

# Standing On Their Own

# Two Feet

**people**  
Has Heart

BY VANESSA PAPAS

IT'S usually an isolated congenital birth defect affecting just one in 1 000 children but for the Regos, clubfoot is a family trait.



Daniel and Cristina have recovered well



Christina's first cast

EVERY week we bring you stories of ordinary people who've overcome extraordinary circumstances and offer you the chance to pay it forward.

**W**ATCHING Adri Rego and her children playing ball, it's hard to believe that the 38-year-old mom of two was born with bilateral clubfeet. It's even harder to believe that both Adri's children – eight-year-old Daniel and four-year-old Cristina – were born with the same condition.

Adri's mother had had a healthy pregnancy and carried to term, and it was only once Adri was born that doctors realised there was something wrong with her feet. "The doctors never picked up that I had bilateral clubfeet in utero," says Adri. "I know it came as a huge shock for my parents. When they gave me to my mom I was all wrapped up and she knew something was not right. When she uncovered me she saw both my feet were very twisted. She was told that the condition was a result from abnormal development of my muscles, tendons and bones, which placed both my feet in an unusual position."

Doctors advised her mother that the best treatment was surgery, something that is today not generally advocated for clubfoot sufferers, and at six months old Adri went under the knife. Doctors cut the Achilles tendons near her heels, and an area near the front of her feet to loosen the tight ligaments and tendons, then they manipulated her feet into a normal position before placing her legs in casts. For four years, Adri had to wear the casts to allow the incisions, tendons and bones to heal, as well as different adjustable shoes during her childhood years, alternating between the casts.

"I have memories of sticking my mom's knitting needles or pens under the casts to try to scratch, and the doctors would often find the pens and needles when removing the casts in theatre. I do also remember the day my last cast came off: I was four years old. I will never forget how the grass tickled my feet and how great it felt."

After the casts were removed, Adri went on to lead a normal and active life, only experiencing occasional pain in her ankles and feet from time to time. Aside from a large scar running down the backs of both of her legs, her feet look normal. But her troubles weren't over just yet...

"My uncle was also born with bilateral clubfeet, and I was warned that our family could be genetically inclined to pass on the condition. So when I fell pregnant it was a concern. My son Daniel's condition was not picked up in utero, but my daughter Cristina's was when I was 19 weeks into my pregnancy," says Adri.

Both Daniel and Cristina underwent The Ponseti Method, which was introduced to South Africa by Karen Moss, who is the founder of Steps SA, after her son was treated successfully in Iowa in 2003. A small operation was suggested for Daniel and Cristina, called an Achilles tenotomy. In this operation the tight tendon on the back of the foot is released so the heel can drop down. After the tenotomy, the Ponseti method was applied.

The Ponseti Method avoids cutting the tight ligaments, tendons and joint capsules. It is a carefully constructed sequence of plaster casts and braces for children with clubfoot. Typically the method takes about four to six weeks of plaster casts, changed

every seven days. For over 80 percent of cases, the tight Achilles tendon is cut and the corrected foot is put in a holding cast for three weeks to allow the tendon to regenerate. When the final cast is removed, a clubfoot brace is fitted – a pair of special shoes attached to an adjustable bar at a specific width and angle. The child wears these for 14 hours a day for four years.

Adri admits that having two children go through The Ponseti Method was challenging and says she was very lucky to have a supportive husband. "Even though it's not painful, Daniel and Cristina did not like the casts, which ran from their toes to their groin area. It was especially hard in winter having to wash off the casts at home before going in for another cast and then waiting for the new ones to dry. Daniel had seven weekly casts while Cristina had four. Then, of course, there was the stress of not being able to feed your hungry baby before the tenotomy operation, the clothing they could not wear (babygrows come with feet, so all the feet had to be cut off), and keeping both my babies comfortable with the casts and the brace during the night – but we learnt from the start to have a very strict routine in which our children knew what was going to happen next. I owe a lot to my wonderful husband Paulo, who has been a tower of strength."

The treatment has been very successful. Daniel has had no relapse at all and Cristina has just three weeks left of her four-year treatment.

## PAY IT FORWARD

BECAUSE of her close personal experiences with clubfoot, Adri is passionate about supporting babies born with the condition, as well as their families, and is today a director of STEPS SA – the only NGO in southern Africa focused on the treatment of clubfoot. The organisation stocks second-hand boots to help families with limited funds and those who are struggling with health insurance. If you have shoes to donate, please contact us at [vancom@telkomsa.net](mailto:vancom@telkomsa.net) and we will make sure that they are distributed to STEPS, and in turn to the families who need them. **people** will mention donations received in an upcoming issue.