

# A Look Back at 2020

## About the FOP Registry

The FOP Registry is open to **anyone with FOP and their physicians worldwide**, and is the **largest and most detailed collection of medical information** about people living with FOP. Information from the FOP Registry is used to **increase our understanding of FOP, improve clinical care, and speed the development of treatments.**

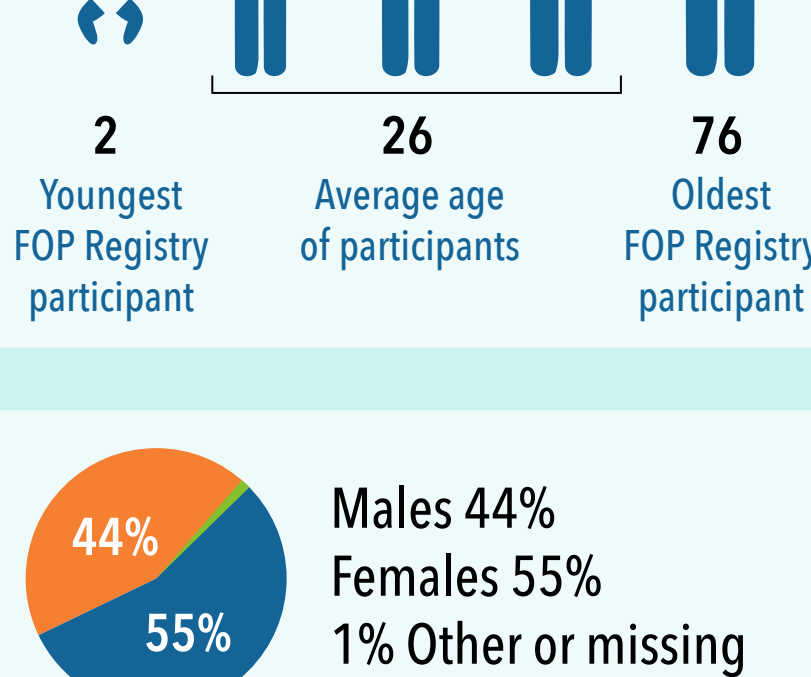
## Who is Participating?

as of December 2020

**323** participants

**69** countries

**6** continents

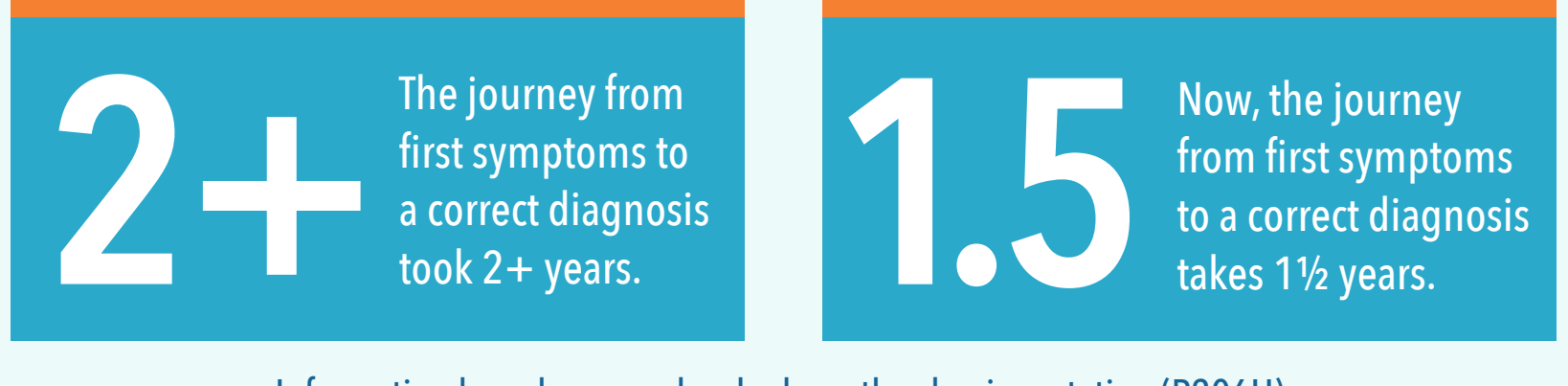


In fact, 45 participants have completed their 60-month time-point survey, meaning the FOP Registry has 5 years of FOP data!

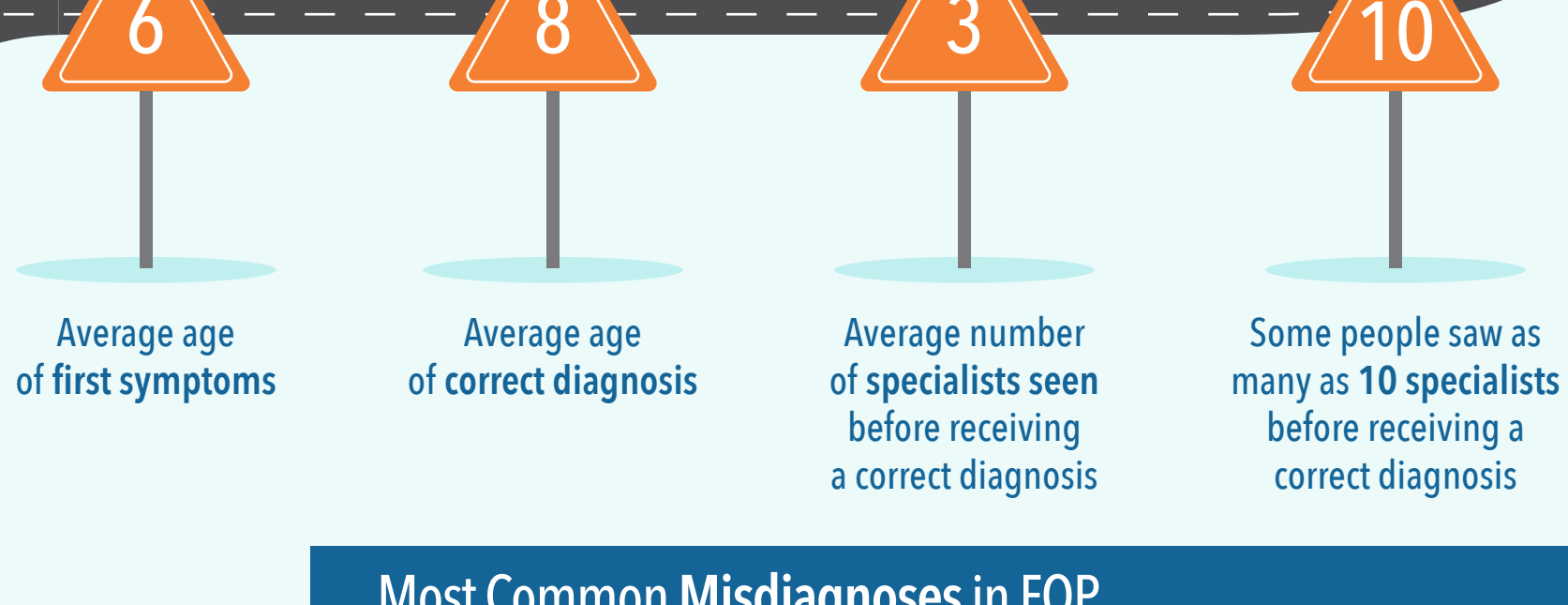
The FOP Registry is growing every year... and so is our knowledge about FOP!

## Road to Diagnosis<sup>1</sup>

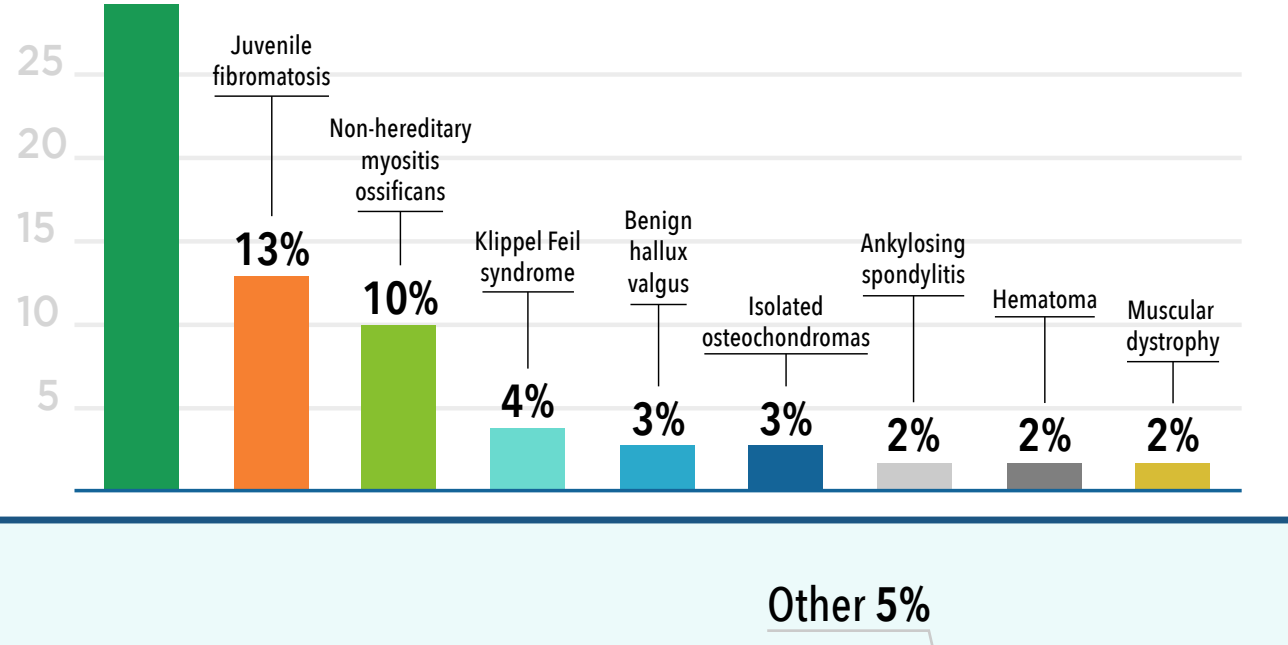
The diagnostic journey has become shorter over the past 5 years.



Information based on people who have the classic mutation (R206H).



### Most Common Misdiagnoses in FOP



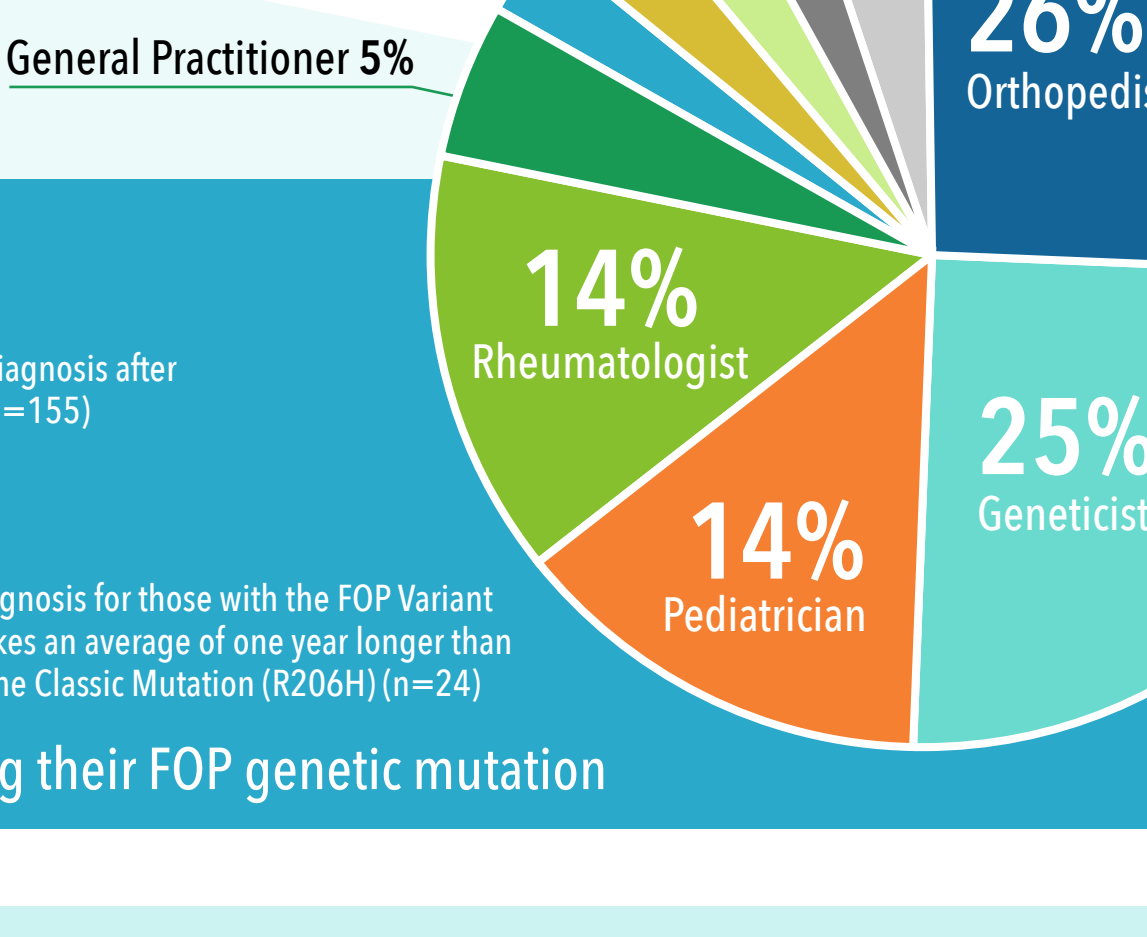
## Physician Specialties Where FOP Diagnosis Was Made

Correct diagnosis takes longer in people who don't have the classic FOP genetic mutation

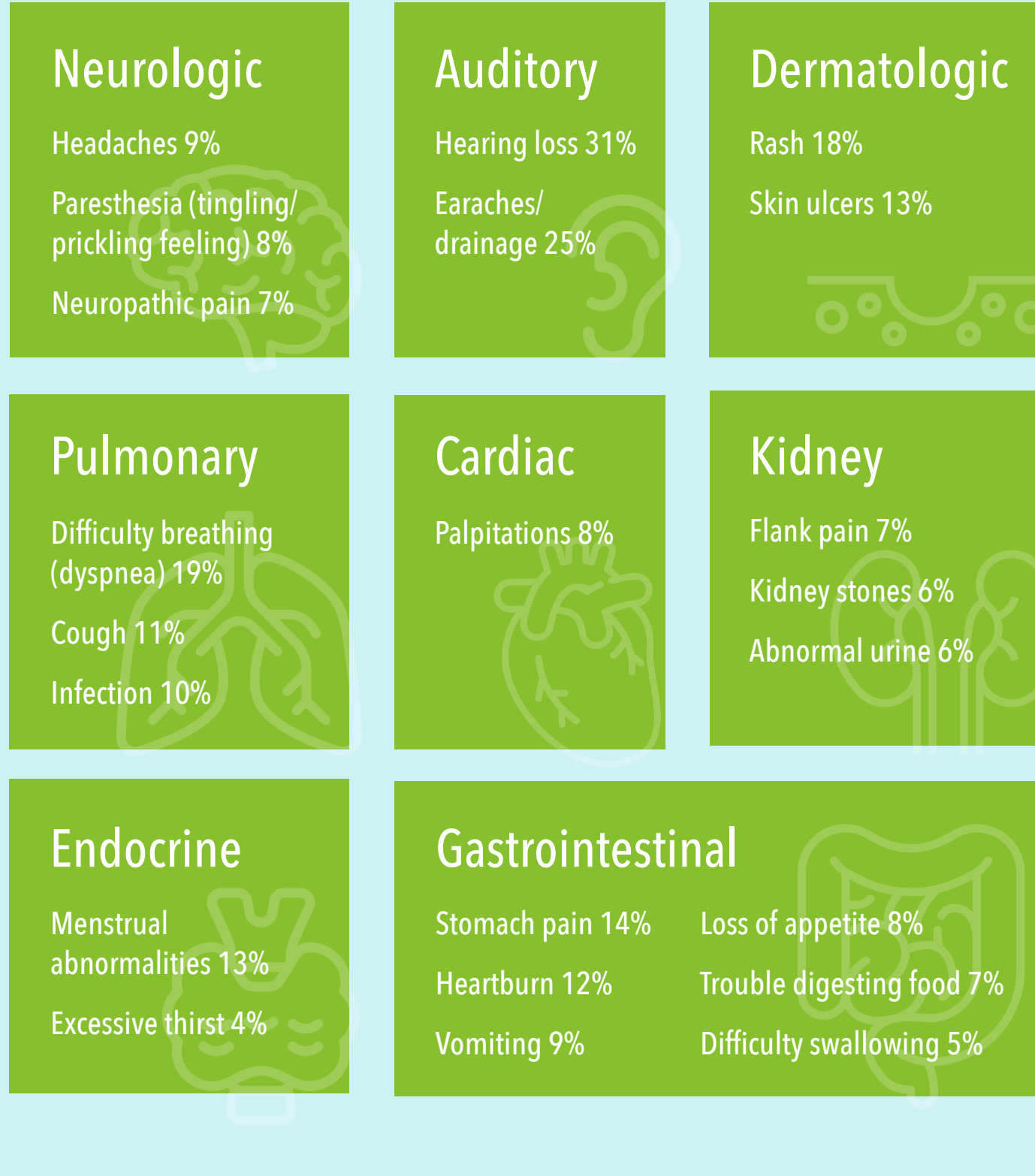
**Classic Mutation (R206H)**  
2.1 Years Average time to diagnosis after symptom onset (n=155)

**FOP Variant Mutation**  
1+ Year A correct diagnosis for those with the FOP Variant Mutation takes an average of one year longer than those with the Classic Mutation (R206H) (n=24)

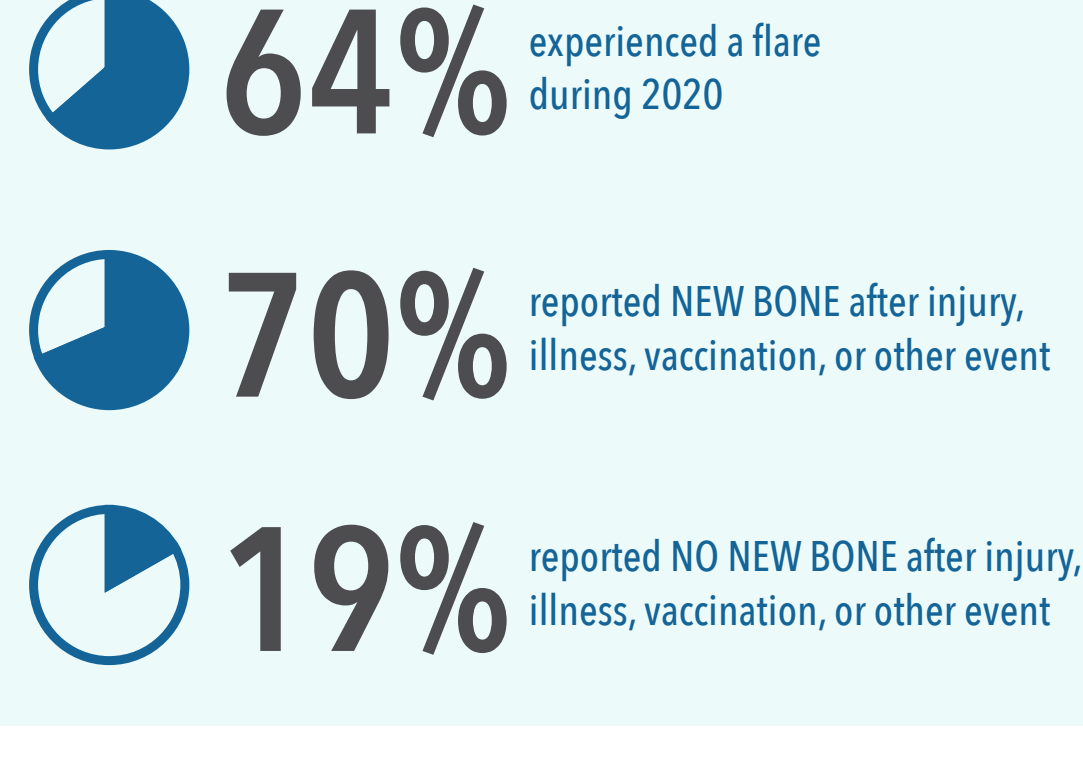
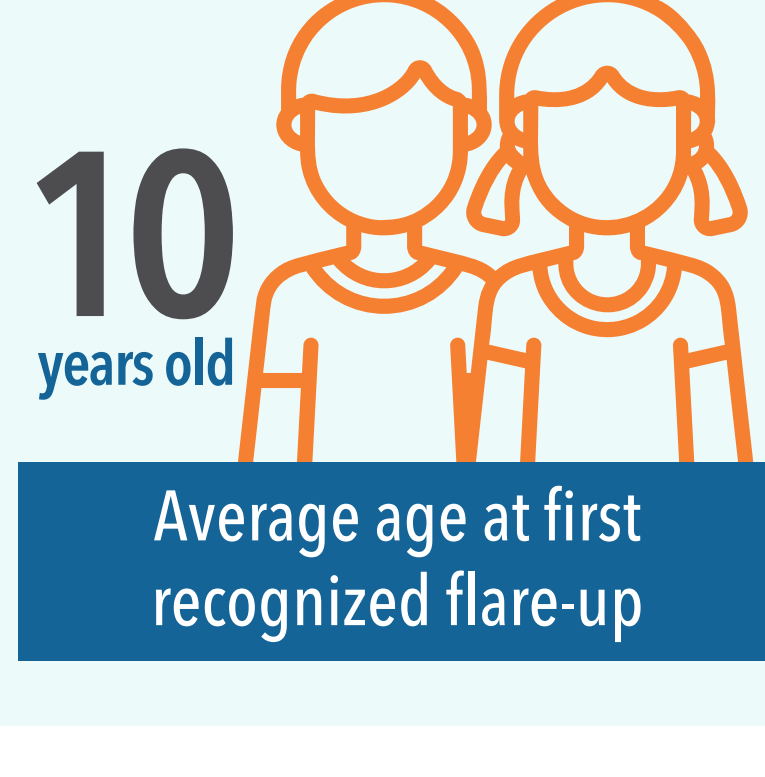
144 participants reported not knowing their FOP genetic mutation



## Signs and Symptoms<sup>1,2</sup>



## Flare-Ups in FOP

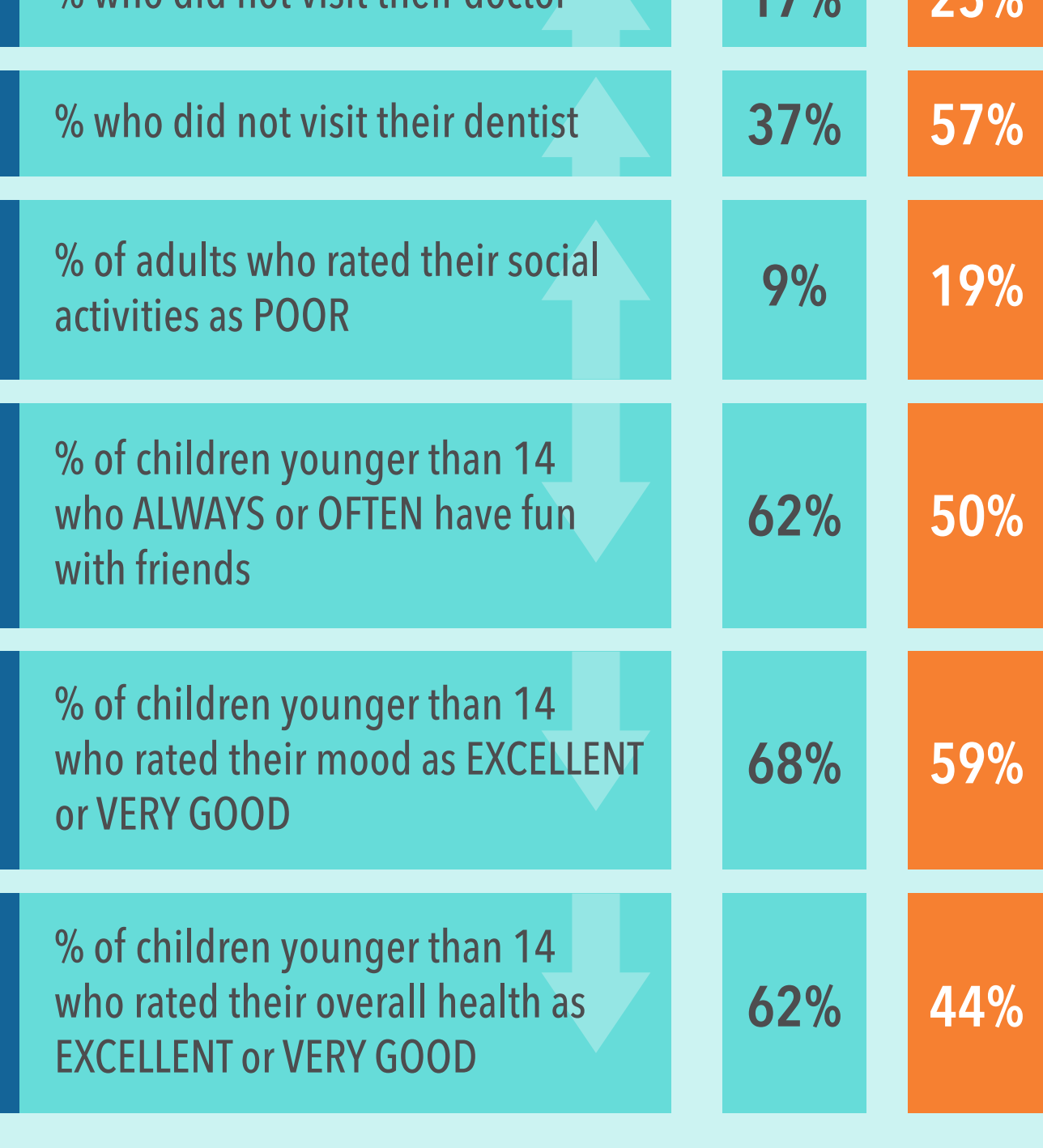


## The COVID-19 Impact in 2020

The disruption caused by the COVID-19 pandemic has affected everyone, and only time will tell the full impact on people living with FOP.

By March 2020, many people were staying home, not visiting with friends, and not seeing their doctors for non-essential appointments.

To get a sense of how COVID may have affected those with FOP, we compared key responses in 2019 to 2020 for a 6-month period starting in March.

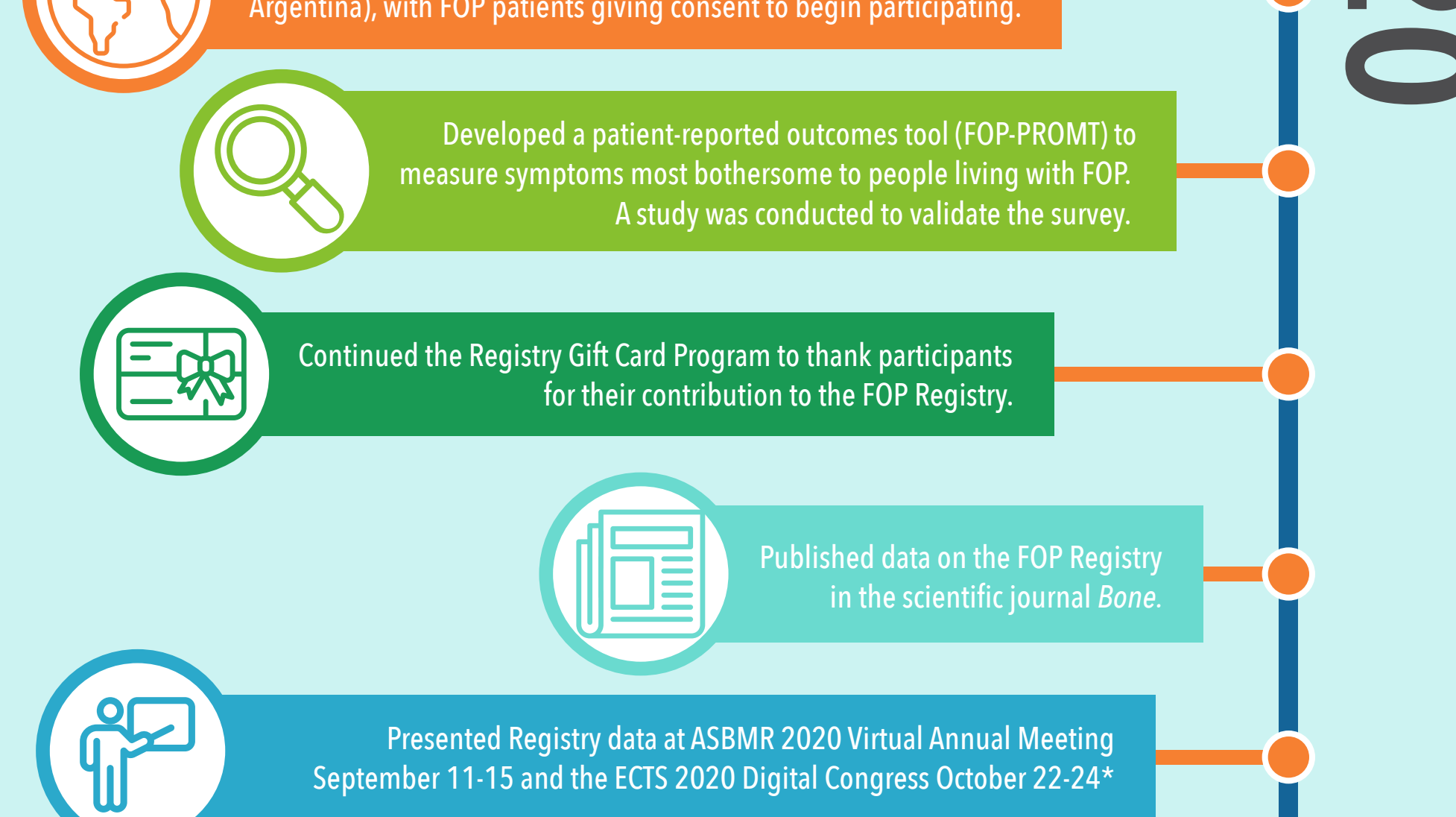


## What are participants saying about the FOP Registry?

"Set aside some time to fill out the surveys and do it when you're not distracted. And always remember why we're doing this - the long-term benefit."  
- Caregiver whose daughter has FOP

"People contributing to the Registry should know that it is helping us find a treatment. It's helping us understand how to better manage the disease today and what FOP does to the body."  
- Physician who treats FOP and participates in the FOP Registry

## 2020 FOP Registry Accomplishments



## A BIG Thank You

Thanks to funding support from Blueprint Medicines, Ipsen, and Regeneron Pharmaceuticals, the FOP Registry has continued to serve the FOP community.

The FOP Registry would not be possible without our medical advisory board members, participant advisory board members, and our Registry participants.

## Special Thanks To:

Special thanks to the Radiant Hope Foundation for the initial vision and funding support of the FOP Registry.

\*ASBMR (The American Society for Bone and Mineral Research) and ECTS (European Calcified Tissue Society) are medical meetings.  
1. Sherman IA, Cheung KI, DeCunto C, Kile S, Pignolo RJ, Kaplan FS. The Diagnostic Journey in Fibrodysplasia Ossificans Progressiva: Insights from the FOP Registry. [Poster] ASBMR Annual Meeting 2020.  
2. Pignolo RJ, Cheung KI, Kile S, Fitzpatrick MA, De Cunto C, et al. 2020. Self-reported baseline phenotypes from the International Fibrodysplasia Ossificans Progressiva (FOP) Association Global Registry. *Bone*. 134.