



## FOP Registry FAQ

IFOPA Version 02.13.2018

### **Q: What is the FOP Registry?**

The FOP Registry is a collection of medical information and other related health information from people with FOP that is stored and used for medical research. Information collected in the FOP Registry will be used to help plan for clinical trials, to better understand FOP, and to assist the development of new FOP treatments. Enrollment in the Registry also empowers people with FOP by enabling your direct contribution to research efforts.

The FOP Registry is managed by the International FOP Association (IFOPA).

### **Q: Who can participate in the FOP Registry?**

There are no exclusion or eligibility criteria to participate in the FOP Registry. The FOP Registry is a global patient registry open to all individuals with any FOP mutation. In the case of a minor, a family member or legal guardian of the individual with FOP can participate as well.

### **Q: Can I participate in the Registry if I'm also in Clementia's Natural History Study?**

Yes, you can still participate in the FOP Registry even if you are in Clementia's Natural History Study (NHS). In fact, *Clementia and the IFOPA strongly encourage all NHS participants to also register in the FOP Registry.*

### **Q: Why do Natural History Study participants also need to register for the FOP Registry?**

Clementia Pharmaceuticals and the IFOPA have established an agreement to allow your NHS data to be shared directly and anonymously with the FOP Registry. However, in order to transfer your NHS data into the FOP Registry, you must first register and consent to participate in the Registry. *By registering for the FOP Registry, you will ensure the FOP research community has access to data from the Natural History Study, which is an important dataset that may help with the development of future therapies.*

### **Q: Can I participate in the Registry if I'm also in the palovarotene or REGN2477 clinical trial?**

There are no exclusion criteria to participate in the FOP Registry; so you may participate in the FOP Registry even if you are in another interventional clinical trial.

### **Q: If I'm a member of the IFOPA do I also need to register for the FOP Registry?**

Yes, IFOPA membership is different than participating in the FOP Registry and you will need to register separately.

As part of the IFOPA membership process, you may have completed a FOP Patient Directory form. Completing this form allows the IFOPA to have your current contact information so that the organization can send you updates about research, clinical trials and other communications. However, completing this form does not register you in the FOP Registry. Registry enrollment requires a separate process than becoming an IFOPA member.

### **Q: How will my data be used in the Registry?**

Information collected in the FOP Registry will be used for medical research, to help plan for experimental clinical trials, to better understand FOP and related diseases, and to develop new medicines for FOP.

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**Q: Once I register, how much time do I need to allocate to the Registry?**

After registering for the FOP Registry, you will be asked to complete an enrollment survey. This electronic survey will ask for background information as well as medical information about your FOP, and will take you approximately 45-90 minutes to complete. After you complete your enrollment survey, you will receive a follow-up survey every 6 months asking you for updated medical information. Many Registry participants complete their follow-up surveys in approximately 30 minutes.

**Q: What are the benefits of participating?**

Your participation in the Registry may help others with FOP by increasing the understanding of FOP. Data in the registry may help speed up research by providing important (de-identified) disease information to researchers and drug developers. Data from the registry may also help medical professionals improve how they treat the disease.

Participants may receive information about opportunities to participate in research, clinical trials, medical advances and other news from the Registry.

Participating in the FOP Registry is voluntary and there is no cost to you to participate. Registration can be accomplished directly through an online portal ([www.fopregistry.org](http://www.fopregistry.org)) and is also quick and free for all participants.

**Q: How will my information be protected?**

Ensuring patient privacy is a primary responsibility and concern of the IFOPA. Oversight for the Registry will be provided by the IFOPA in collaboration with the IFOPA medical advisory board. A protocol for the Registry has been reviewed by the Advarra institutional review board (IRB) to ensure protection of the rights and welfare of participants. An IRB, also known as an independent ethics committee or ethical review board, is a committee that has been formally designated to approve, monitor, and review biomedical and behavioral research involving humans

Steps have been taken to make sure the FOP Registry participants can provide their information in a secure setting. The IFOPA will not rent, sell or share any identifying information in our mailing lists or the FOP Registry.

**Q: How do I participate in the FOP Registry?**

To participate in the FOP Registry, you first need to register. Registration can be easily accomplished through an online portal ([www.fopregistry.org](http://www.fopregistry.org)) and is also quick and free for all participants. You will be required to read and e-sign off on an informed consent as part of the registration process.

**Q: What if I have more questions or need additional information about the Registry?**

You can ask questions about the FOP Registry any time. Please contact the IFOPA if you have any questions or concerns:

Sammi Kile  
Registry Project Manager



International FOP Association  
Website: [www.ifopa.org](http://www.ifopa.org)  
Email: [info@fopregistry.org](mailto:info@fopregistry.org)

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