



friends®

Support Groups for Families

Friendship for Families

You are not alone. The silver lining of a diagnosis of FOP are the people you will meet along the way. Whilst it can feel very isolating living with a rare genetic condition, there are a number of closed, private Facebook groups where you can connect with others who truly understand your journey. These groups can be a great place to make real friends who genuinely understand the high, lows, and the emotional rollercoaster which comes with living with FOP.

To become a member of any of the groups below, message FOP Friends and they can add you to the group, to then be approved by the Administrator of that group. The groups are exclusively for people (patients, family, carers, friends) living with FOP, and there is an expectation of confidentiality and respect in all groups.

However, caution should be taken into consideration when sharing personal and medical information. Basic common sense rules of social media apply, including not sharing personal details such as addresses, phone numbers, and schools etc. unless you are confident you know and trust who you are sharing with. Most of the views expressed are those of the member, who may not be medically qualified to advise.

You should remember this before following any advice. For trusted, medical advice from the FOP specialists, please visit: <https://www.iccfop.org/> and download the ICC Medical Guidelines to share with your own medical practitioner.

Views expressed in these groups do not necessarily represent those of FOP Friends, the IFOPA, or the medical professionals who treat, care and support patients with FOP. FOP Friends cannot take any responsibility for any comments or advice given in these groups.



FOP Families UK

The UK FOP community's group. The members live in the UK so it offers people the opportunity to get to know the people who can become real friends in the real world. It also acts as a 'notice board' for the charity to keep people living in the UK, up to date with the latest information about FOP and POH.



FOP and POH Families' Group

We also have a WhatsApp Group for UK families to chat, ask questions, and get support. It's also where we share news and updates. It's a really useful group!



Support4FOP

The main Facebook group for FOP families. Patients, families, carers and others involved in caring and supporting those living with FOP are welcome to join. The community is has members from all over the world. It is a place to share experiences, advice, ask questions, and keep up to date with the latest developments in FOP research.



Parents of FOPers

A group for parents of a person with FOP. This is a space where parents can ask advice, but also express feelings associated with caring for a child with FOP. It is especially useful for newly-diagnosed parents who feel like they worry about everything: there are no silly questions in this group.



FOP Mothers...for mothers/step-mothers

Mama bears supporting Mama bears! Here mums - or moms! - can share their feelings, emotions, and simply ask for friendship in times of worry or anxiety about their child with FOP.



FOP Ladies

This group's focus is to answer questions of a personal, intimate, or sexual nature, relating to issues that might arise from having FOP, and may not want to ask in the Support group. Mums of girls are welcome to join if they have questions about how to best support their daughter.



Lady FOPers

Women affected by Fibrodysplasia Ossificans Progressiva .. No parents of young girls allowed in here .. Just us gals !!



Dads and FOP

A place for dads who have sons and or daughters who have FOP. Share your stories, ask some questions, reach out for support. Whatever you need.

However if you have FOP or are a Male relative of someone with fop you are more than welcome to join!



FOP Siblings

FOP Siblings is an online community for brothers and sisters of individuals with FOP. The space is intended to provide a safe and supportive place for siblings to share their questions, thoughts, and experiences. The group is moderated by a staff member of the IFOPA who will share resources periodically to help inform participants and invite conversation.group.



FOP Bereaved Families

Losing a loved one to FOP is incredibly difficult. FOP Bereaved Families is a private online group for family and close friends to support each other through their grief and loss. It's a place to connect with others who truly understand what you're going through.



FOP Gamers

FOP Gamers is a private online group where FOP community members can connect over their shared love of video games. This is a fun, welcoming space for friends to game together.



The Bone-Afide Club

A WhatsApp group for adults living with FOP in the UK to just have a chat about nothing in particular!



FOP Online

This is an email group, for individuals living with FOP, their parents and/or other caregivers. To join, contact together@ifopa.org to have an invite sent to your email address.



Other groups

Patient organisations for other international organisations (e.g FOP Australia) have their own groups. Please contact together@ifopa.org for further information.