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In January 2003, Karen Moss gave birth to Alexander. He was born with bilateral clubfoot, a congenital disorder of which the cause is unknown.

Clubfoot refers to the position of the foot, a sharp angle to the ankle like the head of a golf club. It causes the foot to turn inward and point downward.

Karen knew very little about the condition at the time. "My cousin had one clubfoot when I was a child and I remembered him wearing a calliper for some time and having operations. I was worried about the prospects for my baby boy having both feet clubbed."

### **Early treatment**

When Alex was eight days old, he had his first casting session done. New plaster casts were put on every week for eight weeks.

"I had to pull on his toe and hold his knee straight for the orthopaedic surgeon to wind the bandages on and then he would pull his foot straighter while the plaster hardened," says Karen.

However, the treatment had not worked enough to straighten his feet and at three months Alex faced corrective surgery.

"The surgeon told us that the traditional clubfoot surgery was very intricate. It took four hours per foot and often they would do only one foot and then the other later because it was a long time for the baby to be under anaesthetic," says Karen.

They would put pins in his foot and he would have visible scars. Karen knew from her cousin's case and from speaking to other adults who had clubfoot that more surgery could be required as he grew older.

"I felt devastated about the possibility of surgery and kept up the hope that Alex might be lucky enough to avoid it," says Karen.

### **A click of hope**

While doing research on the condition on the internet, Karen discovered the Ponseti method.

The Ponseti method is a gentle manipulation of the foot done in very specific stages. After each manipulation, the foot is put into plaster to hold that part of the correction.

Within five to seven days the plaster is removed and the next manipulation is done and another plaster applied with the foot in the new position. It takes three to six manipulations for the foot to be completely corrected without surgery.

Many patients need percutaneous tenotomy done under local anaesthetic which takes about 10-15 minutes. The surgeon nicks the thick and short Achilles tendon that pulls the foot in a clubfoot. The heel drops and the Achilles heel cord regenerates longer within two to three weeks.

After the final cast is removed, the baby is fitted with a foot abduction brace (FAB) which holds the feet in the correct position and helps protect relapse.

The method is not painful for the child and the baby adjusts to wearing the brace. Parent compliance with bracing is very important for the treatment to be successful.

Karen and her husband decided to take Alex to Iowa (US) to see Dr Ignacio Ponseti.

### **The pitter patter of tiny feet**

Karen says that as soon as they got to the University of Iowa Hospital and met with Dr Ponseti and his team, they knew they had made the right decision.

“The difference in the technique was incredible to see. Instead of being purple in the face from screaming, Alex would grumble a little at first because people were fiddling with his feet, but would fall asleep by the time each casting session was over.”

Even the casts were different from the previous method. These were up to the leg at a 90 degree angle which helps to keep the foot stable in the position that it was put in.

“Alex was ten weeks old when he started the Ponseti treatment. After three casts and 16 days his feet were completely straight at three months, which was the booked surgery date that was cancelled before leaving for the USA,” says Karen.

Alex then had a percutaneous tenotomy done and after three weeks the family returned to South Africa and removed the casts themselves with warm water.

Alex was now at the final and most important stage of the method. He had to wear special shoes attached to a bar (FAB). It is necessary for clubfoot babies to wear it for 23 hours to start with and thereafter it is gradually reduced to only at night.

Most babies stop wearing the brace at the age of four. Wearing the brace helps to prevent relapse in almost 100% of cases.

“We were very pleased to have cancelled Alex’s surgery as Dr Ponseti told us that he originally devised the method in the 1950s after doing follow-up research on adults who had traditional clubfoot surgery. Many of them had early onset arthritis and reduced mobility,” comments Karen.

### **Perfect, fully functional feet**

“Every milestone that Alex got to was special for me: cruising, walking, running. All extra special times that remind me of how lucky we were to find Dr Ponseti in time,” says Karen.

In January Alex will turn five and unless Karen tells people, one would never guess that he had clubfoot. He has no scars, his feet are flexible, he can stand on tip toe, run fast, hop on one foot - all the things his playmates can do.

“He has been checked by a paediatric physiotherapist and podiatrist and had a follow-up with Dr Ponseti this September. All of them say Alex’s feet are perfect, fully functional and corrected,” says Karen.

### **Labour of love**

Alex and his successful treatment inspired Karen to help other babies and children with lower limb disorders and in July 2005 she started STEPS. The charity works closely with doctors and health professionals to improve treatment and care

The STEPS goal is to get consensus on clubfoot so that the Ponseti method becomes the standard treatment at every state hospital, clinic and primary healthcare unit.

In July 2006 STEPS hosted the first Ponseti seminar. “It was a phenomenal success in convincing paediatric orthopaedic surgeons that the method could and did work effectively.

Although it has been around for almost 60 years, doctors were resistant to change and continued to do surgery for all those years. Now they are all changing to the Ponseti method.”

Karen explains that the worldwide occurrence of clubfoot amongst Caucasians is 1:100. South Africa's black population had two to three times the occurrences, making it the second highest incidence of clubfoot in the world.

Karen has done pioneering work that has changed clubfoot treatment for South African babies and was nominated for the 2007 Woman of the year in the health category.

“I get immense satisfaction from this work and I am grateful for the doctors and other people who supported my efforts along the way because I could not have achieved my vision alone,” says Karen.

And to think it all started with the words “I don’t like the look of these feet....”

(Leandra Engelbrecht, Health24, November 2007)

Source:  
Karen Moss, CEO STEPS Charity