

## Annual Impact Report – July 2019 to June 2020

**Expanding best-practice care for children born with clubfoot** 



# BACKGROUND AND INTRODUCTION



## INTRODUCTION

Resilient

Responsive

Ready

## Our key words for 2020, the year of COVID-19 pandemic and lockdown

They say hindsight is 2020. For many of us the year 2020 was more of a steep learning curve. A reset and rethink for the way we will operate in the future. A 'Coronacoaster' of highs and lows indeed, but mostly it's been good for Steps.

We are aware that at clubfoot clinics it's the calm before the storm of regrouping and catch-up that lies ahead. Many clinics are quieter than normal and we know there will be a tsunami of patients to come, from babies to 6 months and older. We know that our partner clinics will be crowded with new patients that have not been able to access treatment and patients that need repeat treatment because of missed appointments. This is due to their parents being too scared to travel or not having the resources to travel, or the clinics being closed.

We have seen how strong, flexible and united Steps is as a team and organisation. We have managed our resources and paid all our staff full salaries through lockdown. Our 'Steam' has been nothing short of incredible in the way they have adapted so positively to working from home and working in clinics to support patients - some in full hazmat gear! We all got stuck in and did what needed to be done. And we all had a purpose and motivation to help our beneficiaries that helped us all continue, especially during the dark days of Level 5 lockdown.

We spent lockdown productively doing internal housework, and have produced some phenomenal tools that will support us and our clinic partners for what lies ahead. We will be more streamlined, structured and automated. We will be ready.

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## BACKGROUND

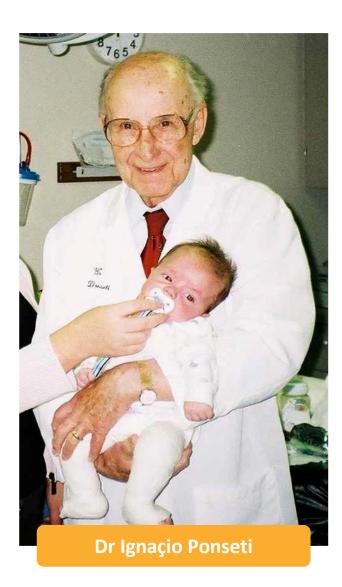
In 2003, Steps founder Karen Mara Moss introduced the Ponseti method for clubfoot to South Africa after her son's successful treatment by Dr Ignaçio Ponseti at the University of Iowa Children's Hospital.

In 2005 Steps Charity NPC was established as a registered NPO with public benefit organisation with 18a status.

The core purpose of Steps is to improve the lives of children born with clubfoot.

We are based in Cape Town and operate nationally, with regional influence.

We are the only organisation working in this space in South Africa. Our proven model focuses on innovative clubfoot treatment, capacity building and maximum impact.



## BACKGROUND

The Steps Clubfoot Care award-winning model\* is aligned to the United National Sustainable Development goals:

- SDG Goal 1. End poverty in all its forms everywhere
- SDG Goal 3. Ensure healthy lives and promote well-being for all at all ages

As a member of the Global Clubfoot Initiative we support the #runfree2030 vision of a world where every child born with clubfoot can walk and run free from disability.

\*2018 Winner SAB Foundation Social Innovation Disability Empowerment awards





## BACKGROUND

Steps works in partnership with the South African Paediatric Orthopaedic Society to expand clubfoot care and establish treatment centres of excellence.

We target four impact areas to contribute towards the elimination of clubfoot as a source of disability in South Africa:

- Access to Ponseti treatment.
- Adherence to Ponseti treatment.
- Awareness and early referral to Ponseti treatment.
- Effective, well-resourced clinics.



# **ABOUT CLUBFOOT**



Clubfoot is a common congenital birth defect.



The affected foot is rigid, pointed downwards and inwards.



Around 180,000 children are born every year with clubfoot, the majority are in developing countries.

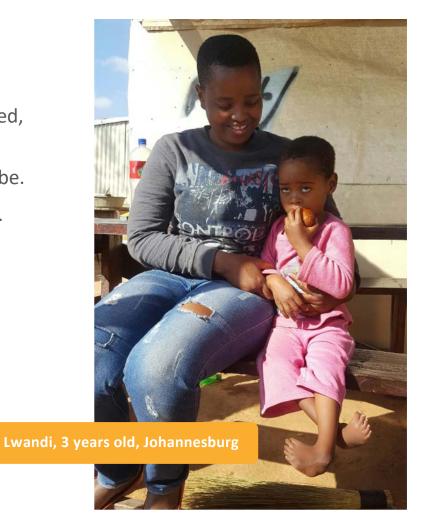


Clubfoot can be successfully treated.



# THE BURDEN OF NEGLECTED CLUBFOOT

- Untreated clubfoot is a disability.
- The ankle is stiff, tendons are tight, foot is twisted, pointed down and inwards.
- The top of the foot is where the bottom should be.
- Can't walk normally, wear shoes or go to school.
- Teased and shunned.
- Mothers blamed for the condition.
- Families hide children from their community.
- Some are told to amputate.
- Life of pain, shame and isolation.
- Trapped in poverty cycle.



# **CLUBFOOT INCIDENCE IN SOUTHERN AFRICA**





There is a higher incidence rate than the global average (according to studies).



Affects ± 1 in 500 children.



Every year the number of new patients diagnosed is:

- ±2,000 in South Africa,
- +3,000 in neighbouring countries.



The ratio is 2:1 boys to girls.



# **CHALLENGES AND BARRIERS TO TREATMENT**

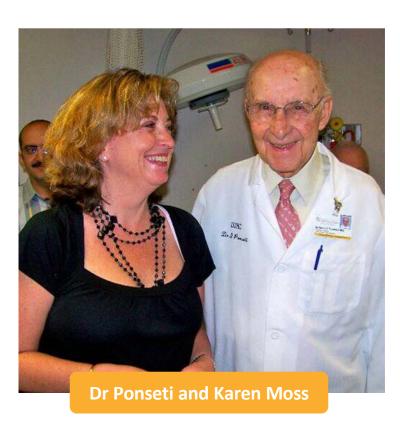
- X Low awareness in the community and health sector that clubfoot can be treated.
- X Delayed diagnosis and late referral to clinics.
- X A lack of trained health workers to treat clubfoot effectively.
- X Long and costly travel for treatment at main centres.
- X Effective treatment can be limited by an under-resourced healthcare system.
- X Establishing government health clinics requires restructuring and training.
- X The treatment is long and requires commitment from families.
- X High patient dropout risk due to socio-economic problems and travel challenges.
- X Stigma or superstition further burdens families who are often poor and dealing with multiple problems such as unemployment and HIV.
- X Shortage of clubfoot braces or braces of sufficient quality, can extend treatment or result in treatment failure.



**Untreated clubfoot** 

## **THE SOLUTION: THE PONSETI METHOD**

- ✓ Suited to low resource settings.
- ✓ Effective, +90% success rate.
- ✓ Global best practice.
- Steps has introduced the Ponseti Method to South Africa, Namibia, Botswana and Seychelles.
- Patient-centred care







## **PONSETI METHOD - FROM BIRTH TO AGE 4**







## **OUR VISION**

## STEPS core purpose is to help give every child born with clubfoot access to the best possible treatment.

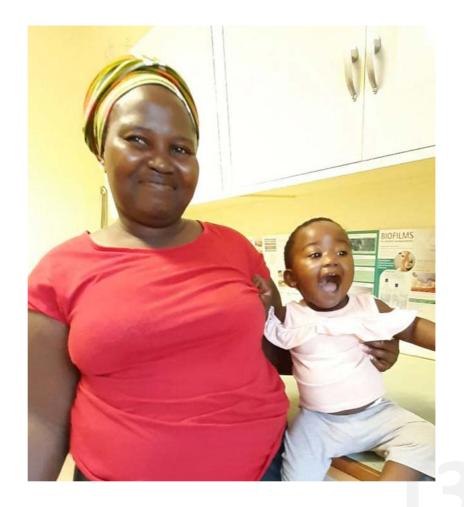
Effective clubfoot treatment means that a child can run, walk, play sport, and go to school – with all the enjoyment and freedom that results from full mobility and straightened, flexible feet.

A child that grows up with untreated or neglected clubfoot often faces a life of poverty, struggles to find work and can even by rejected or hidden away by their family or community.

Treating clubfoot effectively is a solution to one of the root causes of poverty – disability.

Early intervention and successfully treated clubfoot prevents lifetime disability.

That child will not have to live with the poverty and misery of the burden of neglected clubfoot.



## **OUR VALUES**

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**Sustainability** – Lean management, financial responsibility and working smart to secure the future of clubfoot treatment for posterity.

**Trust and Integrity** – Open communication with all our donors, partners and stakeholders.



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**Empathy** – Understanding and prioritising the welfare and wellbeing of our primary beneficiaries - children born with clubfoot.

**Passion** – Keeping and reinvigorating enthusiasm for our cause in the challenging sector of non-profit healthcare.

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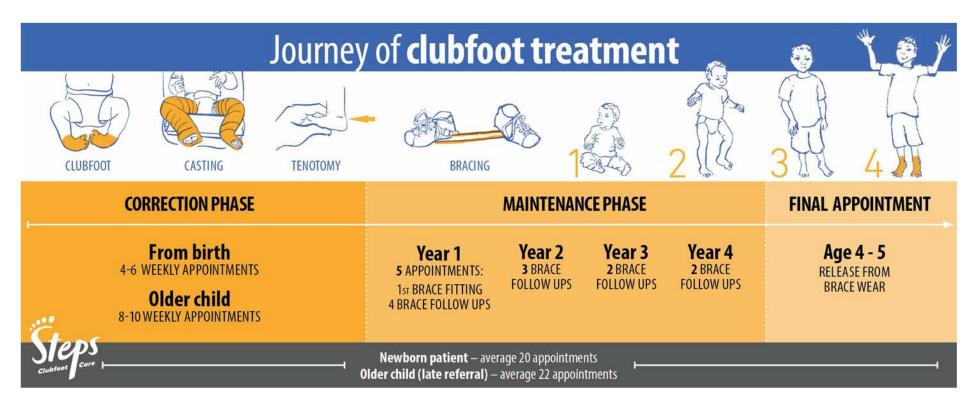
Simplicity – Staying focused on our core purpose with everything we do, while keeping the clubfoot child in mind.

**Connection** – Relationships are everything - we collaborate and share our resources and knowledge.

Innovation – Finding new ways to maximise and improve our impact and dispensing with anything that no longer works, to keep us efficient.



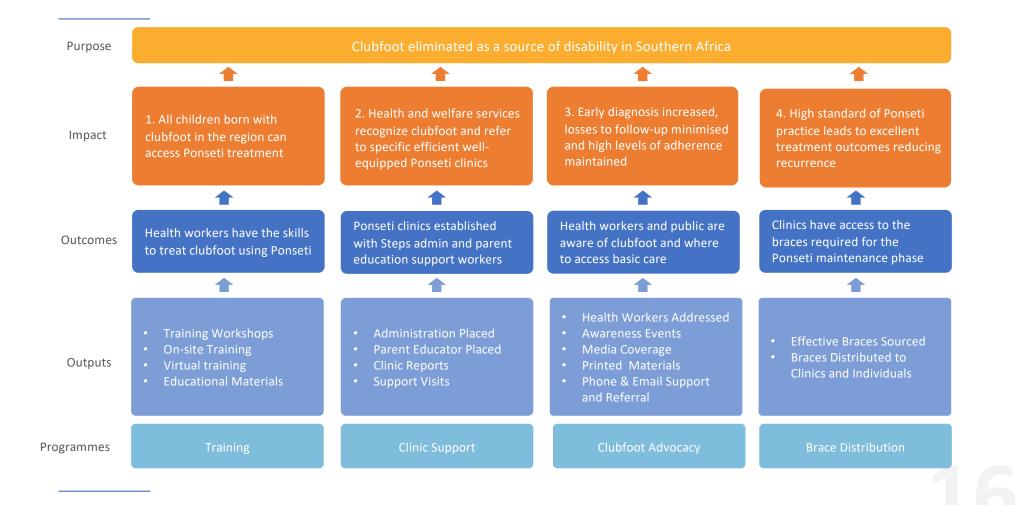
# THE JOURNEY OF CLUBFOOT TREATMENT



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# **STEPS THEORY OF CHANGE MODEL**



## **THE STEPS MODEL: MEASURABLE, EFFECTIVE, LOW COST, HIGH IMPACT, SCALABLE**

## **Four Pillars of Clubfoot Management**





IMPACT: Increase number of children treated.





IMPACT: Improve quality of treatment, reduce patient dropout and good M&E.

**IMPACT:** Remove stigma and increase early referral.

**ADVOCACY** 

CHANGE A CHILD'S LIFE TODAY

stens.org.

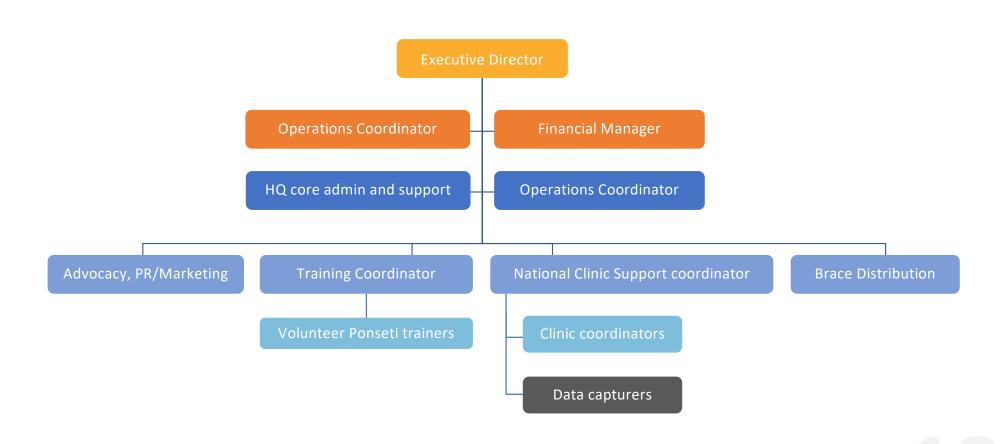
BRACES

IMPACT: Successful 4 year treatment without recurrence.



## **OUR STRUCTURE**







## COVID-19























## When lockdown was announced in March 2020, we:

- ✓ Immediately generated a crisis communication plan and quick turn around for implementation.
- ✓ Secured our essential supplier permit so we could continue clubfoot support.
- ✓ Issued a Steps COVID-19 policy document to staff
- ✓ Issued ongoing updates to clinics and the public and posted information on our website:
  - A pop up box on opening the site with a link to a live document of clinic operational status.
  - Practical advice for parents who were worried about cancelled clinic appointments for their children.
- ✓ Managed finances to keep all staff employed.
- ✓ Set up an online clinic operational status list with weekly updates
- Set up work-from-home communication with a core staff Whatsapp group and Zoom Pro registration (NPO rate from Phambano Technology).
- Check-ins with clinic heads to establish their needs, and attended an online SAPOS meeting to discuss clubfoot treatment recommendations during COVID-19.
- ✓ Attended regular Global clubfoot COVID Zoom meetings to share experiences, challenges and resources.





# Over 40% of South African state clubfoot clinics were closed in the months of March and April 2020.

Those that were open had very limited patients and were working on a skeleton staff.

Some clinics closed for the duration of lockdown March-August 2020.

For those clubfoot clinics that were still operating, a significant number adjusted the one-week casting protocol to two weeks.

Most brace check-ups were booked for 4-6 month follow up appointments, as opposed to 1-3 months (in younger patients).

Clinics took this precautionary measure to limit numbers on clinic days and improve operational flow in the clubfoot clinics.

The pandemic has been very challenging, but teamwork and collaboration between the clinics and Steps has been inspiring.



**A South African** challenge is our shared challenge.

A message and key information regarding COVID-19 and its impact on clubfoot care in South Africa.

#### A South African challenge is our shared challenge

A message from our founder on COVID-19

Dear Steps clubfoot care community,

We are all dealing with an unprecedented situation in our country. As our president has said, "If we act together, if we act now, and if we act decisively, we will overcome it."

We want to reassure you that we at Steps are continuing our work to improve the lives of bebies born with clubfoot,

#### Steps is a registered essential services provider.

We are taking precautions and will remain operating as normal in our service to dubfoot patients.



We have put the following measures in place effective 16 March:

#### 1. Cape Town office status:

- To answer the call for social distancing, the Cape Town office staff will all be working remotely;
   Our executive director has constant contact with all staff via the technology that we have available to us to enable remote working and our work will continue as usual;
- The Steps office landline is operational (021 462 7357), it is re-directed to our office manager's cell phone to take calls on ordering braces and clubfoot support.
- WhatsApp messages to 078 563 0106.
- · We will still be sending out orders via courier as usual, to service patients. We will use sanitising hand cleaner before handling product and packaging.
- Our courier company is taking necessary precautions. More information on their website.
   On delivery you may request that the driver places the delivery package and waybill at your door and steps. back two metres allowing you to sign the waybill in full with your own pen and take your delivery inside, then close the door with the signed waybill outside, which the driver will retrieve

#### 2. Clubfoot clinics status

We are in constant contact with the Steps medical director, and our information is led by the decisions and communications we receive from each individual clinic as well as the Department of Health and the World Health Organisation.

We are keeping a COMD-19 operational status list of all the clubfoot clinics we work with in South Africa.



#### Latest Posts

> Clubfoot care in the time of COVID-19. A front line view

> Removing Ponseti Casts

> Health & Wellness: Concern about impact of Covid-19 on access to Clubfoot treatment

> Alyssa's clubfoot journey

> Clubfoot Champion Hamzah completes his journey - with the help of Legal

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Monthly Archive

 $\sim$ Select Month



## Our forecast for the next 12 months due to the delayed treatment during COVID-19 lockdown:

- Clubfoot clinics are all outpatient clinics and many were closed for part or all of Lockdown 1 and 2. Most are slowly starting to operate again.
- Clinics that remained operational were not doing elective surgery during lockdown, and there will be a lot of catch-up needed.
- Many clinics are working on a 2-week casting rotation schedule, to halve/limit the number of patients attending the weekly clinics.
- We expect that as lockdown eases all clubfoot clinics will see a noted influx of patients, ranging from:
  - New patients (possibly older than average first appointment age).
  - Relapsed cases (lack of adherence due to braces being too small and unable to continue treatment).
  - Untreated (older) and recurrent clubfoot patients.
  - Patients that missed follow up appointments due to clinics being closed, restricted travel, lack of funds, or fear of hospitals and COVID-19 exposure.
- This will bring about a increase in the need from Steps partner clinics for clinic support material, clubfoot braces, and emergency brace stock.
- We have worked hard during lockdown to be prepared for the increased patient numbers and to have sufficient stock and resources in place to be able to support and assist our partner clinics and beneficiaries in the challenging period ahead.

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## **HIGHLIGHTS**



## **STEPTEMBER 2019 CAMPAIGN**

## **Campaign Message: Clubfoot is Treatable**

- Promote health and mobility.
- 10,000 Steps a day challenge for 30 days.
- Raise funds to support a child's treatment.
- R2 500 supports one child's treatment at a partner clinic.



## **STEPTEMBER 2019 CAMPAIGN**

## **EVENT:**

STEPtember pop up on 14 September in Cape Town at a soccer park, was featured in community papers.

Raised R17 500 = 6 children supported



# **2020 WORLD CLUBFOOT DAY**

Because we couldn't have our usual clubfoot awareness days and in-clinic celebrations due to COVID-19 lockdown, we pivoted to digital.

We launched the Steps Uthutho Fund on 3 June to celebrate global World Clubfoot Day.

The Steps Uthutho Fund is a transport support initiative to increase access to clubfoot care.





## **Campaign Launch Ambassador**

**Letshego Zulu:** a biokineticist, mother, and founder of PopUpGym, a health and fitness business, came on board to share the campaign with her audience.

The campaign generated media interest with radio interviews and print and digital news coverage. Direct personal campaign donations during June raised R20,000 despite the pressures of the COVID-19 pandemic and lockdown.

# **CLUBFOOT AFRICA CONFERENCE**

Due to the impact of COVID-19 restrictions, we made the decision to postpone the inaugural Clubfoot Africa Conference 'Moulding The Future' planned for November 2020.

The new date will be confirmed during 2021 according to the pandemic scenario and what will be realistically possible within lockdown constraints. This will be the first full clubfoot conference on the African continent. The website is live and we will continue to add information to it. Some sponsorships have been finalised and we are working on the registration process which will integrate with the Whova App. We are looking forward to hosting the first full clubfoot-focused conference on African soil with an impressive line-up of guest speakers who are all global experts.

### www.clubfootafrica.com



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## **ACT TRAIN THE TRAINER WORKSHOP**

The Southern African ACT Clubfoot Training Workshop for health professionals planned for November 2020 was postponed due to the cancellation of the conference and COVID-19 restrictions. We plan to hold this training in the week following the Clubfoot Africa Conference.

This will be a four-day training incorporating ACT's Ponseti Train the Trainer (introduction and advanced) training with teams of Level 1 and Level 2 trainers and Level 3 delegates. The ACT Training will be held in Gauteng, with patients from the various clubfoot clinics in the province.

We will invite key clubfoot providers in neighbouring countries: Namibia, Botswana, Namibia, Lesotho, Zimbabwe and Mozambique, and the South Africa delegates will be from under-resourced areas in Gauteng, Limpopo, Mpumalanga and North West Province.

We will run the ACT training in partnership with Global Clubfoot Initiative and with the support of Steps Worldwide (UK).



## **2019 947 RIDE JOBURG STEPS TEAM**



An enthusiastic team of cyclists competed in the iconic 947 Ride Joburg cycling event, including orthopaedic surgeons. The team raised R15 500 for Steps which will support the treatment of 6 children.







## **GRATITUDE GATHERING**



In November 2019 we hosted our first Steps Gratitude Gathering to thank our generous supporters who do pro bono work for Steps. We invited them to an intimate gathering to acknowledge their kind contribution to improving the lives of children born with clubfoot. We will repeat this event when COVID-19 restrictions allow.



## **MICKLEFIELD TALK**

Our founder gave a talk at Micklefield primary school in Cape Town about clubfoot treatment. A 12-year-old pupil, Jemima McQueen, who was born with clubfoot, chose Steps as her social project. With her friend Aalia Jawoodeen, she raised awareness and R2,600.00 for Steps.

Aalia's mother Waheeda said:



"Your hard work and dedication to Steps really is inspiring to all of us. I am grateful that both Aalia and I had the opportunity to see the work in action.

I hope that you will be able to keep expanding the reach of Steps to clinics so that more and more children and families can benefit from the life changing work you do – even in these strange times we find ourselves in."



## **NEW STEPS AMBASSADOR**

We were thrilled to welcome a new ambassador to help us spread the message that clubfoot is treatable. Thato Molamu was introduced to Karen Moss of Steps at a social gathering and will assist with the 2020 STEPtember campaign.

Thato is a popular celebrity, philanthropist, business owner and now – a Steps Ambassador. He is very generous with his time, his network and his social media following.

> "No action is ever too small when it comes to changing the world. Every child deserves an opportunity to have a happy life"



## **THE DISRUPTORS**

Senior Management Development Programme (SMDP) is part of the University of Stellenbosch Business School's Executive Development Programme.

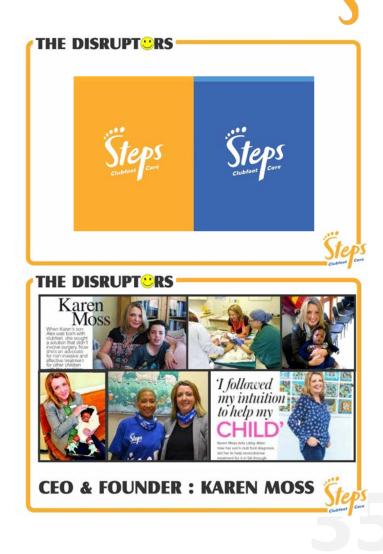
'The Disruptors' team contacted us to ask if they could select Steps for their "Business Driven Action Learning" project.

To make a relevant and informed business decision, the team did an environmental scan on Steps, identified challenges and found a relevant benchmark to create an ideal state to work towards.

They analysed Steps from a strategic perspective, formulated a strategy to increase performance and designed a plan to implement their strategic direction.

The goal was to make a contribution to social responsibility.

Our thanks to Nina van Niekerk, Jacques van Aarde, Karin du Plessis, Sithembiso Ngubane and Teddy James for contributing their time and expertise.



## **THE DISRUPTORS**

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"For me personally it was an extremely humbling experience. One gives monetary donations quite easily to 'organisations in need' but it's not always about funds, it's realising that your time can also make a big difference. Once I understood the amount of time and effort and personal sacrifices you Karen and the rest of the Steps team put into ensuring Steps is a success, to ultimately make a difference to as many children as possible, I have a newfound respect for the work you and your colleagues do. It's almost as if a person develops a personal connection to the people and the organisation, I certainly did. I found the working relationship extremely beneficial to the success of our assignment and for your contribution we say a BIG THANK YOU. "

THE DISRUPT ORImage: Stress of the stres

- Jacques van Aarde

### **EDUCATIONAL VIDEOS**



Steps created three educational videos for the clubfoot community. They have been sent to Steps partner clinics and are also available on our website. The videos will be shown in the waiting areas at clinics that have TV screens.

- 1. A Parent's Guide to Clubfoot
- 2. Brace Fitting Instructions for Parents and Caregivers
- 3. Clubfoot Brace Fitting for Healthcare Professionals





# **CLINIC CO-ORDINATOR TOOLKIT**

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We took the opportunity during lockdown to focus on projects that would support clinics when they are managing an increased number of patients that couldn't access treatment due to COVID-19.

The Steps Clinic Coordinator toolkit is a collection of resources, processes, tools, checklists and educational material. This can be used by anyone working in a clubfoot clinic in a support role for clinic admin and data records, parent education and the issuing of braces.

Every Clinic Coordinator at a Steps Partner Clinic will have a copy of the toolkit by October 2020. Any person joining a Steps Supported Clinic team will have access to this comprehensive resource that is used in conjunction with our Steps Ponseti for Parents© Parent education materials.



### **CLINIC CO-ORDINATOR TRAINING**

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We had to postpone our 2020 Steps clinic coordinator training because of lockdown and are working on a webinar for 2021 that covers all the components needed to run a streamlined clubfoot clinic.





## **STRATEGIC PUBLICITY PLAN**



We commissioned a communications agency, MANGO-OMC, to produce a strategic advocacy plan. This is intended to increase the reach of our message that clubfoot is treatable.

#### Key outcomes are:

- 1. Website audit and plans for redevelopment.
- 2. Social media audit and plans in place for implementation.
- 3. Recommendations on key messaging and campaigns.
- 4. Concepts produced for World Clubfoot Day and Steptember 2020.

MANGO-OMC is continuing to work with Steps on a project basis as we roll out the recommendations.





### **STEPS PROCESS MANUAL**



In line with our 2020 focus to streamline all processes to ensure that we function the best we can as an organisation, Steps invested time into documenting all of our processes, improving those where it became evident that they could be better streamlined and consolidating structures.

The Steps Process Manual outlines the processes and procedures for our core organisational activities, providing guidance to Steps staff to ensure we all perform correctly and efficiently to provide the best service to our beneficiaries.





### **OUR GLOBAL REACH**



# CEDA

Steps was a contributor to the development of the **CEDA Project** (Clubfoot Early Detection and Adherence) - a project of Hope Walks. CEDA produced a complete set of teaching resources designed to strengthen training and delivery capacity for clubfoot early detection, referral and treatment adherence. This will be made available globally to all members of the Global Clubfoot Initiative. We attended a pilot training in Zambia to finalise the training content.

- Parent Advisor Training (PAT) Train the Trainer Course Length: 1 Day
- Parent Advisor Training (PAT) Advanced Course Course Length: 2 Days
- Early Detection and Referral Training Course Length: 10-15 min. OR 1 Hour

Film Length: Each film is between 5-6 minutes in length

- 1. What is clubfoot?
- 2. The Ponseti Method.
- 3. 10 Steps of a Clubfoot Clinic.
- 4. Foot Abduction Braces.





# **GLOBAL CLUBFOOT INITIATIVE**



#### We are a member of the Global Clubfoot Initiative.

The Global Clubfoot Initiative is an umbrella body of international organisations working together to eradicate the disability caused by clubfoot with coordinated biannual surveys of treatment providers in LMIC and UMIC to assess provision of, and access to, effective treatment. Steps executive director Karen Moss is a member of the GCI #runfree2030 Working Group and the GCI Clubfoot Training Working group.

On World Clubfoot Day in 2017, GCI launched Run Free 2030: A Global Strategy to End Clubfoot Disability. Run Free 2030 sets out an ambition to ensure that by 2030 at least 70% of children born with clubfoot in lower and middle income countries can access treatment.



### RUNFREE#2030

By working towards 2030, the Global Clubfoot Strategy aligns with the World Health Organisation Rehabilitation 2030 Call to Action, the Lancet Commission on Global Surgery 2030 and the UN Sustainable Development Goals 2030.

Objectives for target low and middle income countries by 2030:

- 100% to have a national clubfoot program delivering comprehensive clubfoot care.
- At least 70% of children born with clubfoot in target countries to have access to Ponseti treatment..
- 100% of national clubfoot programs to meet at least 70% of the global clubfoot quality metrics.
- 100% of national clubfoot programs to meet at least 70% of the global clubfoot sustainability metrics.

https://globalclubfoot.com/runfree2030/

2030 RUNFREE



#### GLOBAL INITIATIVE FOR CHILDREN'S SURGERY – GICS IV CONFERENCE (JOHANNESBURG, JANUARY 2020)

#### **GCI Presentation 'RunFree2030:** 'Accelerating global progress in clubfoot treatment'

#### **Speakers:**

Rosalind Owen (Global Clubfoot Initiative) Norgrove Penny (Hope and Healing International) Scott Reichenbach (Hope Walks) Alaric Aroojis (Miracle Feet) Karen Mara Moss (Steps South Africa)

GICS is a consortium of providers, institutions, and allies from around the globe and from a wide range of both LMICs and high-income countries (HICs). They believe that children's surgery includes all provision of surgical care to children, not just paediatric surgery. GICS includes all specialties and subspecialties involved in children's surgical care, such as neurosurgery, plastic surgery, orthopaedics, anaesthesia, intensive care, radiology, pathology, laboratory medicine, paediatrics, nursing and physical and occupational therapy.



#### SOCIAL ENTERPRISE ACADEMY OSLO PROGRAMME



Solveig Midttun Baera from Norway, joined Steps for a 3-month period as a junior consultant. We were one of the selected host organisations for a project run by The Social Enterprise Academy, UCT Graduate School of Business, and Western Norway University.

Solveig's project focused on investigating and analysing some of the most important processes of Steps and find ways of improving, changing and streamlining them.

The map depicts the main conclusions and six process documents linked to three of the four pillars of Steps - Training, Clinic Support and Brace Distribution - were generated.

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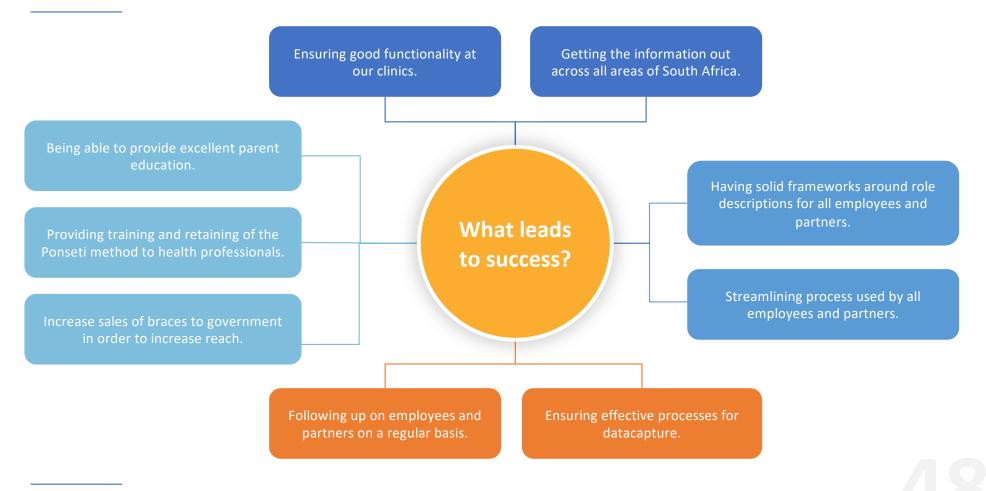
"This experience has been utterly amazing, educational, inspirational and rewarding. I sincerely hope and believe that my contributions will be useful for Steps in many years to come."

- Solveig



Solveig Midttun Baera

### SOCIAL ENTERPRISE ACADEMY OSLO PROGRAMME



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# **STATISTICS**



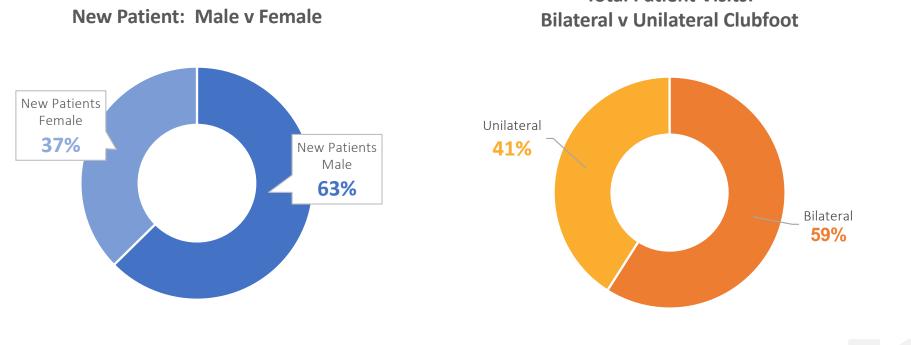
### **OVERVIEW STATS JULY 2019 – JUNE 2020**



## **CLUBFOOT PATIENT TRENDS**

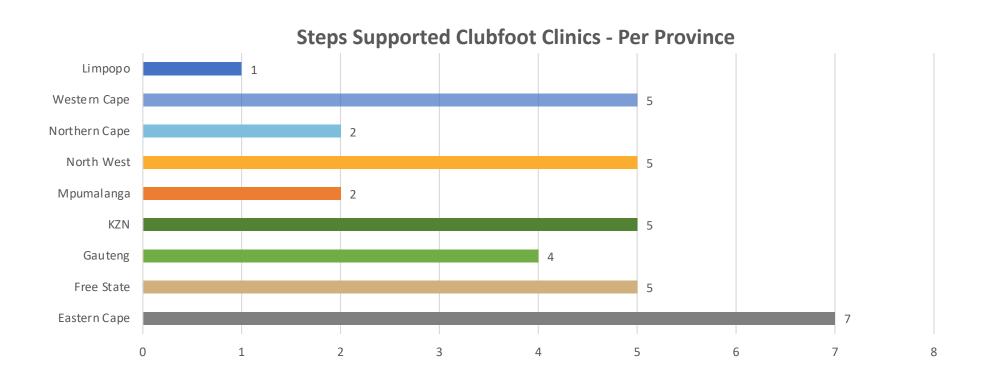


From statistics collected at our partner clinics the following trends were observed



**Total Patient Visits:** 

# **STEPS SUPPORTED CLINICS PER PROVINCE**

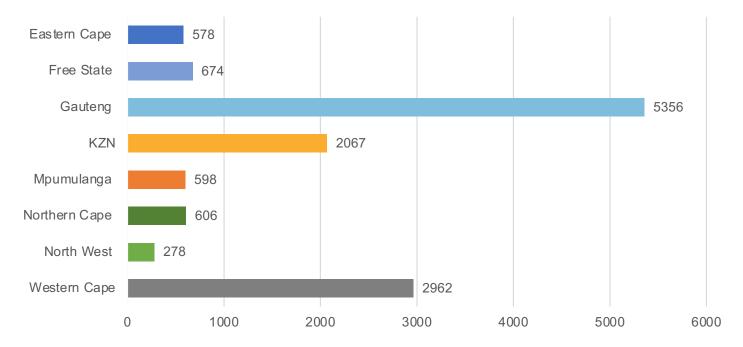


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# STEPS PARTNER CLINICS PATIENT VISITS PER PROVINCE

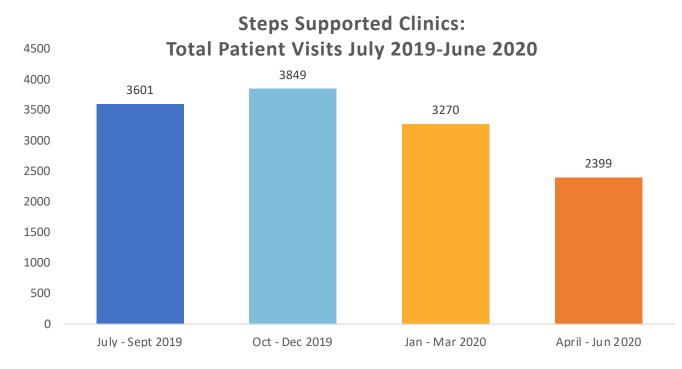
#### Total Patient Visits per Province in Steps Supported Clubfoot Clinics: July 2019-June 2020



13 119 Total patient visits nationally

# STEPS PARTNER CLINICS PATIENT VISITS PER QUARTER

This graph clearly illustrates reduced patient visits during lockdown 1 in quarters 3 and 4



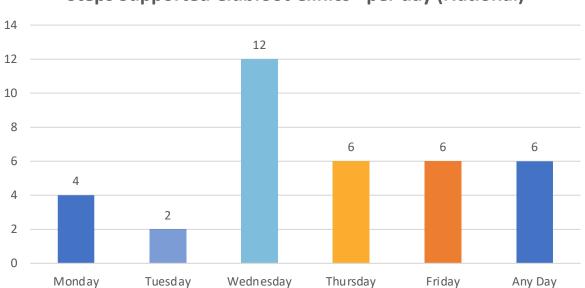
#### 13 119 patient visits July 2019 – June 2020



# **STEPS PARTNER CLINICS – WEEKLY CLINIC DAYS**

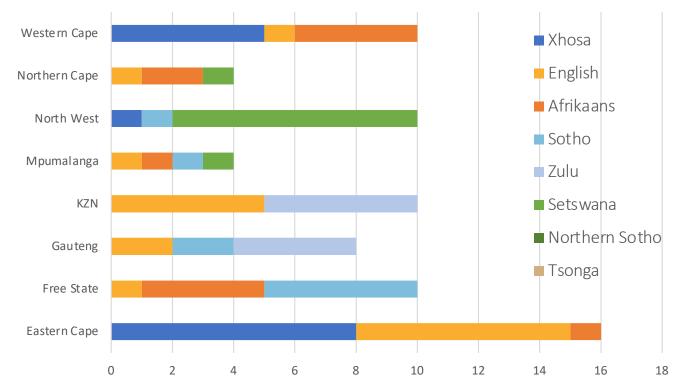
Most hospitals set a specific day aside to run their weekly clubfoot clinics.

There are five clinic partners that treat clubfoot patients 'any day.' These are very small, rural hospitals/clinics and do not have enough patients to set aside a morning solely for the treatment of clubfoot.



#### Steps Supported Clubfoot Clinics - per day (National)

# **STEPS PARTNER CLINICS – LANGUAGES PER PROVINCE**



#### Language at Clinics Per Province

56



# OUTCOMES BASED ACTIVITIES: HIGHLIGHTS



# **PILLAR 1 TRAINING : HIGHLIGHTS**

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New online resources to support families at home with patients who could not continue with their treatment due to COVID-19 lockdown.

Steps Clinic Coordinator Toolkits distributed to partner clinics.

- In-clinic staff trained on clinic coordination and parent education.
- **Outreach visits** for in-clinic training supported.
- **Educational videos** produced to support families and health professionals.

**Outcomes:** 

- Build capacity to treat more patients.
- More clinic workers have access to Ponseti and clubfoot patientcentred care learning materials.
- New clinics opened and existing clinics strengthened.
- Skills improved.



### **PILLAR 2 CLINIC SUPPORT : HIGHLIGHTS**

**Partner clubfoot clinics** supported in South Africa.

New clinic partners added in South Africa.

Ponseti clinic in Limpopo Province to be opened at Letaba Hospital thanks to assistance from the George Mukhari Hospital team. The clinic is equipped and ready to run, but the initial opening date of February 2020 was postponed due to COVID-19.



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# **PILLAR 2 CLINIC SUPPORT : HIGHLIGHTS**



#### Outcomes:

- More new patients enrolled for treatment.
- More parents get education and support through their child's treatment.
- Families have less travel time and costs as new clinics open closer to their homes, resulting in regular clinic visits and less drop out.
- Improved skills and data capture at partner clinics.





#### 2020 World Clubfoot Day – Uthutho Fund

TV: Expresso Show.

**Radio:** Cape Talk Pippa Hudson interview, Good Hope 'Disability' 360 interview FM, Smile FM Digital: GoodThingsGuy (1.5 million people reach), Briefly, Social TV, Porky's People, Backabuddy.

#### 2019 September Campaign

Radio: Interviews on Goodhope FM
'Disability' 360, Bush Radio.
Digital and print: Stories in News24,
People's Post, community papers (Southern Sun Tatler) GoodThingsGuy.







#### Media Interest

- Your Family Magazine. •
- Pretoria News wrote a story after their visit to • George Mukhari Academic Hospital clubfoot clinic.
- The Citizen newspaper wrote a feature about • clubfoot after a visit with us to Chris Hani Baragwanath Academic Hospital.

#### 2019 September Campaign

- Interviews on Goodhope FM 'Disability' 360, Bush • Radio.
- Stories in News24, People's Post, community • papers (Southern Sun Tatler) GoodThingsGuy.



would be cut and repositioned, pins congenital clubfoot, which was inserted into the feet and Alex would be never picked up in his scans. in full leg casts for six weeks. He'd later Doctors and nurses assured us that a few have another anaesthetic, so the pins casts would fix his feet in no time. He was fitted with his first plaster casts up to the of further surgery when he was older, knee by an orthopaedic surgeon when he depending on how his feet developed. was six days old. But at nine weeks old, the surgeon However, I was against surgery because I didn't want to subject our baby told us Alex would have to undergo major to pain, a long anaesthetic and possible to pair, a long interstitute of an ergo major surgery on both feet when he reached to weeks. We were shocked, as we'd hoped research online, which led me to the the casts would work, but he said 90% of Liniversity of Iowa Children's Hospital all bables in the country with congenital clubfoot were operated on after casting. Surgery involved a minimum of three in the 1950s by Dr Ignacio Ponseti, the method was used successfully in 95% of ours per foot. The ligaments and tendons

all cases. The procedure involved a series of casts, gentle manipulation and a special brace for the feet. This treatment was the most cost-effective, with no side-effects. Limmediately contacted Dr Ponseti himself. We spoke on the phone and emailed him photos of Alex's feet, after which he confirmed he'd be able to treat him successfully. My husband Steve also spoke to a few other doctors, who onvinced him that it was a good idea to fly to Iowa. Soon enough, we'd booked our flights

local anaesthetic, was all that was needed to straighten Alex's feet. I was blown

8 yourfamily.co.za



#### **Clubfoot: keep walking**

STEPS FOUNDATION: HELPS CHILDREN WITH THE DEFECT LI

-> Correct, effective treatment changes children's lives for the better.

#### Chisom Jenniffer Okoye

fter the news that her child had been born with a severe case of talipes equinocarns, also known as club-foot, ayoung mother is now onher my to witnessing her daughter sking her first steps more than



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Paris - Vaping devices, par-ticularly popular among teens, and the chemicals they deliver may damage the cardiovascular system. a study said this week, add-ing to a chorus of concern injury and deaths re lated to e-cigarettes. The latest findings, pub-lished in the journal Cardi-oraseular Research, come after the US Centers for Dis-ease Control and Preven-tion (CDC) last month de-clared an "outbreak of lang injuries" linked to vaping. nicotine, particulate ter, metal and flavour not just harmless wate pour," senior author L Wold of Ohio State Un sity wrote in the study, pollution studies show

hits hearts





EXPERTS at the Clubfoot Clinic, George Mukhari Academic Hospital, assist a child born with the musculoskeletal defect, or clubfoot. Oupa Mokoena African News Agency (ANA)

#### George Mukhari hospital clinic gives children with club feet a chance at a normal life

By GOITSEMANG TLHABYE 🕓 Oct 30, 2019

PRETORIA NEWS

In October 2019 Steps supporter Lauren Cox hosted a **#ROCKFORSTEPS** fundraising event at the Barnyard Theatre in Johannesburg.

#### The event raised R30 000

to support 12 children born with clubfoot. At the event we were introduced to Thato Molamu, an actor with a big following, who has now become an ambassador for Steps.





# **PILLAR 4 CLUBFOOT BRACES : HIGHLIGHTS**

The clubfoot brace is a vital part of treatment. Without a reliable supply of comfortable and effective clubfoot braces, treatment fails.

Steps works with international partners to source and supply medically endorsed clubfoot braces for southern Africa.

Steps also supplies parents, doctors and orthotists in the private health sector and provides support for sizing, fitting, brace protocol.

We distributed **2 026 clubfoot braces**.

Value of brace donations to our partner clinics: R 537 630.00.

#### **Outcomes:**

- Clinics and patients have consistent access to the braces required for successful treatment.
- Risk of recurrence reduced.
- Burden on clinics decreased.





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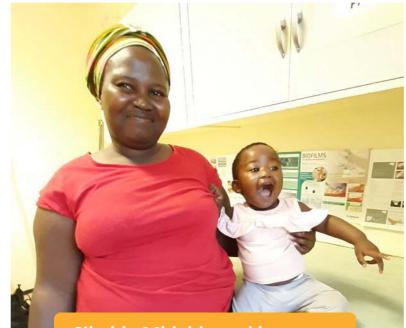
# **CLUBFOOT CHAMPION STORIES**



#### **SIBAHLE MHLAHLO'S CLUBFOOT JOURNEY Mom's determination**

Sibahle Mhlahlo (aged 1) who is currently in the maintenance phase of her clubfoot treatment, is a patient at our clinic partner Tygerberg Hospital's clubfoot clinic. Sibahle and her mom live in Strand, Western Cape, and they have to travel for 2 hours, taking 3 taxis each way, a total of four hours travel time for each clinic visit.

> "When my daughter was born I found out that she had clubfoot. I was very surprised and worried, I had never heard of clubfoot. The doctor assured me that there are clubfoot clinics and that it can be fixed. He made an appointment for me to take my daughter to the Tygerberg Clubfoot clinic."



Sibahle Mhlahlo and her mom

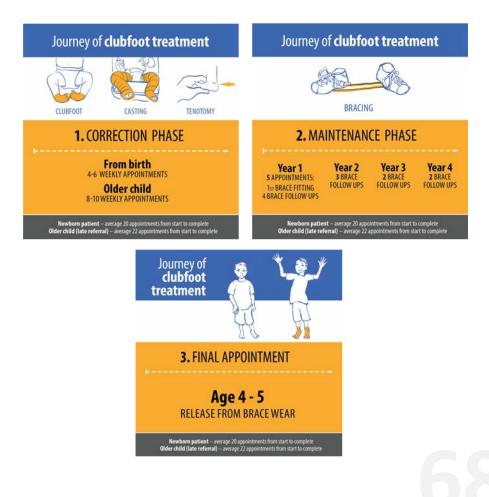
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#### SIBAHLE MHLAHLO'S CLUBFOOT JOURNEY Mom's determination



"My daughter had nine casts, so I travelled to the clinic every Thursday for nine weeks. The travelling to the clinic was difficult for us as I do not work and it is so expensive. It's a very long trip for us, taking two hours and three different taxis for us to get from our home to Tygerberg Clinic. But I tried my best for my daughter.

Steps helped me on my journey with lots of support and advice. They told me to come back and I did. I am very very happy as my daughter is no longer disabled. She is a very happy and healthy child."



#### ALYSSA'S CLUBFOOT JOURNEY Message of hope

When Felicia Nel gave birth to her baby girl, Alyssa – with clubfoot, she was devastated.

The casting started off as traumatic but soon became reassuring for the family since they could see change- with each cast, and understanding that their precious little girl wasn't in pain and didn't know any better.

> "I'd like to say that STEPS was wonderful. They explained everything from how the boots and bar worked to when to start looking at getting up sized booties and what kind of socks to buy if necessary because the grip socks were a little pricey, but worth it. What helped me personally more than anything else was knowing that another mom, who has been through the very same journey we had only just embarked on, was the founder. This was very comforting to me in a way."

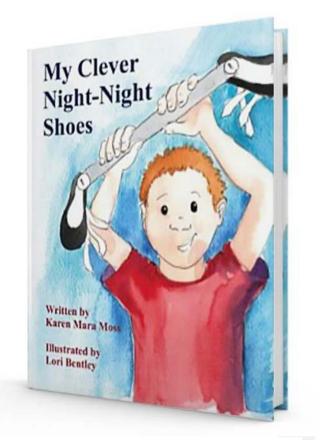


#### ALYSSA'S CLUBFOOT JOURNEY Message of hope

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"Reading Karen's book to my daughter every night helped her see the fun side of what the booties were and why she had to wear them. She was so little and to her it became normal. It helped to show her there was nothing "wrong" with her. The illustrations are so cute and fun and easy for very little children to relate to and she still reads this book.

Steps made us feel like normal parents and not parents of a child with a disability. Knowing Karen and Alex's story made it that much more personal. It felt like everything we did with STEPS was from the heart  $\heartsuit$  so we will always be eternally grateful for all their help, their guidance, their patience with us and the compassion shown towards us as very inexperienced and scared, first time parents to our baby with her 'special foot'"



#### **CLUBFOOT CHAMPION HAMZAH** The Lego story

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Sameesha Osman Latib went to her 21-week scan during her pregnancy and was told that her baby would be born with clubfoot..

While Sameesha felt scared, confused and guilty – she says "we were Incredibly grateful that we were granted something that's treatable."

The first casting session was stressful for her son Hamzah Mukuddem and his supportive family because no one in the family knew what to expect or how to handle the situation.

> "We had 7 weeks of casting, tenotomy, and a another month of being in a cast. Hamzah has been in 23 hour brace wear for five months so far because his condition was so severe. It has been a huge eye opener for us. We witnessed tears, frustration, joy and immense pride watching Hamzah navigate his way through the day – even when he had to wear the brace all day."



#### **CLUBFOOT CHAMPION HAMZAH** The Lego story



To make Hamzah's treatment journey positive and fun, his mother used Lego. By decorating and visualising a story around his boots and casts she created a wonderful and comforting atmosphere around his condition. Because of this, treating his disability was a joyful experience.







"Speak to family and friends about it. Join the support group and know that you're not alone. Remember that your little one won't remember this.

Be kind to yourself and your baby especially when they seem fussier than usual because they are going through a lot more than we could ever imagine."





## **FRONT LINE STORIES**



Ivy Muffler is a Steps clinic coordinator working at the weekly clubfoot clinics at Charlotte Maxeke Johannesburg Academic Hospital and Steve Biko Academic Hospital (Pretoria). Ivy says:

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"Working as a Steps clinic coordinator during the COVID-19 pandemic has certainly been interesting. When the lockdown was first announced we were all filled with confusion and fear. My phone buzzed the whole day with patients wanting guidance on what they should do. Some wanted to rush back to their family homes, some were too scared to leave home. But they all knew that they didn't want to discontinue treatment if it was still available, and they were worried about what a break in treatment would mean for their child's progress.

After the initial shock was over, things settled in quite quickly and most patients who were still in the active casting stage returned to the clinic for treatment. The parents were cooperative and understanding, and adhered to the new stricter safety protocols. They understood that these were exceptional times and that it would take us all working together as a team to make it through this time safely."



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"When the numbers of COVID-19 cases increased, they partially converted our consulting area in Charlotte Maxeke hospital into a paediatric casualty unit as the hospital was rapidly running out of space. That meant that half of the room where we apply our plasters was now filled with specialised emergency equipment. We had less space to work in and could only allow limited people inside the area.

It also meant that this area was now considered an 'orange zone' or high risk area. It therefore became necessary for staff working inside the area to be dressed in full PPE at all times. This includes a gown or disposable hazmat suit, head cover, shoe cover, gloves, mask and visor or shield.

The increase in use in PPE made it more challenging to communicate with parents. The mask and visor make it more difficult to talk which makes it harder to explain procedures to patients' families and to give them support and guidance. It also made it more interesting working with the children.

A lot of what we do as Steps clinic coordinators is interaction with the children, so when they can't see facial expressions, it leads to some curious looks. The children also love grabbing at the visor and mask which also makes things more interesting."



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"Working in full PPE certainly has its challenges and I think it has increased fear in some of our parents, but all in all we've managed to make it work. We continuously cast patients every week. We do our all tenotomies in-clinic as theatres are reserved for emergencies.

We manage to run a successful, busy clinic despite the challenges. We even had a clinic during a power outage a few weeks ago and had to cast patients in the dark!

Our doctors and nurses are phenomenal and power through despite the risk and challenges they face. Our nurses do the work of three or four people at a time as the clinics are short staffed due to the pandemic.

Some of our nurses volunteered to go and work in the COVID-19 wards and have returned with terribly sad stories of the patients they have treated and lost. One of our nurses tragically lost her husband due to COVID-19 and she was also infected and ill. Our staff all tell stories of someone they lost, shortages in PPE and shortages of equipment. You can see the sheer exhaustion on their faces. But they show up every day and give their best, because that's what they were called to do."





"This is certainly a time none of us were prepared for, but it is astounding to see the determination and strength in not only our frontline workers but the parents of patients who risk everything to get treatment for their newborn babies, who ask for help at clinics near their homesteads, who follow up and don't give up."





## PROGRESS, FINANCIALS AND SUSTAINABILITY, OUR TEAM



### **PROGRESS MADE TOWARDS REALISING OBJECTIVES**

- More clinics and better reporting are showing more children being enrolled and treated with the Ponseti Method.
- We have facilitated the use of modern braces in public clinics at less cost to the taxpayer.
- We diversified our income stream by increasing our public profile and securing new donors and partnerships.
- Our award-winning model has proven it has the flexibility to adapt to clinic needs and we can refine our clubfoot support programmes to suit local conditions.
- We expanded our support and reporting for a number of smaller and outlying clinics.
- Even with the challenges of COVID-19 we have met and in some cases exceeded our objectives. Our purpose remains the same despite the pandemic.

#### **PROGRESS MADE TOWARDS REALISING OBJECTIVES**

We have improved awareness of clubfoot and Ponseti treatment among health workers and the public through campaigns, media coverage and social media.

Thousands of children are wearing clubfoot braces secured and supplied by Steps reducing the risk of recurrent clubfoot.

In the next financial year, our goal is to grow Steps support to children born with clubfoot in South Africa by 10% by continuing to expand clinic partners with specific focus on outlying areas where children have to travel far for treatment.

We deeply appreciate and give credit to all of our partners, donors and supporters for this financial year. We are only able to make the impact we do because of your generosity and collaboration.



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#### SUMMARY OF AUDITED FINANCIAL STATEMENTS 1 JULY 2019 – 30 JUNE 2020

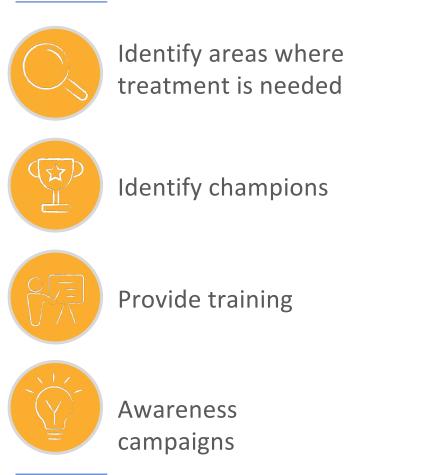
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REVENUE	4 656 713
Donations received and event raised funding	2 111 069
Donations in kind	1 110 131
Brace sales	1 435 513
COST OF SALES	(2 442 458)
Braces	2 442 458
GROSS SURPLUS	2 214 255
INVESTMENT INCOME	56 972
TERS UIF RECEIVED	121 607
OPERATING EXPENSES	
Core Activity	(1 756 291)
Clinic Advocacy	375 705
Clinic Support	703 317
Ponseti training & facilitation	442 991
Support Activity	
Support <b>cost</b>	234 278

OPERATING SURPLUS FOR THE YEAR 636 543

81

#### **ENSURING SUSTAINABILITY OF QUALITY CLUBFOOT CARE**





Assist with resources for clinic set-up:

- Education literature
- Admin and parent education staff
- Clubfoot data capture
- Clubfoot braces

#### Social enterprise:

Braces and training

## **OUR SUSTAINABILITY STRATEGY**



Diversified revenue stream.

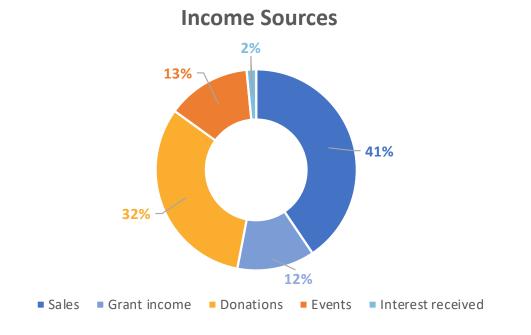
- $\circ$  Grants
- Fundraising campaigns
- $\circ$  Events
- Product sales
- $\circ$  Training
- Partnership with South African Paediatric Orthopaedic Society.
- Innovative resources and tools.
- Integrated into the South African Public Health System.
- **)** Lean management principles.



#### **OUR SUPPORTERS**



We thank our generous supporters and partners. Without you we would not be able to create the impact that we do.



Our funding comes from many sources, from a person donating R50.00 at an event, to major private donors who invest large amounts to make a sustainable impact, to corporates and private foundations.

We are immensely grateful to you all.

We also generate our own income through sales of medical devices and events.

#### **OUR TEAM**

#### **Steps Clubfoot Care**

Jeanne Day-Spriestersbach Smangele Dladla Luke Engel Penny Hlakula Lynne Huppert Refiloe Khosa Ursula Kibido Jane MacKinnon Alan Millar Karen Mara Moss Ivy Muffler Gabrielle Rademeyer Ann Wallis-Brown Phumzile Zondi

#### **Steps Ambassadors**

Bernelee Daniell Charne Felix Thato Molamu Cameron van der Burgh

#### Clubfoot Africa Conference Local

#### Committee

Dr Marilize Burger Jeanne Day-Spriestersbach Prof Jacques du Toit Karen Mara Moss Dr Mari Thiart

#### **Steps Directors**

Prof Jacques du Toit (Medical Director and Chair) Cheryl Howard (Treasurer) Shumi Kupara (Secretary) Karen Mara Moss (Executive Director) Denalda Tuckett (Non-executive Director)

## A LETTER FROM OUR FOUNDER AND EXECUTIVE DIRECTOR

At the time of writing this year-end letter in early December 2019, who could have possibly imagined the change we were going to face in 2020. Much has changed in our world, but the sentiments of this letter remain the same.

Dear Steps friends and supporters,

As we near the close of 2019, I reflect on our year at Steps and the theme of 'Change'.

Steps has been a change agent from the start. In 2003 when I arrived home from Iowa after meeting Dr Ponseti, having watched his hands moulding my son's feet into position without the need for surgery, my promise to him was to convince doctors to change how they were treating clubfoot. Since then, Steps was born and we have changed the lives of so many children in South Africa and other countries in our region by training health professionals, supporting clubfoot clinics and parents, raising awareness and sourcing the essential clubfoot brace.

A few years ago we developed a 'theory of change' model describing our four pillars of impact that support a child from a disabling birth defect to full mobility. This award-winning model has given us better focus and clarity to work in the challenging environment of public health.

Change is felt both internally and externally. Sometimes we can choose to change and sometimes we have to adapt to changes that we have no control over. They call that resilience. During 2019 we said sad goodbyes to valued team members who left for new adventures. We welcomed and got to know new team members who brought in refreshing new ideas and energy. We have changed and refined our internal structure and expanded our connections globally.

# A LETTER FROM OUR FOUNDER AND EXECUTIVE DIRECTOR

One of the exciting developments is that we are planning the first Clubfoot Conference on African soil, in Cape Town. We have also refined and streamlined how we work. As a 14 year old 'teenager', Steps needed the structure and some 'adulting' as we developed and grew into a mature organisation! I have found that process frustrating at times, but the results have been really worth it as we enter 2020 feeling ready.

#### Change a child's life.

That's what we work for, and over our 14 years of existence, that hasn't changed. Our core purpose remains the same and keeps us focused on what matters most - the child with clubfoot.

What does change mean to a parent of a child born with clubfoot? It's absorbing the loss of what you expected to have with the birth of a new baby and accepting that it will be different. What is supposed to be an intimate and happy family time, becomes one of medical appointments, heavy plaster casts applied to a small baby's legs, worrying about the future and often many sleepless nights struggling to adapt to the clubfoot brace. But it's also watching the changes to your child's foot as the plaster casts work their magic, becoming part of the supportive clubfoot community, under the care of skilled health

professionals and realising that although the journey is hard and long, it will be alright.

Change is both terrifying and thrilling. I feel the ever present urge to reach more children and the excitement of new possibilities. I wake up with new ideas, but experience has taught me that they don't all work, or they take longer than I expected. What always remains the same though is that my vision remains unchanged and the core purpose is clear. This is the internal anchor that steadies the ship in turbulent times.

#### A LETTER FROM OUR FOUNDER AND EXECUTIVE DIRECTOR

As we enter 2020, we all face change. We only have to check the news to know that nothing is guaranteed and there is a surprise around every corner. Thankfully, we have people to support us through whatever comes.

I am so grateful for the wonderful and constant support from my incredible team, the caring clubfoot clinics we serve, skilled doctors and other health professionals we work with daily, the clubfoot organisation colleagues who share our vision and inspire us and our loyal and generous donors.

You are all part of this wonderful journey to change lives and I thank you from the bottom of my heart.

Warmest regards,

Karen

Karen Mara Moss Cape Town, December 2019





## Thank you.

Further information: info@steps.org.za www.steps.org.za