Support Groups

The following online support groups via Facebook and email allow individuals living with fibrodysplasia ossificans progressiva (FOP) and/or their family and friends to connect with others.

Facebook Groups: Secret, Closed and Public
Please note that Facebook groups are set to either secret, closed or public. Secret groups cannot be found from nonmembers in a search. Only current members can see who is in the group. To join, one must be invited or added by a member, and then approved by a group administrator. For a member to add you to the group, you must be connected as friends on Facebook. Closed groups are visible in a search to nonmembers, but they will not be able to view the page posts. To join, anyone can ask by clicking the “Join Group” button on the page. They will then have to be approved by a group administrator. Public groups are visible and open to anyone. Individuals can join by clicking the “Like/Follow” button on the page.

For further clarification on the group types, please see this [table from Facebook’s Help Center](https://www.facebook.com/help/article/179870806000357). If you have questions about joining a specific group, please contact the group administrator(s) listed. For general questions, contact together@ifopa.org.

FOP Support Groups on Facebook (Secret)

To join any of the secret groups below, contact one of the group administrators listed so that they can invite you to join from Facebook, or ask a current member (if you know of one) to invite or add you. Once a member, you can invite others to join by using the Facebook invite tool. Make sure to send the administrator a private message and let them know the relationship so that he/she can approve it.

**Support4FOP**
Support4Fop has been established as a community for the support of individuals living with FOP, their immediate family, and their caregivers. Currently, there are over 600 participants from around the world. Community members have a wealth of experience and information to share to help you understand and live with FOP. Please feel free to ask any question you may have. Most questions get some response within a couple of hours, and often within a few minutes.

Administrators: Steve Eichner steve.eichner@gmail.com, Nancy Eichner, Theresa Caruso hamsancity@aol.com and Oliver Collins olivercollins93@gmail.com
**FOP Bereaved Families**
FOP Bereaved Families is a private online forum for family members and close friends of loved ones with FOP who have passed away. The IFOPA and FOP Community supported us during our FOP journey; this group is an opportunity for those of us who have lost a family member to FOP to support each other in our loss and grief.

Administrators: Marilyn Hair [marhair1@frontier.com](mailto:marhair1@frontier.com) and Nancy Sando [nasando@chartermi.net](mailto:nasando@chartermi.net)

**FOP Trash Can**
A place for adults 18+ living with FOP and/or their parents to communicate freely and vent without judgment.

Administrators: Marie Fahlberg [mariehfahlberg@gmail.com](mailto:mariehfahlberg@gmail.com), Sweden; Suzanne Hollywood [suziewood811@verizon.net](mailto:suziewood811@verizon.net) and Rory Otto [roryotto@gmail.com](mailto:roryotto@gmail.com), USA; Brooke Scott [brooke_scott@y7mail.com](mailto:brooke_scott@y7mail.com), Australia

**Leva med FOP (Living w/ FOP Scandanavia)**
For individuals living with FOP or anyone who is affected by FOP (family and friends). Topics include FOP, the Scandinavian FOP Association and the IFOPA.

Administrators: Annalena Josefsson and Ann-Sofie Klint at the Scandinavian FOP Association [info.fopforeningen@gmail.com](mailto:info.fopforeningen@gmail.com)

**Parents of FOP’ers**
Designed for parents (or primary caregivers/guardians) and grandparents of individuals living with FOP to discuss issues surrounding parenting an FOP child. No FOP’ers are in this group unless the parent themself has FOP and has a child with FOP.

Administrators: Helen Bedford-Gay [helen@fopfriends.com](mailto:helen@fopfriends.com) and Suzanne Hollywood [suziewood811@verizon.net](mailto:suziewood811@verizon.net)

**UK FOP’ers**
A UK-centric group for individuals living with FOP and their parents, primary caregivers and grandparents.
Administrators: Helen Bedford-Gay [helen@fopfriends.com](mailto:helen@fopfriends.com) and Christopher Bedford-Gay [chris@fopfriends.com](mailto:chris@fopfriends.com)

**FOP Support Groups on Facebook (Closed)**
To join any of the closed groups below, go to the page website and ask to become a member by clicking “Join Group.” One of the group administrators will follow up with you.

**FOP Australia – Patients and Families**
An Australian-centric group for individuals living with FOP and/or their families.
Administrators: Brooke Scott brooke_scott@y7mail.com and Talia Wilson taliajwilson@hotmail.com
FOP Australia - Patients and Families Group page

**FOP Ladies**  
For women living with FOP (age 13 and older) and mothers of girls with FOP, where no topic is off limits.

Administrators: Brooke Scott brooke_scott@y7mail.com and Stacie Miller fightingonproudly@gmail.com  
FOP Ladies Group Page

**FOP Men**  
For any man (including dads, brothers, uncles, husbands or other male caregivers) affected by FOP.

Administrator: Kyle Wallace kyleawallace@gmail.com  
FOP Men’s Group Page

**FOP Mothers**  
For mothers and step-mothers of individuals living with FOP.

Administrators: Lori Henrotay henrotay19@me.com and Suzanne Hollywood suziewood811@verizon.net  
FOP Mothers Group Page

**FOP Closed Email Support Group**

**FOP Online**  
For individuals living with FOP, their parents and/or other caregivers.

Administrator: The IFOPA together@ifopa.org  
To join: Contact together@ifopa.org to have an invite sent to your email address.

**Questions about Support Groups**

These groups are generally administered by FOP individuals or, in the case of Parents with FOP’ers, by a parent of a child with FOP. If you have questions about joining a specific group, please contact the group administrator(s) listed. For general questions, contact together@ifopa.org.