


A young boy is captured in mid-air, jumping joyfully with his arms outstretched and a wide smile. He is wearing a dark t-shirt, blue jeans, and black sneakers with white laces. The background is a solid, vibrant blue. The text 'Steps Clubfoot Care' is overlaid on the image in white, with 'Steps' in a large, elegant script font and 'Clubfoot Care' in a smaller, sans-serif font below it.

# Steps

Clubfoot Care

We will walk with you



# STEPS ENHANCES THE LIVES OF CHILDREN BORN WITH CLUBFOOT.

Steps Clubfoot Care was founded in 2005, by Karen Mara Moss, after the successful treatment of her own son's clubfoot by Dr Ponseti - the pioneer of the Ponseti Method of treatment - in Iowa, USA. Upon returning to South Africa, she made it her personal mission to introduce the Ponseti method as a gentle, non-invasive and effective option to replace the complex foot and ankle surgery that was standard practice at the time. Since then, Steps Clubfoot Care has revolutionised clubfoot treatment in Southern Africa, resulting in thousands more children having access to effective treatment, who would otherwise have lived life with a preventable disability.

Based in Cape Town, South Africa, but operating nationally with regional influence. Steps Clubfoot Care supports the treatment of children 38 partner clinics in South Africa, focused on patient-centred care.

We are motivated by the belief that every child deserves the best treatment available, regardless of where they are born. Accurate diagnosis, early intervention and referral is critical.



## WHAT IS CLUBFOOT?

Clubfoot is the most common musculoskeletal birth defect. The baby is born with one or both feet twisted downwards and inwards, in a rigid position. The South African black population has the second highest rate of clubfoot incidence in the world - an estimated 1 in 500 live births. Every year over 2,000 babies are born in South Africa with clubfoot, and another  $\pm$  3,000 in neighbouring countries. If left untreated, the child will be unable to walk properly, leading to a life of disability.

Clubfoot, however, can be treated. Early and effective treatment allows the child to live a life without disability, so that they can walk, run and play like any other child.

## CLUBFOOT TREATMENT.

Worldwide studies confirm that if the Ponseti Method is done correctly by a well-trained provider, it is over 95% successful. The Ponseti method is internationally endorsed as the gold-standard for treatment of congenital clubfoot. The full treatment starts from birth until age four or five.

### The Ponseti Method of treatment consists of two phases:

- **The Correction Phase:** the foot is gradually positioned into place with a series of manipulations and full-leg plaster casts, changed weekly over a 4 - 8 week period, before a minor procedure is done under local anaesthetic in the clinic.
- **The Maintenance Phase:** the child wears a clubfoot brace full-time for three months, and then when sleeping. The clubfoot brace - boots connected to a bar - holds the foot in position until the correction stabilises at age four to five.

## OUR BENEFICIARIES.

Our beneficiaries are predominantly children attending state clinics, from birth to five years old. The families are from low income households, they have not received adequate prenatal care, and do not have access to clubfoot education. In addition, awareness in the larger community is low. Through our intervention and support we change these children's lives, by ensuring that they have the correct, effective treatment, and can become healthy, contributing members of their communities and society.

# LETHABO'S CLUBFOOT SUCCESS STORY: "STAY PATIENT AND REMAIN HOPEFUL"

Gorgeous little Lethabo was born with clubfoot at Victoria Hospital in North West Province, South Africa. She has an older sister who absolutely adores her. Her sister does not have clubfoot.

When she was born her mother, Lerato, was distraught and asked herself how this could happen. She did some research and went to visit Dr Bogatshu at his practice in Pretoria. He recommended she visit the Mahikeng Provincial Hospital in Mahikeng, her hometown, where she would be able to receive free treatment for her baby.

She was so overwhelmed and relieved to hear that there was help available for her and that it was available near her home.

At her first visit to the Mahikeng Ponseti clinic supported by STEPS, she was thrilled to meet other moms going through the same experience. The moms shared advice and support that reassured her she was not alone.

The Mahikeng clubfoot clinic gave her a STEPS Ponseti for Parents® pamphlet and explained to her in detail what the treatment entailed. She believes the key to the success of the treatment is to stay patient and remain hopeful.



Lethabo has made great progress and Lerato is so grateful to the doctors and clinic staff for being so good to her and Lethabo, and for inspiring and encouraging them to continue with treatment.

"Do not give up hope, there is help available. Your child does not have to grow up with a disability," is Lerato's advice to other parents of clubfoot babies.

Lethabo is a budding young model and has even appeared in an advertisement for a children's clothing company. She is proof that clubfoot is treatable and should never prevent you from living life and fulfilling your dreams.

# THE STORY OF NICOLE M

Nicole is a 16 year old girl with a complex case of clubfoot. She stays in a deep rural area of north eastern South Africa, close to Acornhoek, Mpumalanga.

Nicole did not have treatment when she was born as there was no clinic nearby and her parents did not have funds to travel. She was admitted to our partner clinic at Tintswalo Hospital in 2015 because of recurring septic sores on the skin over her knees.

Nicole had an old manual wheelchair which she did not use because she has a partially paralysed right arm that makes it difficult for her to be able to push the wheelchair herself. This meant that she couldn't keep up with her friends on the playground and in dusty streets, so she preferred to crawl which unfortunately resulted in the septic wounds on her knees.

Nicole had been forced to leave school in grade 1 as the staff felt the school was not well equipped to handle a scholar with Nicole's special needs, and also the school was not wheelchair friendly.

Nicole had already been on the waiting list for a wheelchair for months, but it would have taken years, and then been useless to her as only manual wheelchairs are available through the state clinics.

STEPS arranged for Nicole to travel to Johannesburg to be assessed by an expert orthopaedic surgeon. Sadly, he confirmed that Nicole had a form of neurological clubfoot, but it was too late for treatment to correct her feet. We were all devastated as Nicole could have had a better prognosis if she had access to a clubfoot expert before the age of six.

After consulting with her physiotherapists, STEPS raised enough funds for Nicole to get a one-handed wheelchair with solid puncture proof tyres for the rural terrain around her village.

Nicole finally received her wheelchair at the end of 2016 after it was custom-made for her. Her life has been transformed by mobility and she can now live a more independent and comfortable life. Nicole's case is a typical example of how challenging life can be for a rural child born with a disability. The fact that this was a treatable condition emphasises the importance of early intervention and support for these children who are otherwise needlessly disabled for life.





## STEPS AWARD-WINNING THEORY OF CHANGE MODEL .

Our model targets four areas to increase the number of children receiving effective treatment:



### TRAINING

(increase number of skilled health professionals in public health sector)



### CLINIC SUPPORT

(parent education to reduce dropout, admin, data capture)



### ADVOCACY

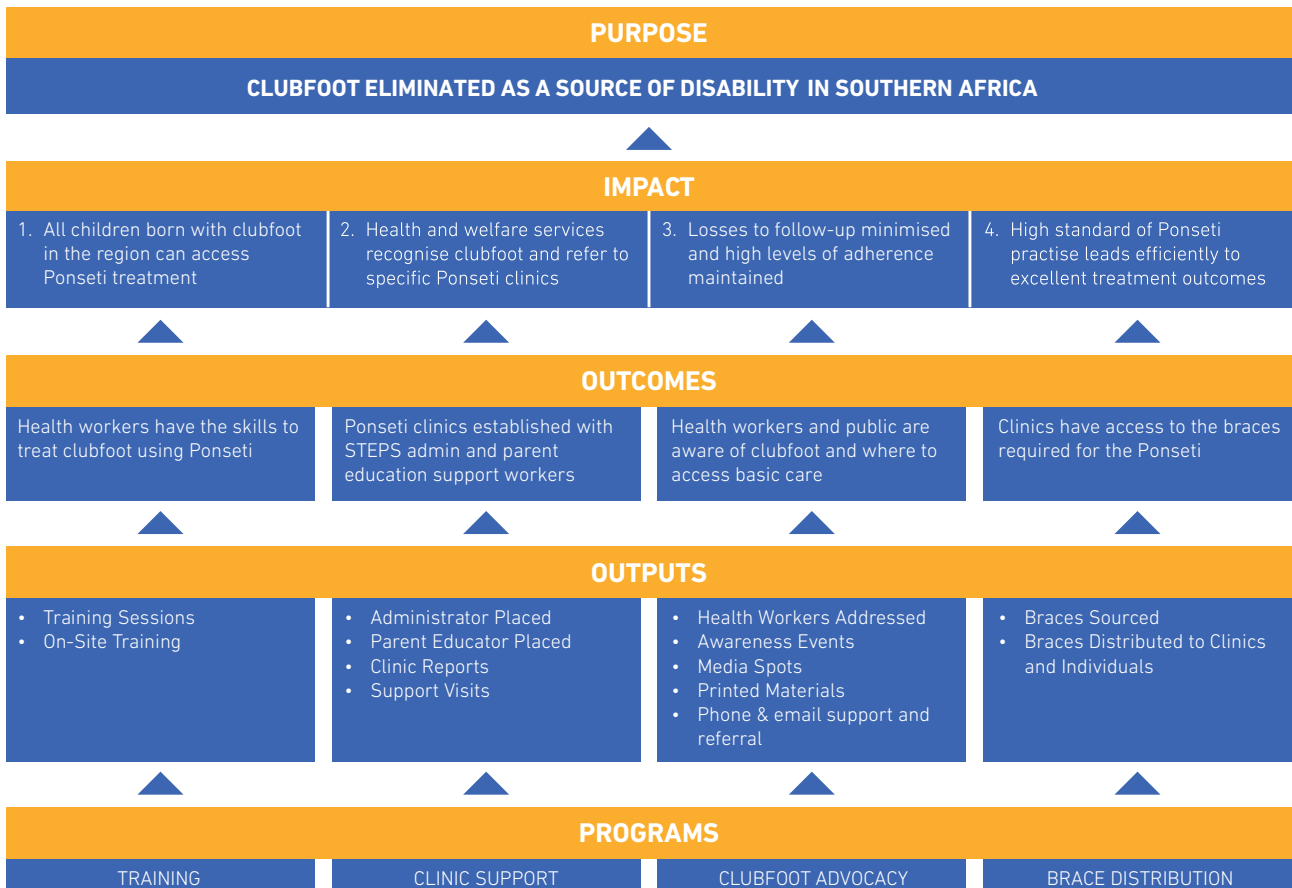
(community awareness, early intervention)



### BRACES

(distribution of essential clubfoot equipment for successful treatment, also a diversified income stream)

## STEPS MODEL FOR CHANGE IN CLUBFOOT



STEPS' four pillars of impact in the above model directly contribute to the elimination of clubfoot as a source of disability. In South Africa, our model is successfully implemented in nine provinces with 38 partner clinics in our Steps Clubfoot Care clinic support programme. Our work and model was recognised with a Gold by the Impumelelo Social Innovation Centre and won at the SAB Social Innovation & Disability Empowerment Awards.

# STEPS IMPACT (2005-2022)

- **17,000+** patients treated with Ponseti method
- **38** partner clinics
- **1424** healthcare professionals trained directly by STEPS
- **6,662** children enrolled at partner clinics
- **14,750+** clubfoot braces distributed

## WHY SUPPORT STEPS?

- STEPS responds to a huge regional need. Less than 8% of patients have access to health insurance or means to pay for treatment.
- STEPS is the only organisation working in this space in South Africa, Namibia, and Botswana. From our Cape Town office we support 38 public sector Ponseti clinics across South Africa through our Steps Clubfoot Care programme, and support clubfoot providers in Botswana, Lesotho, Swaziland and Namibia.
- Award winning model. STEPS has devised and implemented a model that has been tested, and proven to be successful in aiding the treatment of clubfoot in the region.
- We are innovative and collaborative. In addition to introducing the Ponseti method, we set up a constant supply of cost-effective clubfoot braces, introduced data capture systems, developed our Ponseti for Parents© educational programme which is already in 10 languages and used globally by other clubfoot organisations and doctors.
- We are effective. After 17 years of active involvement in the clubfoot community, there are at least 17,000 children who have benefited from our training and support of health professionals and facilities.

## HOW WILL YOUR INPUT HELP US?

- Increase the number of children treated
- Reduce disability
- Offer every child the chance of a mobile productive life, no matter where they are born
- Establish new Ponseti clinic partnerships in rural areas
- Ensure accurate patient statistics
- Deliver the effective medically-endorsed clubfoot braces that prevent recurrence of clubfoot
- Deliver specialist clubfoot braces to treat complex clubfoot for best comfort and outcome
- Educate and inform the public to improve early diagnosis and reduce stigma

