reconstructive surgeon, who performed both surgeries.

"It wasn't a tumour that could grow and spread, but was abnormal tissue that has been present since birth," explains Graewe.

The first surgery was to address the vascular malformation on her chest and chest wall. This second surgery was to address her left arm and fingers.

"Due to the specific pathology of these lesions, they are a mixture of vascular and lymphatic malformations; bleeding and haemorrhage are possible serious complications," Graewe says about the dangers of the surgery.

"To minimise the risk and surgical complications, as well as the need for blood transfusions, the [surgery] is done in stages. During the second surgery, two large growths on her lower arm were removed. Four fingers on her left hand were opened up and de-bulked as much as possible."

Graewe explains that the procedure is not new, but not often performed. "Because of the rarity of the syndrome, the surgery can be dangerous. We had to be very careful with this surgery as there is no clear demarcation of the tumour versus normal tissue, so our dissection was very precise."



*A little fighter. Nicela has undergone two surgeries and here her mother is comforting her. Photo: Supplied.*

Read: [14-year-old SA girl dies of rare disease](#)

### **'We are optimistic going forward'**

Graewe is optimistic about Nicela's future. She will need a few more surgeries in the coming years and compression therapy (designed to support her veins and increase circulation) on her left arm and hand.

"However, it is not possible to remove all the abnormal tissue, as it infiltrates normal and healthy tissue. We will try to remove as much as possible of the abnormal tissue without causing unnecessary damage to the rest of her body. It is a long road ahead, but we are optimistic going forward."

Nicela's mother is thankful to Dr Graewe and his team. "I honestly wouldn't entrust my child to any other surgeon. He has promised to walk this very long road with us, and Nicela is doing extremely well," she says.

"She's currently not on any pain medication, and she is very upbeat and talkative."

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