



FACT SHEET

WHAT IS FOP?

Fibrodysplasia Ossificans Progressiva (FOP) is a **rare** genetic disorder where muscles, tendons, ligaments, and other connective tissues turn to bone. **This** extra (heterotopic) bone that forms is **like** normal bone.

A second skeleton is formed which can result in locked joints, making movement difficult or impossible.

WHO IS TIN SOLDIERS?

Tin Soldiers is a not-for-profit patient finding organisation.

With an estimated incidence rate of 1 in every 1 million, there should be close to 8,000 people living with FOP around the world. We currently know of around 800-900 people. With a baby being born with FOP every 44 hours, it makes our mission to find the missing people, critical.



MISSION

To find every person with FOP who is either undiagnosed or not connected and get them diagnosed and on a pathway of care and support.



THE TIN SOLDIERS VALUES

CARE:

To first educate families and healthcare professionals on 'do no harm' and **then connect them to networks for both medical and community support.**

ENDING ISOLATION:

To find people who are living in isolation, without a proper medical diagnosis, who are alone, scared and not knowing what to do.

LEAVE NO-ONE BEHIND:

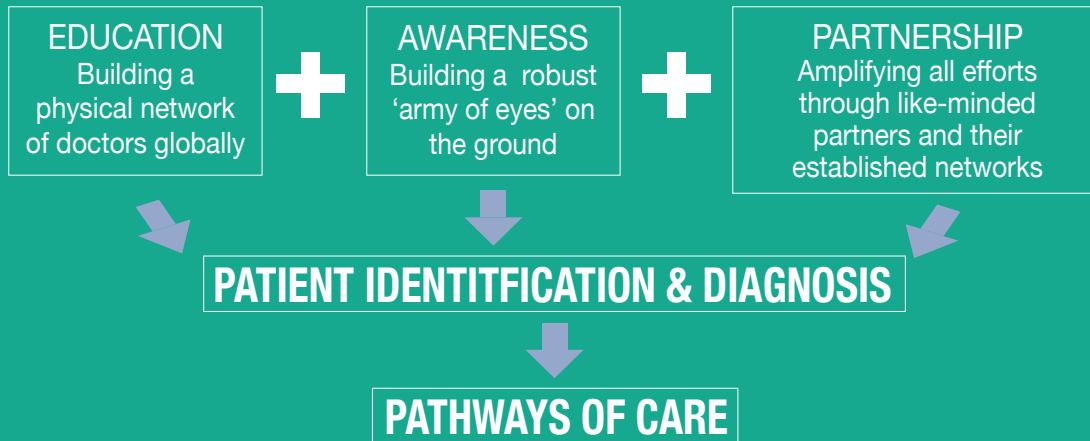
While finding people with FOP we also find others. We make sure we leave no-one with **other rare** musculoskeletal conditions behind.





FACT SHEET

THE TIN SOLDIERS PROCESS



SUSTAINABILITY

We are building a sustainable program, which includes the following:

- A growing global clinicians' network and directory
- Customised messaging that is regionally sensitive and lead by a local partner who remains as the country lead
- Partnering with local health organisations and governments to ensure a continuous program rollout
- Leaving a diagnostic educational footprint behind that continues to educate HCPs about FOP
- Multi language materials that ensure readability and exposure

CONTENT DEVELOPMENT

The cornerstone of the Tin Soldiers strategy is based on the development of quality, engaging multi-media content that tells a story and gives people with FOP a voice. The content shares with the viewer human stories that are not easily forgotten.

Our extensive content library is always expanding. Some of the most used content is as follows:

- Continuing Medical Education 7-part master series on FOP
- Step by step diagnostic handbooks for health care workers
- Public service announcements
- Short story patient videos
- Diagnostic videos
- Diagnostic posters, leaflets and t-shirts
- Documentaries

CONTACT INFO

Email: info@tinsoldiers.org
Website: www.tinsoldiers.org
Facebook: [TinSoldiersFOP](https://www.facebook.com/TinSoldiersFOP)
Instagram: [tinsoldiersfop](https://www.instagram.com/tinsoldiersfop)

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

Donations are also accepted via IFOPA (501C3 organization) at: <http://ifopa.org/tinsoldiersfop>

For more information on FOP go to: ifopa.org

MALFORMED BIG TOES + LUMPS + STIFFNESS = FOP

KEY OUTCOMES

2020 - 2023

Approximately **3200 Healthcare professionals** trained. A database of over **1100 consenting HCPs** from across **6 continents** and **74 countries**



60 patients with a musculoskeletal condition diagnosed and referred - **38 with FOP** and **1 with POH**

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

Tin Soldiers content used in **8 countries**

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



 clinicians in our network
 patients found

Scaled program into Brazil and India

Establishment of the **Clinician Champions Alliance**, which consists of clinicians from 16 countries, who are committed to promoting the diagnosis and connecting children with FOP and other musculoskeletal conditions to appropriate care pathways.

Made inroads into Argentina, The Nordics, Switzerland, Russia, Kenya and Morocco

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

Robust global partnerships

