

CURRICULUM VITAE : Karen Mara Moss

Name: Karen Mara Moss (née Toffoli)

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Occupation: Founder and Executive Director STEPS Charity (2005 – Current)

Languages: English (fluent), Italian, Afrikaans, French

Introduction

In July 2005, Karen diversified her career portfolio to include community work and social welfare. A passionate vision, driven by her son being born with bilateral clubfoot, led her to establish STEPS Charity NPC in South Africa.

In July 2006 Karen organised a pioneering medical seminar, the first in southern Africa, to introduce the Ponseti method for clubfoot to Paediatric Orthopaedic surgeons. Since then she has organised Ponseti training for over 600 medical professionals in four countries, South Africa, Botswana, Namibia and the Seychelles.

Karen's groundbreaking work has revolutionised the medical outlook for clubfoot care. As a direct result of Karen's work in introducing the Ponseti method for clubfoot to southern Africa, the number of babies successfully treated is now in the thousands.

Core strengths

Leadership, innovation, programme development, writing, editing, communication, public relations, media spokesperson, networking, social media, coaching and motivating individuals and groups, project implementation, start-ups, website content, marketing strategy, financial management, social enterprise, public speaking, training, and advocacy.

Specialities

With reference to her work with clubfoot, Karen's special interest is patient care and the role of the parent. She has written education materials to support and motivate parents and caregivers to adhere to treatment. Her advocacy work is focused on building a strong clubfoot community, improving communication between key stakeholders, and publicity campaigns to remove the stigma and ignorance that is associated with clubfoot. She considers all aspects of clubfoot treatment and the patient experience, and creates innovative solutions to barriers and challenges in LMIC and UMIC countries. She has developed an award-winning clubfoot care support programme that successfully implements a method from the United States within the South African state health sector. She utilises her entrepreneurial, communication and marketing skills to build a self-sustainable solution to treating clubfoot effectively.

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Education and qualifications

- Pathways to Sustainability Programme (5-month diploma) : Social Enterprise Academy, University of Cape Town Graduate School of Business
- Damelin Business School : IMM, Marketing Management 2-year diploma
- PRISA Public Relations Institute of South Africa : 1-year Diploma
- COMENSA certified executive coach
- Writers Write Creative Writing Course graduate
- Bryce Courtenay Writing Workshop graduate

Professional Awards

1st place:	2010 CEO's Most Influential Women in Business and Government (Health & Welfare) Award
Nominee:	South African Woman of the Year (Health) 2007, 2008, 2010
Honouree:	2014 FNB 'You Can Help' Community Hero Campaign, Television, YouTube and website campaign
Gold Award:	2017 Impumelelo Social Innovations Awards
2nd place:	2018 SAB Foundation Social Innovation Disability Empowerment Awards
Audience choice winner:	2018 SAB Foundation Social Innovation Awards

Achievements and highlights

2003	Conceptualised, wrote and launched a clubfoot support website with information on clubfoot that was read by thousands of people worldwide, translated content used for support websites.
2005	Founded Steps Charity NPC as a clubfoot support organisation.
2006	Organised the 1 st Ponseti training seminar to be held in southern Africa at Donald Gordon Medical Centre, Johannesburg, South Africa.
2007	Organised a Ponseti training workshop at Charlotte Maxeke Johannesburg Academic Hospital to focus on challenges at state health clubfoot clinics.
2007	Organised a Steenbeek FAB training workshop at Chris Hani Baragwanath Hospital in November 2007, resulting in sustainable manufacture and supply of clubfoot braces for South Africa's largest province, Gauteng.

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- 2008-current Created and coordinated a national South African clubfoot awareness campaign for World Clubfoot Day to increase awareness and early diagnosis.
- 2009 Established and facilitated an on-line support group for southern African parents. Moved over to Facebook, with current membership of 750 parents.
- 2011 Attended a planning meeting in Kampala, Uganda to strategise on expanding the network of Ponseti providers in South Africa.
- 2011 Ponseti method officially endorsed by the South African Paediatric Orthopaedic Society as best practice.
- 2013 Started a clinic support programme for South African state health sector.
- 2013 Introduced the Ponseti method to Botswana, training workshop at Princess Marina Hospital in partnership with Botswana Ministry of Health and Social Services, resulting in the first Ponseti clubfoot clinic in Botswana.
- 2013 Introduced the Ponseti method to Namibia with a training workshop at Windhoek Central Hospital in partnership with Namibia Ministry of Health and Social Services, resulting in the first Ponseti clubfoot clinic in Namibia.
- 2013-2016 Botswana clubfoot programme established. Worked with health professionals and local clubfoot champions to organise and facilitate Ponseti training workshops, organise clinic outreach by South African doctors, set up a clinic support programme, collect data and donated clubfoot braces,
- 2013-2015 Namibia clubfoot programme established. Worked with health professionals and local clubfoot champions to organise and facilitate Ponseti training, organise clinic outreach by Namibian clinicians, facilitated the supply of clubfoot braces for government clinics.
- 2014 Introduced the Ponseti method to the Seychelles, organised training in Mahe with the Seychelles Ministry of Health.
- 2014 Published a children's bedtime story book to encourage brace adherence. Sold globally and translated into other languages.
- 2014 Developed the Ponseti for Parents© parent education programme.
- 2013-current Registered as a medical device supplier and organised a consistent supply of clubfoot braces for distribution, sale, and donation.
- 2015 Developed a logic model 'Steps model for change in clubfoot'.
- 2015-current Registered as government supplier and introduced a diversified revenue stream using social enterprise with the sale of cost-effective clubfoot braces.
- 2017 Steps logic model wins gold at Impumelelo Social Innovation awards.
- 2017 Selected as one of four featured participants in the South African Airways 'Seat Stories' advertising campaign, personal story with focus on clubfoot.

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2017	Introduced Cameron van der Burgh, Olympic gold medallist and world breaststroke swimming champion as Steps Ambassador.
2018	Steps Clubfoot Care logic model wins 2 nd prize and audience choice award at the SAB Foundation Social Innovation disability empowerment awards.
2018	'One small step' Gala fundraising event hosted at the One & Only Hotel Cape Town with Marc Lottering, Cameron van der Burgh and Dan Nicholl.
2018	Dr Deb Carneol runs 7 marathons on 7 continents in 7 days to raise funds for donated braces for Steps partner clinics.
2019	Attended Global Clubfoot Initiative meeting in London and #Runfree2020 strategy meeting, presented on Steps Clubfoot Care model.
2019	Featured on Expresso morning show segment 'Mandela Monday Heroes'.
2019	Worked with Social Enterprise Academy Norwegian post-grad programme to map Steps key processes and develop a clubfoot clinic coordinator toolkit.
2020	Created Steps Clinic Coordinator Toolkit to standardise non-clinical processes.
2021	Launched the Clubfoot Africa Conference, inaugural conference to be held in Cape Town in 2022.
2021	1 st Webinar series: Steps Clubfoot Clinic Coordination 3-part Webinar series

Other interests

Member of the Cape Town Philharmonia choir, hiking, open water swimming, travel, theatre, creative writing.

Publications, books and videos

- Ponseti for Parents© 'A step by step guide to treating clubfoot for new patients' translated into Afrikaans, isiZulu, isiXhosa, Setswana, French, Hungarian (2014)
- Ponseti for Parents© 'Maintaining clubfoot' translated into Afrikaans, isiZulu, isiXhosa, Setswana, French, Hungarian (2014)
- Ponseti for Parents© 'Ponseti for Parents parent adviser manual' translated into Afrikaans, isiZulu, isiXhosa, Setswana, French (2014)
- Author of "My Clever Night-Night Shoes", a bedtime story for children wearing the clubfoot brace at night. Sold 4,000 copies globally. Translated into Italian, German, Swedish, Afrikaans and Xhosa (2014).
- 'Congenital Clubfoot' information leaflet for paediatric healthworkers (2018)
- Steps Ponseti for Parents© Clubfoot parent education video for in-clinic and online (2019)
- Steps Ponseti for Parents© education video 'Brace fitting for caregivers' (2019)
- Steps Ponseti for Parents© education video 'Brace fitting for professionals' (2019)
- Steps Coordinator Training Manual (2020)
- Steps Clinic Coordination Webinar Series (2021)

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Lectures and poster presentations:

- 2006 South African Ponseti Seminar Donald Gordon Medical Centre, Johannesburg. Lecture: 'A Parent's Perspective of Clubfoot Management'
- 2007 South African Ponseti Seminar, Charlotte Maxeke Johannesburg Academic Hospital. Lecture: 'A Parent's Perspective of Clubfoot Management'
- 2012 2nd International Clubfoot Symposium, University of Iowa. Lecture 'South Africa: Model of change for clubfoot treatment'
- 2012 SAPOS Clubfoot Instructional Course, Cape Town. Lecture 'Introduction to Steps: Our role in South African clubfoot care'
- 2014 3rd International Clubfoot Symposium, Barcelona Spain. 2014 lecture: 'The Steps Experience: From Ponseti parent to Ponseti programmes'
- 2014 3rd International Clubfoot Symposium, Barcelona Spain. Poster presentation: 'Ponseti for Parents - A positive message for a positive outcome'
- 2014 3rd International Clubfoot Symposium, Barcelona Spain. Poster presentation: 'STEPS to sustainability - 10 years of Ponseti in southern Africa'
- 2016 4th Giornata Internazionale del Piede Torto Congenito, Italian international clubfoot day meeting, Florence, Italy. Lecture: 'A step forward - Promoting Ponseti as a parent in southern Africa'
- 2016 Africa Clubfoot Training, Addis Ababa, Ethiopia. Observer for pilot training, talk on 'Ponseti treatment - The role of the parent'
- 2017 Global Clubfoot Conference, Delhi India, Lecture: 'Ponseti for Parents – role of the parents for a successful outcome'
- 2018 CEDA pilot training Lusaka Zambia. Various presentations and assessments of trainees
- 2020 GICS IV Global Initiative for Children's Surgery Conference, Johannesburg South Africa. 'RunFree2030: A global initiative to end clubfoot disability', co-presenter with Dr Norgrove Penny, Dr Alaric Aroojis, Rosalind Owen and Scott Reichenbach.
- 2020 LER Expo Webinar Guiding Parents Through Clubfoot Treatment (NYC). Keynote speaker and panellist: 'Parent's Perspective - The Role of Parents in the Clubfoot Journey'.

Clubfoot Workshops organised

- 2006 1st South African Ponseti seminar: Achieving consensus (Johannesburg)
- 2007 South African Ponseti seminar: Focus on state health sector rollout (Johannesburg)
- 2007 South African Steenbeek Brace training workshop (Johannesburg)
- 2013 1st Botswana Ponseti training workshop (Gaborone)
- 2013 1st Namibia Ponseti training workshop (Windhoek)
- 2014 Botswana Ponseti training workshop (Mahalapye)

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- 2014 1st Seychelles Ponseti training workshop (Mahe)
- 2014 South Africa Ponseti Training workshop (Mahikeng)
- 2015 Botswana Ponseti training workshop (Maun)
- 2015 Namibia Ponseti Training workshop (Keetmanshoop)
- 2015 Namibia Ponseti Training workshop (Oshakati)
- 2015 Namibia Ponseti Training workshop (Windhoek)
- 2016 Botswana Ponseti refresher training (Maun)
- 2016 South Africa Ponseti Training workshop (Pietermaritzburg)
- 2016 South Africa Ponseti Training workshop (Worcester)
- 2017 South Africa Ponseti training course (Nelspruit)
- 2017 South African Clubfoot information workshop for healthcare workers, Western Cape Department of Health (Cape Town)
- 2018 South Africa Ponseti Training workshop (Durban)
- 2018 South African Ponseti Clubfoot information workshop for Limpopo province (Polokwane)
- 2018 South Africa Ponseti training course (Cape Town - Northern Cape trainees)
- 2019 1st Steps clinic co-ordinator training workshop (Johannesburg)
- 2021 South Africa Ponseti Training course (Port Elizabeth)

Conference workshops and meetings

- 2007 Participated in Parents for Ponseti workgroup meeting and the Ponseti Races at the 1st International Clubfoot Symposium, University of Iowa. The Iowa Clubfoot Declaration resulted from this symposium.
- 2011 Participated in the Cape Town Clubfoot retreat (Kampala, Uganda). 2-day meeting with Dr Shafique Pirani, Dr Marc Sinclair, Dr Stephanie Boehm and Dr Jacques duToit focused on establishing a national network of Ponseti of providers.
- 2015 Organised and attended 'Introduction to Ponseti for clubfoot' educational talk for the South African Society of Physiotherapists Paediatric special interest group during World Bone & Joint Awareness week with Dr Stewart Dix-Peek, Dr Stewart Mears and Zara Marthinus.
- 2016 Organised and attended Ponseti providers meeting at COMOC International Combined Congress Meeting of the Combined Orthopaedic Associations (Cape Town, South Africa), featuring Dr Matthew Dobbs.
- 2017 ISPO conference, CTICC Cape Town, South Africa. Presented symposium 'The role of the orthotist in Ponseti' with Dr Kobus Smit, Michiel Steenbeek, and Peter Moopa.
- 2019 Africa Health expo sponsored stand. Exhibited clubfoot braces and met healthcare professionals from various African countries and government.

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Support to community

- Ponseti for Parents© educational materials shared with Zambia, Tanzania, Francophone Africa, Madagascar, Hungary
- Tanzanian feasibility and fact-finding trip to Dar es Salaam, Mwanza and Usa River for the proposed set up of a clubfoot clinic programme (2013)
- Facilitated and chaired first Tanzania national network meeting in Dar es Salaam, clinic visits to Mwanza and Ukerewe (2014)
- Africa Clubfoot Training project, attended pilot workshop in Ethiopia as observer and contributed parent educational materials for use in the curriculum workbook (2016)
- Member of advisory committee, CEDA (Clubfoot Early Detection and Adherence) training for clubfoot clinic advisers, attending online meetings and review content (2018-current)
- Faculty and facilitator of CEDA 2018 clinic adviser training pilot in Zambia (2018). 2-day training session and 1-day evaluation and strategy
- Member of Global Clubfoot Initiative #runfree 2030 campaign strategy workgroup (2019-current). Prepared rating tool draft for 'Ponseti in curriculum'
- Member of Global Clubfoot Initiative training workgroup

Media coverage (selected)

- 2006 Femina Magazine feature, 'Best foot forward'.
- 2007 Daily Iowan, interviewed for feature on 2007 International Clubfoot Symposium
- 2010 True Love Magazine feature, 'Standing on your own two feet'
- 2011 Mercury News syndicated feature, 'Standing on their own two feet'
- 2012 Sunday Times column feature, 'Mom with a mission'
- 2014 Carte Blanche DSTV, actuality programme feature
- 2014 Nation Seychelles, 'Hope for children born with clubfeet'
- 2014 The Ngami Times Botswana, 'Clubfoot deformity treatment comes to Maun'
- 2015 Fair Lady Magazine, 'People we admire – Karen Moss'
- 2015 E News Channel 'Against all Odds'
- 2015 Hands On, Physiotherapy magazine, 'Correcting Clubfoot'
- 2016 VOA TV in-depth feature, broadcast in the USA
- 2016 Fair Lady magazine, 'Mothers changing the world'

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- 2016 Your Baby magazine, 'Understanding birth defects'
- 2016 Natal Witness, 'Ponseti training workshop at Grey's to tackle clubfoot'
- 2017 South African Airways 'Seat Stories' advertising campaign on TV, YouTube and in-flight movies.
- 2017 Lowvelder Newspaper, 'Steps can be taken to treat a child with clubfoot'
- 2017 SABC TV News interview to announce new clubfoot ambassador
- 2017 Weekend Argus in-depth profile, 'Chance to walk on their own two feet'
- 2018 SAB Foundation Social Innovation awards featured video online and during ceremony
- 2018 ExpertHub online newspaper, 'Cape Town innovators clean up at the SAB Foundation's disability awards'
- 2018 ' Woman & Home magazine in-depth profile, 'I followed my intuition to help my child'
- 2018 Rooi Rose magazine, 'Mooi maak vir babas'
- 2019 Espresso Morning Show TV special insert for World Clubfoot Day
- 2019 Pretoria News, 'George Mukhari Hospital clinic gives children with clubfeet hope for a normal life'
- 2019 Good Hope FM, 'Disability 360: Clubfoot care'
- 2019 Cape Talk, Health and Wellness : World Clubfoot Day in-depth radio interview
- 2020 Your Family Magazine, 'First Steps to a Better Life'
- 2020 Cape Talk, Health and Wellness: World Clubfoot Day radio interview
- 2021 Espresso Show, World Clubfoot Day

Affiliations and memberships

- South African Paediatric Orthopaedic Society
- Global Clubfoot Initiative
- Ponseti International Association
- GCI #Runfree 2030 workgroup
- Steps Charity Worldwide
- Wits Medical School CPD Office

Testimonials and references:

It has taken the involvement of the families to convince many doctors that surgery is unnecessary and indeed harmful. I think your efforts to make the parents aware of the fact that the deformity should be treated without surgery is very important. It is wonderful work you are doing to get the doctors to give up surgery and learn how to properly manipulate and cast the clubfoot - Ignacio V. Ponseti MD (2006)

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Karen Moss is a talented writer, speaker and teacher. She has an engaging manner, putting people at ease with a well-chosen word or a smile. Karen is possibly the most talented author of what could be called South African popular women's fiction to have come through my course, Writers Write. I look forward to the publication of her first novel. I would endorse Karen in any path she chooses. She has so much to offer - *Amanda Patterson, CEO The Write Company (2009)*

I worked with Karen at STEPS Charity. She is a great leader who inspires people to work together as a team and in getting people to identify their strengths for the greater good. She has a positive way with people and is a great networker - *Jennifer Harding, Healthcare consultant (2010)*

Karen's work at putting together the STEPS charity and highlighting the plight of those needing treatment for clubfoot has been remarkable. Her stories and messages have helped keep me going at times when things have been tough and she has provided information which was crucial at numerous times - *Eve Morris, Clubfoot parent (2011)*

Reference 1: Dr Shafique Pirani. *Paediatric Orthopaedic surgeon, University of British Columbia, Canada. Founder Uganda sustainable clubfoot programme (2004-2010)*. Mentor for clubfoot training and education.

Email: sppirani@gmail.com

Reference 2: Professor Arnold Christianson. *Geneticist, Cape Town South Africa. Retired, sat on World Health Organization's expert advisory panel on Human Genetics, developed international policy related to medical genetics and medical genetic services*. Consulted on birth defect education and patient care in limited resource settings.

Email: arnoldc@webmail.co.za

Reference 3: Professor Robert Golele. *Paediatric Orthopaedic surgeon, Head of department Orthopaedics Sefako Makgatho Health Sciences University*.

Collaborated on training, clubfoot braces and clinic support, Limpopo Province and North West outreach and training.

Email: c/o leonie.strauss@smu.ac.za

Reference 4: Dr Makgabo John Tladi. *Orthopaedic surgeon, Louis Pasteur Hospital, Pretoria South Africa*. Collaborated on strengthening clubfoot clinics in limited resource settings.

Email: mjtladi.ortho@gmail.com

Reference 5: Ms Rosalind Owen. *Executive Director, Global Clubfoot Initiative, London UK. Member of the African Clubfoot Training curriculum workgroup*.

Email: rosalind.owen@globalclubfoot.org Colleague on #runfree2030 workgroup, and Africa Clubfoot Training workshops.