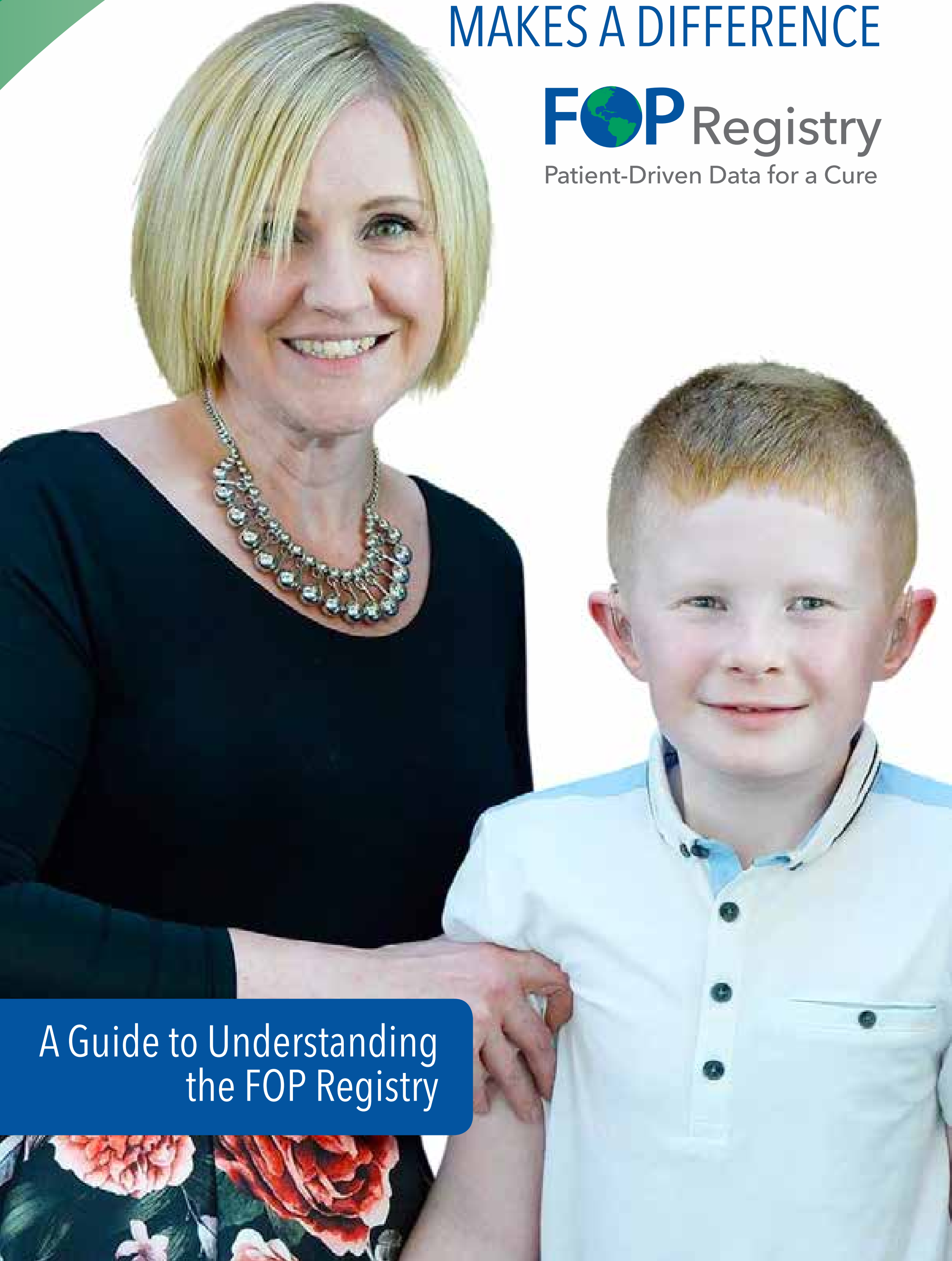
Your Contribution MAKES A DIFFERENCE

FOP Registry

Patient-Driven Data for a Cure



A Guide to Understanding the FOP Registry

Did You Know?

The FOP Registry is independently operated by the IFOPA and is dedicated to:

- Accelerating FOP research
- Enabling clinical studies in FOP
- Improving the understanding of FOP

It's an easy way to make a big contribution that can really make a difference.

About the FOP Registry and Why It's So Important

The FOP Registry is the largest and most in-depth collection of clinical and medical information about FOP and those who are living with the disease.

The best part about this database is that it is growing every day. That's because people like you from around the world, and their FOP physicians, are contributing to it. And that means that the understanding of this rare disease is growing all the time.

The FOP Registry collects this information for a single purpose: to help clinicians and researchers better understand FOP in order to **accelerate the development and availability of disease-modifying treatments**, and one day, a cure.

IT TAKES ALL OF US

Because the FOP Registry is only as good as the information that goes into it, everyone with FOP needs to take part.

Take a look at the information in this brochure and think about participating. Other people living with FOP now and in the future, will benefit from your contribution.

You can make a positive difference by participating in the FOP Registry.

Who Can Participate in the FOP Registry?

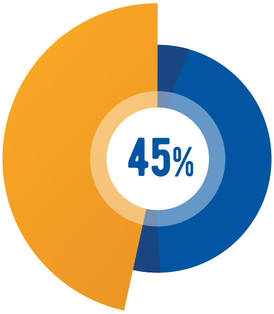
The FOP Registry is open to **anyone with FOP**. The information can either be provided by the person living with FOP or their caregiver — someone who can provide detailed information about symptoms, flares and doctor visits.

You enter this information on a dedicated website or the smartphone app every 6 months. It's secure and simple, and participant anonymity is always assured.

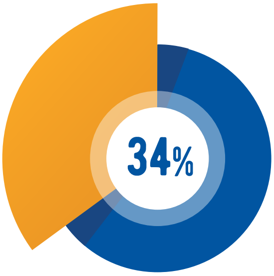
Physicians, patients and caregivers from around the world contribute information to the Registry to help improve the lives of those with FOP.

WHAT WE'VE LEARNED FROM PEOPLE IN THE FOP REGISTRY

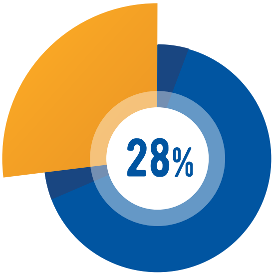
Here's just a small sample of the information uncovered that was previously not well-understood by doctors:



45% of patients in the FOP Registry report symptoms affecting their ears



34% of patients in the FOP Registry report skin problems



28% of patients in the FOP Registry report problems with sleeping, breathing and stomach/digestion

Why Should I Take Part?

The FOP Registry was started in 2015, and since then, it has already become a tool that has helped doctors better recognize the complexities of the disease and improve patient care.

HERE'S WHY YOU SHOULD TAKE PART:

- Contribute to the knowledge about FOP
- Help academic and pharmaceutical researchers design clinical studies that test medications to treat FOP
- Help other patients and families better understand the disease and how it can affect their lives

What Happens to My Information Once I Add It?

Information contributed by people like you has made it possible for physicians to develop publications that help the medical community better understand FOP and how it affects people, with the ultimate goal of improving care and treatment.

Physicians and researchers can submit requests for data from the FOP Registry, which they can use to write articles about FOP or to help develop new treatments.

Did You Know?

The survey questions and other Registry information are available in **7 LANGUAGES:**

- » English
- » French
- » German
- » Italian
- » Portuguese
- » Russian
- » Spanish

How Do I Get Started?

Enrolling in the FOP Registry is easy but you'll be asked to gather some information first, including the report that confirms your FOP diagnosis. Be sure you dedicate 30 minutes to an hour for this first step (the Enrollment Survey).

ALLOW 30-60 MINUTES
Don't worry, though, you can always take a break and come back later to finish.

Start by going to the Registry website at **FOPregistry.org** and click the **Join Now** link.

TIP

You'll be asked to set up a username and password to keep your private information secure. Be sure to write down your new username and password because you'll need this information each time you log in and complete the Surveys.

From there, the site will take you step-by-step through the enrollment process. After completing the Enrollment Survey, you'll be sent a reminder every 6 months to sign back in and fill out a new Follow-Up Survey, which you can either do at the website or using the smartphone app. These Surveys don't require you to upload any medical records or images — you'll just be answering questions.

Do I Need to Keep Filling Out the Surveys Every 6 Months?

Yes, absolutely, which is why we make it easy to do so. The key value of the FOP Registry is that data is collected over a long period of time — over much of a person's lifetime. That means the information shows the way FOP affects people over time. This is critical to helping doctors understand the disease.

Your participation really makes a difference.
Get started today at FOPregistry.org.

Did You Know?

The FOP Registry was started with the cost entirely funded by contributions and special events undertaken by FOP families! Today we're fortunate to have Registry sponsors, who help keep the Registry going and growing. To see the list of FOP Registry sponsors, please visit ifopa.org/fopregistry

Join the FOP Registry and Contribute to this Important Research Effort!

LARGEST DATABASE

The FOP Registry is the largest database on FOP in the world because of people like you who take part and contribute their information.

- Help grow the knowledge about FOP
- Contribute to helping find effective treatments and possibly a cure
- Take part in something that directly benefits the entire FOP community

Questions about participating in the FOP Registry?

✉ help@fopregistry.org

☎ +1 866 761 0145
(answered 24 hours a day, English only)

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Patient-Driven Data for a Cure