

Building a new generation of FOP healthcare professionals: The Tin Soldiers patient-finding program

Rare Drug Development Symposium 1-3 May 2023

INTRODUCTION

Diagnosis and pathways to care for FOP are dependent on geography, access to informed professionals and effective information. Global socio-economic inequity leads to missed opportunities for appropriate care and maldistribution of already scarce and inadequate healthcare worker resources for FOP. Established in 2019, the Tin Soldiers Global FOP Patient Search Program aims to identify patients from all parts of the world living with FOP and connect them to pathways of diagnosis/ care as well as to patient support organizations.

AIM

To describe the methods and results of the Tin Soldiers patient-finding strategy as well as efforts to educate and support a new generation of FOP experts able to provide a pathway for diagnosis and care.



METHODS

Multimedia awareness and educational campaigns to target healthcare professionals from all parts of the world. Reach is magnified by collaborating with key partners such as the Global Task Force for Paediatric Musculoskeletal Health, nursing networks, educational bodies, the International Clinical Council for FOP, patient organizations such as the International FOP Association and NGO's working in the health care space. Education of healthcare workers is provided at all levels to facilitate early diagnosis (e.g community nursing level) and to establish a robust and expert pathway of care (e.g specialist physician masterclass on FOP). Educational materials such as the FOP CME Master Series are used, in whole or in part, across the globe by universities, nursing educational facilities, medical conferences, healthcare facilities and national FOP support organizations.

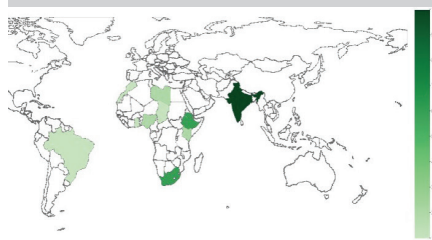


Fig 1 Year map of patients identified by Tin Soldiers Patient Search

RESULTS

Since official operations commenced in March 2020 Tin Soldiers has trained 535 medical professionals, has grown the FOP physician network and increased the number of African patients with a diagnosis of FOP from 25 patients in December 2020 to 31 in March 2022. In total 34 patients have been identified in 12 countries. (fig 1)

Along the journey, patients with other rare bone conditions have been discovered and diagnosed and connected to care and support.

clinicians in our network patients found



DISCUSSION

The Tin Soldiers Global FOP Patient Search Program has increased the number of patients connected to care and bolstered the development of a new generation of clinicians in FOP. These outcomes have important implications for care of patients world-wide but also have key relevance to the conduct of global clinical trials, disease data collection and access to approved therapies in the future.

DOES THE PERSON CURRENTLY HAVE OR HAD THE PERSON HAD ANY OTHER LUMPS ON THEIR BODY?

- None
- FOP lumps (fibrous and/or bony) can be found, even on the hands, and even on the back
- FOP lumps can appear and change quickly, often in a matter of days
- FOP lumps can be mistaken for warts, but lumps do not change and never appear in warty areas
- FOP lumps appear suddenly, they can also disappear quickly if they are not prepared for being present
- FOP lumps in the body, neck, back, chest and arms are especially visible
- FOP lumps in the hand/wrist area can be harder to see
- FOP lumps may appear after other type of FOP or orthopaedic injury

PHOTOS OF PATIENTS HAVE BEEN POSTED ON THE BLOG. PATIENTS HAVE TO TAKE AN OATH THAT THEIR INFORMATION IS NOT BEING USED OUTSIDE OF THE PROGRAM FOR ANY OTHER PURPOSE.

APPROVED ORTHOPAEDIC INJECTION CAREERS EXPLANATION:
Approved Orthopaedic Injection Careers are currently being sought for the path of program from the back, arms, and hands. The number of interested professionals is high. If you are interested in the program in the above, legs, arms, and hands, please contact us.

PLEASE ACTUALLY TO CONSIDER A DANGEROUS
DOES IT DO YOU HARM?

Scan the QR code for more info on Tin Soldiers



TOES + LUMPS + STIFFNESS = FOP