

TIN
SOLDIERS

GLOBAL
FOP PATIENT SEARCH



Annual Report **2022**



Connecting with Tin Soldiers changed our family's life. Not only has our son, Rian, been diagnosed with FOP at a very early age, but medical advice and support has been available around the clock with any flare-ups or just for moral support.

Riaan Snr. never had this as he was put through numerous tests, poked and prodded before the diagnosis was made. He was given no medical advice after his diagnosis until we connected with Tin Soldiers.

For Riaan Snr., Tin Soldiers has been a blessing that has changed his way of living. From not being able to open his mouth and being in constant pain trying to eat, to being able to eat pain-free. That is thanks to Tin Soldiers connecting us with the most amazing doctors, not just from Cape Town but from all over to assist with his dental extraction operation. This would never have been possible if we weren't able to connect with this amazing organization."

ANDI - FOP Mother and life-partner to FOP Warrior, Riaan Erasmus

Tin Soldiers made a great and lifetime change in my life, I now can take pictures and wear whatever I want like anyone else. It brought my self confidence back in my hands. Getting a diagnosis and the right doctors made me happy because I knew what was happening. Also knowing that I was cancer free made me even happier."

VUYELWA - Diagnosed with Multiple Osteochondromas





It has been a fantastic year for our Tin Soldiers, and we cannot thank you enough for your unending commitment.

We are thrilled to announce that Dr Patricia Delai and Matodzi Tshidzumba have joined our Board of Directors, while Dr Mona Al Mukaddam and Dr Abdelali Madji have become members of the Advisory Committee.

With their help, we continue the mission of locating individuals with FOP, providing them with a diagnosis, and giving them access to pathways of care.



Co-founding Tin Soldiers with Odette has been the culmination of many years of work with FOP and brought me to a pivotal point of understanding that without a diagnosis, there is little that will follow. Diagnosis is the single most important step to a treatment. Tin Soldiers is on a mission to find 8,000 people with FOP, they are missing, they are not connected, they are ones alone”

AMANDA CALI – Tin Soldiers co-founder & Advisory Committee Member



We really got a very best help from Tin Soldier on getting Unathi to be diagnosed on her long condition of illness. Since then she's been getting her medical treatment and attention from the wonderful doctors at Chris Hani Hospital with support of the Arthritis Kids SA.

In addition, I wanna send my gratitude to all of the Tin Soldiers team and to thank you so much for helping us with our daughter. Keep up the good work and effort of helping other people who need help like us."

DUMISANI - Father of child diagnosed with JIA

Our son Nathan was born on May 3rd, 2016. When he was just one year old, we started noticing something bony in his neck. We went from doctor to doctor for a year, but no one could give us a diagnosis. We were desperate for answers, and that's when local news published a story about Nathan's condition on Easter Sunday.

Shortly after, a FOP patient named Ciske contacted me and asked if she could pass along our contact information to Odette, who she thought might be able to help. Desperate for answers, we agreed, and Odette and her team at Tin Soldiers quickly sprang into action.

Within four days, Odette had arranged for us to speak with Professor Chris Scott and Professor Kaplan in the USA. Thanks to Odette and her team, we finally received a diagnosis for Nathan's disease, Progressive Osseous Heteroplasia (POH), which is related to FOP and is an ultra-rare disease with only about 30 diagnosed cases in the world.

Though there is currently no treatment for POH, we are staying positive. We're so grateful to Odette and the Tin Soldiers team for their life-changing help"

DISEREE - Mother of child diagnosed with POH



Overview

Our objectives and strategy remain simple and focused - educating healthcare professionals, creating awareness through multi-pronged strategies such as video content, online content and PR, and collaborating with existing networks to extend our reach.

In 2022, we were proud to have participated in several conferences, including the ICCBH conference in Dublin, Ireland, the ASBMR conference, and the 20th National Conference of Paediatric Rheumatology Society. Our team presented posters and gave presentations, and we were able to educate over 1400 clinicians.

We launched our refreshed website and consolidated our directory, resulting in a 96% delivery rate, 46% open rate, and 2% click-through rate.

We also conducted a literature review, which resulted in the identification of 161 cases of FOP. We plan to reach out to FOP patient organizations for verification and cross-referencing, and prepare a paper for publication.

We are honored to be part of the Rare Bone Disease Alliance (RBDA), Global Genes (GG), and Women in Philanthropy South Africa (WiPsa). Additionally, we partnered with the International Clinical Council on FOP (ICC) to create a diagnostic handbook.

In South Africa, our outreach efforts took us to Vhembe district in Limpopo province, where we visited 8 clinics and trained 44 healthcare workers. To ensure our footprint remained after we left the province, we set up WhatsApp groups for clinic staff to assist with diagnosis, and referral support. The initiative was filmed to help raise awareness on social media and to be used as medical content for education.

Most recently, the team took flight to India where we filmed "The Whisper," – a documentary which highlights the journeys of two young women with FOP and an Indian artist giving voice to their stories through her work. We also presented to roughly 250 clinicians at the 20th National Conference of Paediatric Rheumatology Society. We distributed 75 diagnostic handbooks in both English and Hindi and added 44 names to our HCP directory. Our work in India resulted in the identification and diagnosis of 5 people with FOP—mostly children—with 9 more likely cases waiting for verification. Additionally, we supported FOP India in hosting a Family Gathering where we showcased our program alongside the International Fibrodysplasia Ossificans Progressiva Association (IFOPA).

Our next steps in India are to collaborate with Dr. Vrisha Madhuri on creating an instructional video regarding FOP and distribute it through Dr. Sujata Sawheney's extensive network of more than 600 medical professionals. We also plan to publish educational materials, present at international conferences sometime over the next two years, and work with local clinicians to create an "Indian Clinicians Alliance" for early diagnosis of people with FOP, connecting them with the proper care. All of this is part of our commitment to sustainability.

In collaboration with Clinician Alliances in India and Africa, we are creating a "Town Hall" style concept for quarterly virtual meetings for clinicians to discuss FOP news, difficulties, and treatments. These webinars will also provide professionals with the option to present their cases (FOP & Musculoskeletal) in a 'grand rounds' form. We plan to send invitations to external HCP teams through the Global Paediatric MSK Task Force, PReS, PAFLAR, ICC, and other associations to be involved with the 'grand rounds'.

After launching our work in 2020, we've made incredible strides over the last three years. Our medical education initiatives have impacted 3000 healthcare professionals, leading to 34 people with FOP being identified and connected to necessary resources. We have also achieved groundbreaking success with a neo-natal screening program implemented in Brazil. Additionally, our operations have expanded to include Brazil and India and have seen notable progress in other countries including Argentina, Russia, and the Nordics. We are delighted to collaborate with venerable organizations such as the Global Paediatric Musculoskeletal Task Force, the International Clinicians Council on FOP, the IFOPA, FOP Brazil, FOP India, Mercy Air, and the Unjani Nurses Network.

Finances

Tin Soldiers has secured support from a major investor until (and including) 2024, which covers staff retainers, operational costs, and other expenses. As most of our projects are conducted internally, we don't need to spend money on external service providers or consultants. Consequently, donations can go towards specific projects that help advance the Tin Soldiers mission.

Most of the donated funds come from private individuals. We also receive corporate sponsorships and in-kind contributions, which allows us to produce audio-visual content beyond what we could do within our budget.

The charity's financial records for the year show a net surplus of R750,148 (compared to a deficit of R36,130 in 2021). Income rose from R4,193,648 in 2021 to R6,013,226 due mainly to increased investments and generous private donations. Expenditures amounted to R5,274,707 (as opposed to R4,229,778 the previous year).



One of the most profound realisations in my early career in paediatrics was the power of a diagnosis—it's the key that unlocks management, of course, but it also is so powerful in terms of empowering the carers and patients to put to rest uncertainty and the huge anxiety accompanying an unknown medical condition"

DR CHRIS SCOTT – Tin Soldiers Medical Director & Board Member



A Word from **Odette** ...

When we launched operations in early 2020, we knew it was bold work. Many it was a fool's errand - trying to find needles in haystacks. As the pandemic hit, the doubtful voices grew louder. Who would care about something so rare when the world was in chaos?

However, we were fortunate to have those who believed in us and continue to do so. Our donors, board of directors, advisory committee, volunteers, and staff have all been a part of our success. Thanks to them, we are making progress in finding individuals with FOP and other musculoskeletal conditions and connecting them with the appropriate care and support.

I am honored and grateful to have so many people standing behind Tin Soldiers' courageous mission, and I eagerly anticipate our journey to find the missing together.

As Margaret Mead said,

"A small group of thoughtful people could change the world. Indeed, it's the only thing that ever has."



With this inspiration, we carry onwards and upwards!

Only Good Things and Green Lights,



ODETTE SCHWEGLER

TIN SOLDIERS – CO-FOUNDER AND EXECUTIVE DIRECTOR
FOP AFRICA – PRESIDENT

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Tin Soldiers play a vital role in rural communities where there is no infrastructure, they are able to go there and identify potential FOP patients. Tin Soldiers exist to make a difference in people's lives and that is very special about this group."

MATODZI TSHIDZUMBA – Tin Soldiers Board Member

Snapshot of 2022 ...

CONFERENCES ...

- ICCBH conference Dublin, Ireland
 - Dr Scott presented poster and Odette attended
- ASBMR conference
 - Mona presented, and Julie attended
- DDF abstract presented
 - ‘Building a new generation of FOP healthcare professionals: The Tin Soldiers patient-finding mission’
- 20th National Conference of Paediatric Rheumatology Society
 - Dr Madhuri & Dr Scott presented, Tin Soldiers Team exhibited

Dr Scott spoke at the following events:

- Department of Paediatrics, St Joan de Déu, EULAR (European League of Associations for Rheumatology) in Copenhagen
- Paediatric African League of Associations for Rheumatology (virtual)
- South African Rheumatism and Arthritis Association meeting in Durban
- Spoke Virtually at FOP Action in Manchester
- Grand Rounds for the University of Saskatchewan in Canada (virtually)

Dr Delai spoke at the following events:

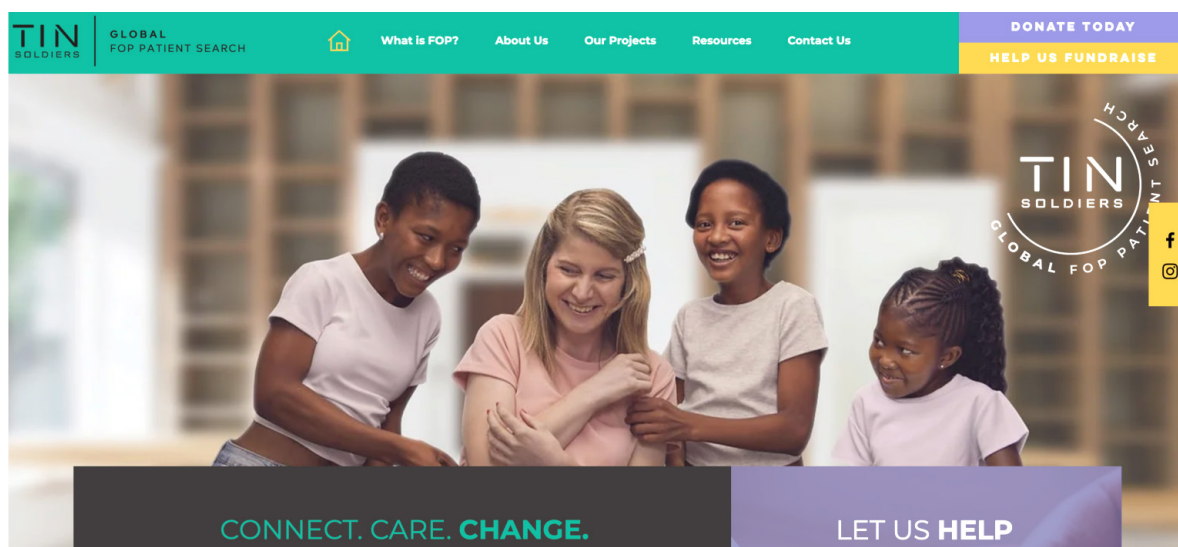
- Launch of FOP day and the big toe identification recommendation
- Medscape presentation online
- Presentation for the Rare Diseases Post Graduation in João Pessoa
- Presentation in Chile Congress of Muscle Skeletal diseases for Ipsen

Total of +- 1400 clinicians educated



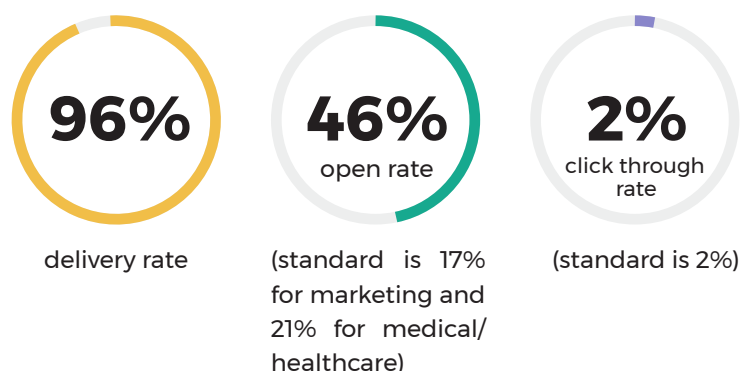
Tin soldiers is unique in how it has developed educational tools to help reach rural and isolated communities including place like Nunavut in Northern Canada. Its educational material comprising film, diagnostic handbook and webinars that can be utilized across many forums with appropriate ability for identifying and providing follow up care is unlike any other organization I have worked with"

Dr CLIVE FREIDMAN – Advisory Committee Member



ONLINE PRESENCE ...

- Launched www.tinsoldiers.org in July
- Consolidated our directory and sent an opt-out email – no opt-outs received. A few direct replies about people wanting news from us
- The stats:



ONLINE PRESENCE ...

- Total of 109 papers reviewed and 161 cases of FOP identified
- Next steps: Reach out to FOP patient organisations for verification and cross-referencing and prepare a paper

COLLABORATIONS ...

- Rare Bone Disease Alliance (RBDA) membership
- Global Genes (GG) membership
- Women in Philanthropy South Africa (WiPsa) membership
- ICC – Development of Diagnostic Handbook



OUTREACH ...

The team travelled to Vhembe district in Limpopo province, South Africa from 7-10 March, together with Mercy Air and Flying for Life and visited 8 clinics

- FOP specific educational resources in the form of diagnostic handbooks, posters, flyers and T-shirts. (Translated into Venda)
- Sixteen paediatric patients were seen, and 6 children were referred to specialists.
- While Dr Scott is a paediatrician, he also assisted with the consultation of several adult patients several of whom require knee surgery.
- 44 healthcare workers trained and added to the Tin Soldiers HCP database.
- WhatsApp groups set up for the purposes of education, assistance with diagnosis and referral support.
- Local spokesperson to support the Tin Soldiers program by translating information on the WhatsApp groups.
- The outreach was filmed, and content has been used for awareness and education across social media platforms and to raise the TS profile in communications with collaborators; sponsors and partner organizations.

Tin Soldiers is compelled to reach and to connect individuals contending with FOP, so that they can share the dignity of standing together and the hope that builds toward the promise of a treatment that will confound the ill effects of this disease. Tin Soldiers is committed to accelerating the momentum of this precious hope for these individuals, their families, their caregivers, and their communities"

ERIC GRINSTEAD - Advisory Committee Member



Tin Soldiers operates on the frontier of a rare disease and frontiers are where worlds change and horizons become reality. It is exhilarating to be there.”

DR FRED KAPLAN – Advisory Committee Member



Tin Soldiers has been a lifeline, not only in worldwide education and access to FOP, but also in the stories of the extraordinary people who live with it and who have triumphed over the limitations that have been imposed upon them. Likewise, it shares the dedication and extreme efforts of some of our best and brightest in medicine, who have devoted their lives to resolving and eventually curing one of nature’s most challenging situations”

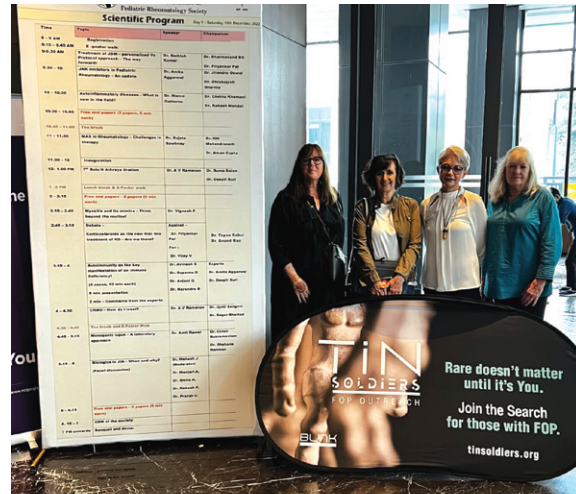
DIANE NASSAU WEISS – Advisory Committee Member

India Trip ...

(Delhi, Faridabad, Bangalore, Vellore)

OBJECTIVES:

- Content creation: 13-day shoot
 - Documentary (approx. 40mins): “The Whisper” – highlighting the journeys of two young woman with FOP and an Indian artist giving voice to their stories through her work
 - Medical content and the family gathering (including 4 clinics)
 - All content can be repurposed & used across multiple platforms
- Medical conference – presented to around 250 paediatric rheumatologists
 - Added 44 new names to the TS Directory; some already have patients
 - 5 patients identified and verifying another 9
 - 75 diagnostic handbooks distributed (in English and Hindi)
- FOP India Family Gathering
 - TS presented alongside FOP India and IFOPA



The Tin Soldiers project has pioneered the way to put a rare condition under the spotlight via creative, productive and inspiring initiatives that indeed increased FOP awareness and improved FOP diagnosis in many countries around the world...It has given -and should continue to give- many incredible individuals a chance to belong to a strong and loving international FOP community and to be provided with precious expert advice and better care”

STÉPHANIE HOFFMANN – Advisory Committee Member

NEXT STEPS:

- Edit "Intro to FOP" with Dr Madhuri - distribute through Dr Sujata's network of +- 600 doctors & explore opportunities at conferences in 2023/24
- Formalise the Indian Clinicians Collective:
 - Work with local clinicians to set up an organizational structure with defined mission
 - Develop a "Town Hall" Concept - Quarterly meetings where clinicians meet to talk about FOP news, challenges, management etc. Also a place where they present cases (FOP & Rare Bone) in a 'grand rounds' format.
 - Opportunity to extend invitations to "Town Hall" webinars to international HCP community through the MSK Task Force, PReS, PAFLAR, ICC etc.
 - Concept to be developed possibly in collaboration with the ICC



TIN SOLDIERS Key Outcomes 2020 - 2022 ...

Approximately **3000 Healthcare professionals trained**. A database of 750 consenting HCPs from across 6 continents

54 patients with a rare condition diagnosed
34 with FOP and **20 with other MSK conditions** found in **10 countries** across **4 continents**

Tin Soldiers content used in **8 countries**

Made inroads into **Argentina, Russia and the Nordics**

Introduction of **neo-natal screening** protocol in **Brazil**

Scaled program into **Brazil and India**

Development of a **diagnostic handbook** in collaboration with the ICC

Literature review has produced a total of **109 papers reviewed** and **161 cases of FOP identified**



Robust global partnerships



SpringerHealthcare



MERCY AIR



BLINK



Objectives 2023 ...

- To consolidate in countries where we have already established a presence
- To repurpose existing content and distribute globally
- Continue to pilot new initiatives in the SA market
- Continue to educate HCPs mainly through conferences, events and CME opportunities
- Launch India documentary "the whisper" into the market and create awareness around it
- Literature review paper published

SOUTH AFRICA (Incubator)	SOUTH AMERICA (Argentina, Brazil, Chile)	ASIA (India)	NORDICS (Sweden)	EUROPE & RUSSIA	UNITED STATES
HCPs: <ul style="list-style-type: none"> • Post Grad curriculum for doctors at Wits • Conferences to educate • Formalise African Clinicians Collective 	HCPs: <ul style="list-style-type: none"> Conferences to educate Work with Ipsen on the public awareness and education campaign 	HCPs: <ul style="list-style-type: none"> Connect with Indian docs Circulate educational material through connections made Edit Vrisha's intro to FOP Package & distribute Vrisha/Chris talk Conferences to present Establish clinician's collective/ Grand Rounds idea 	HCPs: <ul style="list-style-type: none"> Identify key clinicians – and conferences to present at 	HCPs: <ul style="list-style-type: none"> Identify key clinicians – and conferences to present at 	HCPs: <ul style="list-style-type: none"> Partner with Spring Health on CME Identify key conferences to present and exhibit
AUXILIARY HCPs: <ul style="list-style-type: none"> Baby screening at vacc stage through Unjani Clinics 	AUXILIARY HCPs: <ul style="list-style-type: none"> Repurpose CME for use in other SA countries 		AUXILIARY HCPs: <ul style="list-style-type: none"> Continue to educate nurses 		
PATIENTS & FAMILIES: <ul style="list-style-type: none"> African family meeting: FOP Clinic, physician education and industry meeting 	GOVERNING BODIES: <ul style="list-style-type: none"> Push for policy change in other SA countries eg. Argentina, Chile 	PATIENTS & FAMILIES: <ul style="list-style-type: none"> Mini documentary to be submitted to film festivals and circulated on television 	PATIENTS & FAMILIES: <ul style="list-style-type: none"> Present at FOP Family Meetings 	PATIENTS & FAMILIES: <ul style="list-style-type: none"> Present at FOP Family Meetings 	PATIENTS & FAMILIES: <ul style="list-style-type: none"> Present at FOP Family Meeting

PARTNERSHIPS

BUILD CLOSER RELATIONSHIPS WITH OTHER ORGANISATIONS EG. GLOBAL MSK TASK FORCE, RBDA ETC.

DISTRIBUTION OF CONTENT

Diagnostic handbook: printed, video & published	Repurpose key content eg lifecycle of the program, PGALS video, miniseries with RBDA	Literature review & publish	Social media content incl Linked In	PR	Other printed materials eg: posters, tshirts etc.
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I will admit, when Amanda Cali first informed me of her project to find the undiagnosed, I was sceptical. Then I watched videos of the remarkable work they were doing in South Africa with Dr Chris Scott and Odette Schwegler and her team and I just wanted to be part of this inspiring, creative and forward thinking group. And now, Tin Soldiers has morphed and transformed into a beautiful, artistic power machine. They have developed database, CME learning modules, documentaries, networks and so much more in a very short period of time and I am honoured to be part of this journey"

DR MONA AL MUKADDAM
- Advisory Committee Member



"Tin Soldiers is a caring bridge between the undiagnosed living with FOP and the loving community that has its arms open to them"

SHARON NEUMANN - Advisory Committee Member

Tin Soldiers play a vital role in rural communities where there is no infrastructure, they are able to go there and identify potential FOP patients. Tin Soldiers exist to make a difference in people's lives and that is very special about this group."

DR PATRICIA L. R. DELAI
- Advisory Committee Member

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Tin Soldiers is a registered section 18A non-profit organisation in South Africa. NPO number 240-903.

