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

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INTRODUCTION

Diagnosis and pathways to care for FOP are dependent on geography, access to informed professionals and effective information. Global socioeconomic inequity leads to missed opportunities for appropriate care and misdiagnosis 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, to improve care and connect them to pathways of diagnosis and 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 targeted at healthcare professionals from all parts of the world. Reach is magnified by working 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 NCO’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.

RESULTS

Since official operations commenced in March 2020, Tin Soldiers has trained 335 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.

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 worldwide but also have key relevance to the conduct of global clinical trials, disease data collection and access to approved therapies in the future.