

Whilst it can feel very isolating living with a rare genetic condition, there are a number of closed, secret Facebook groups where you can connect with others who truly understand your journey.

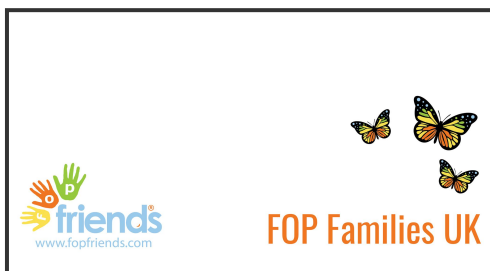
To become a member of any of the groups below, message FOP Friends and they can add you to the group, to then be approved by the Administrator of that group.

The groups are exclusively for people (patients, family, carers, friends) living with FOP, and there is an understanding 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's FOP community group. The members all reside 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.



### Support4FOP

This is the main Facebook group for people living with FOP and their families. It is a place to share experiences, advice, ask questions, and keep up to date with the latest developments in FOP research. It's also a place to make new friends to help you along this journey.



### Parents of FOPers

A group for parents of a child 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.



### FOP Men's Group

This is a group for dads with a child who has FOP, but also for men who have FOP and want to ask a personal question they don't feel comfortable sharing in the main groups.



### FOP Trash Can

Fed up with FOP? Or maybe just generally fed up? Want to scream, shout and swear? Then this is the group. You can rant all you like and no-one will advise, comment or judge. All posts are deleted at the end of the month, and like a phoenix, the group rises once more.