



There is so much to take in when dealing with a new diagnosis. Overwhelming is not the word. At times there can feel like there is too much information; at other times, not enough.

When you feel like you are ready to learn more, or that you need to know more, the following guides will prove invaluable. All of the following information is from trusted sources, and verified by medical professionals who are both knowledgeable about FOP and have many years' experience of supporting people with FOP. You may find it helpful to share these documents with the medical, educational, and health professionals who are involved with your care.



### What is FOP? A Guidebook for Families

This is an excellent guide for parents, people with FOP, teachers, or anyone who needs to know about FOP. It is written in an easily accessible way. It covers all aspects of living with the condition, from an explanation of FOP to how to manage the condition. It answers many questions people have and is an invaluable resource to have available to refer back to. Download is free, or contact FOP Friends.

[bit.ly/whatisfopguidebook\\_ifopa](http://bit.ly/whatisfopguidebook_ifopa)



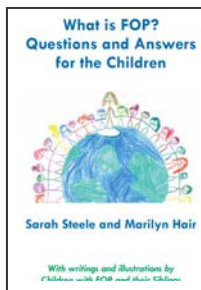
### The 'International Clinical Council for FOP' Medical Guidelines

The ICC is an independent group of internationally-recognised clinician experts in FOP from 14 nations. They have produced a set of medical guidelines to provide information for medical practitioners to support them to provide the best possible care for their patient. *Any person with FOP, or their carer, should be familiar with these guidelines so that in the event of an emergency, they are able to direct the medical team to the necessary information as quickly as possible to reduce the potential for harmful intervention.* [www.iccfop.org](http://www.iccfop.org)



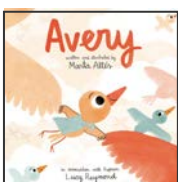
### Supporting a Child with FOP: a practical guide to their learning journey

This guide has been written for parents, teachers, and other educational professionals to provide guidance to provide the best possible learning experiences and opportunities for a child with FOP. The guide is available for purchase, or free for parents and the school of a child with FOP. Contact FOP Friends to receive a copy or visit our website to download the pdf.



### What is FOP? Questions and Answers for the Children

Written by a young person with FOP and her mum, this is a book that aims to explain FOP to a child who is living with the condition, or perhaps their siblings. It is written in the style of Q&A, and is illustrated throughout with drawings by children from the FOP community. It is advisable for parents to read this book before giving it to their child, to check for suitability. Download is free, or contact FOP Friends. [bit.ly/whatisfop\\_forkids](http://bit.ly/whatisfop_forkids)



### Avery, by Marta Altes with Prof. Lucy Raymond, University of Cambridge

This book tells the story of a little bird who is born to be different from other birds. It can help start conversations with a child, or explain the challenges of having a genetic disorder. It is sensitively written: little bird feels differently on different days. Some days little bird can join in, other days little bird has to be brave, but ultimately little bird finds his own way to soar. Contact FOP Friends.