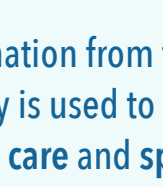


2019 Year In Review

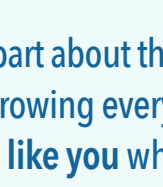
Fast Facts About the FOP Registry:



It's the largest and most detailed collection of medical information about people with FOP.



Information from the FOP Registry is used to improve clinical care and speed the development of treatments.

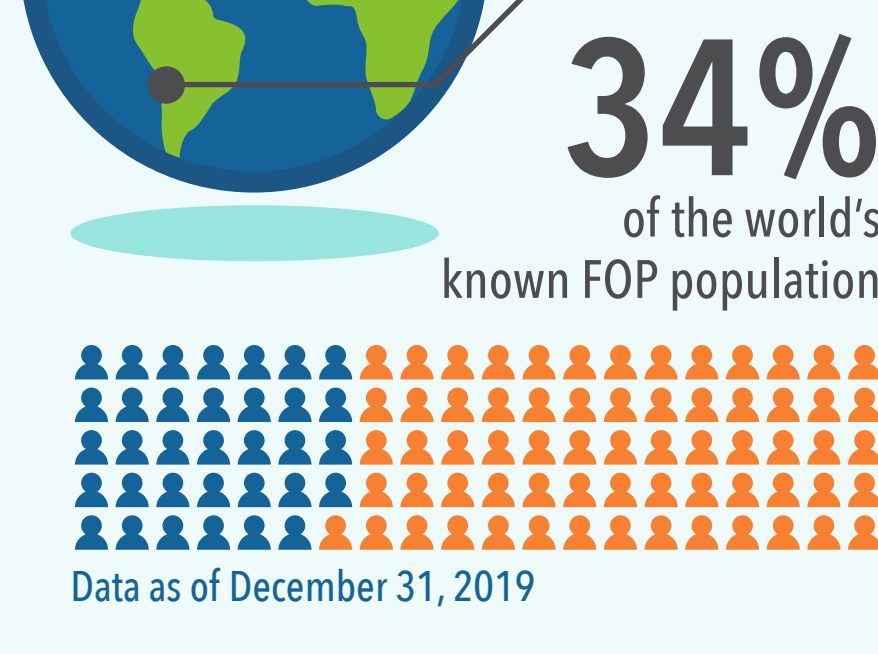
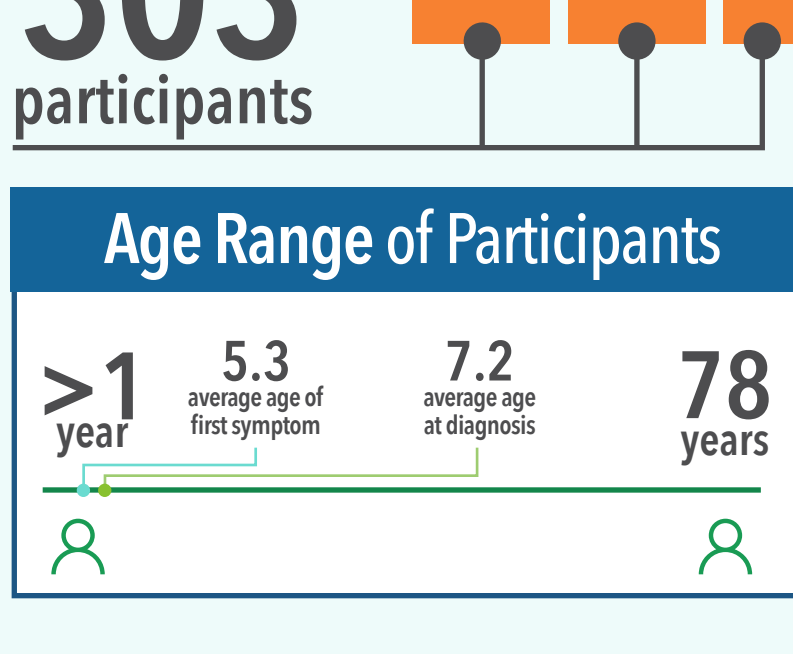


The best part about this database is that it's growing every day, thanks to people like you who continue to participate in the Registry.

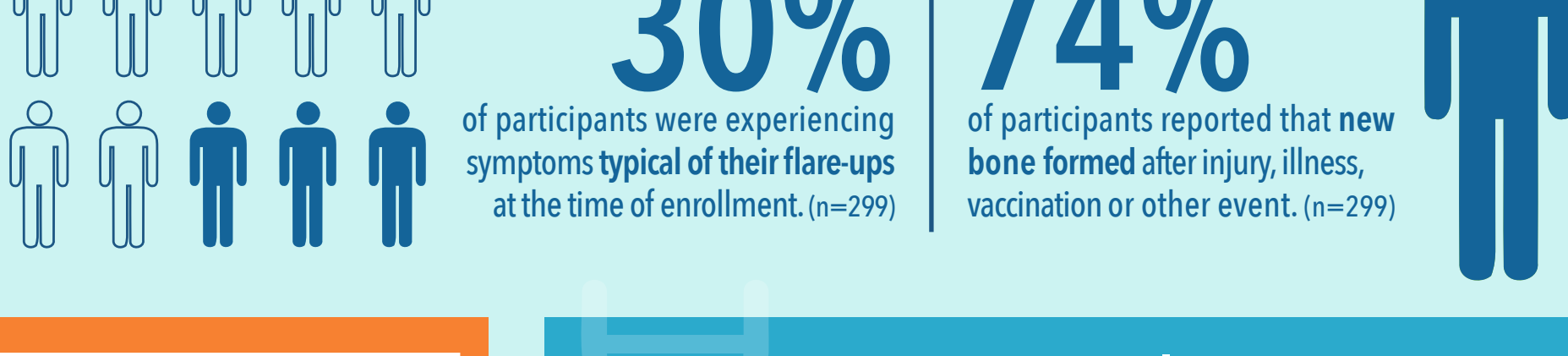
People living with FOP from around the world, and their physicians, are contributing to this important resource.

Who is Participating? More People Every Year!

Which means more FOP data than ever before...



Flare-Ups in FOP

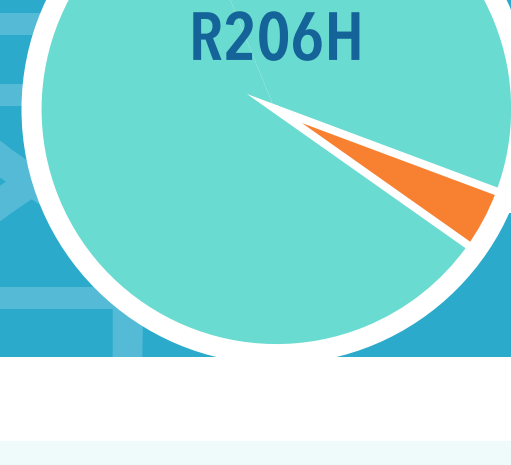


Did you know?

FOP patients tend to have more flare-ups that seem to be caused by:

- Illness
- Injury
- Vaccination

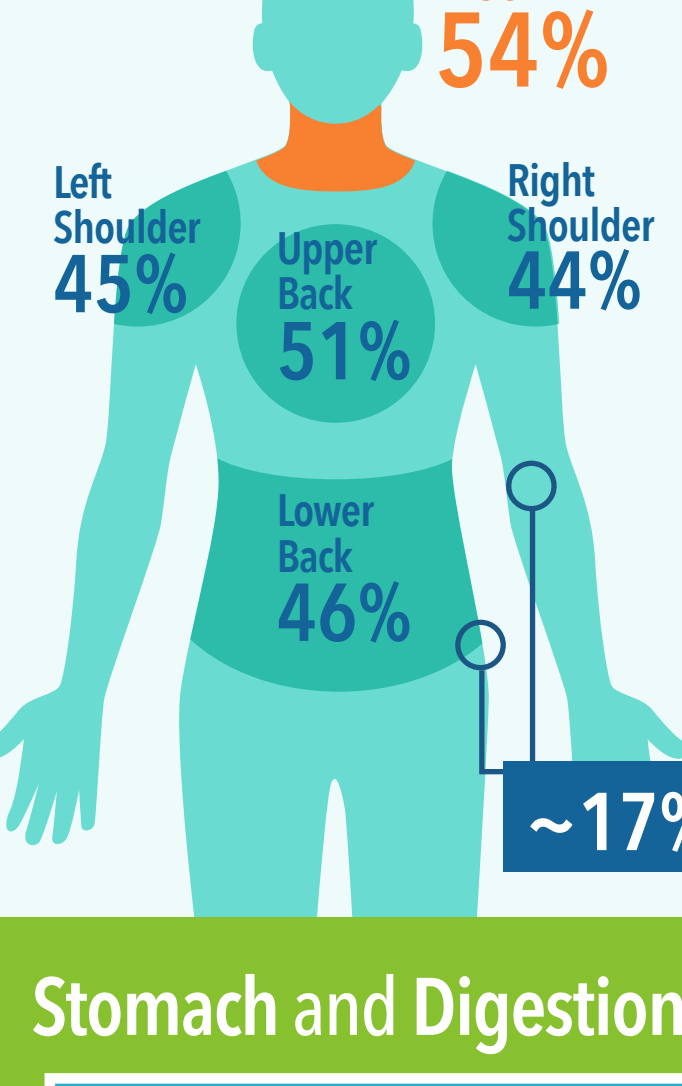
Genetics



Of Registry participants with knowledge of their mutation,

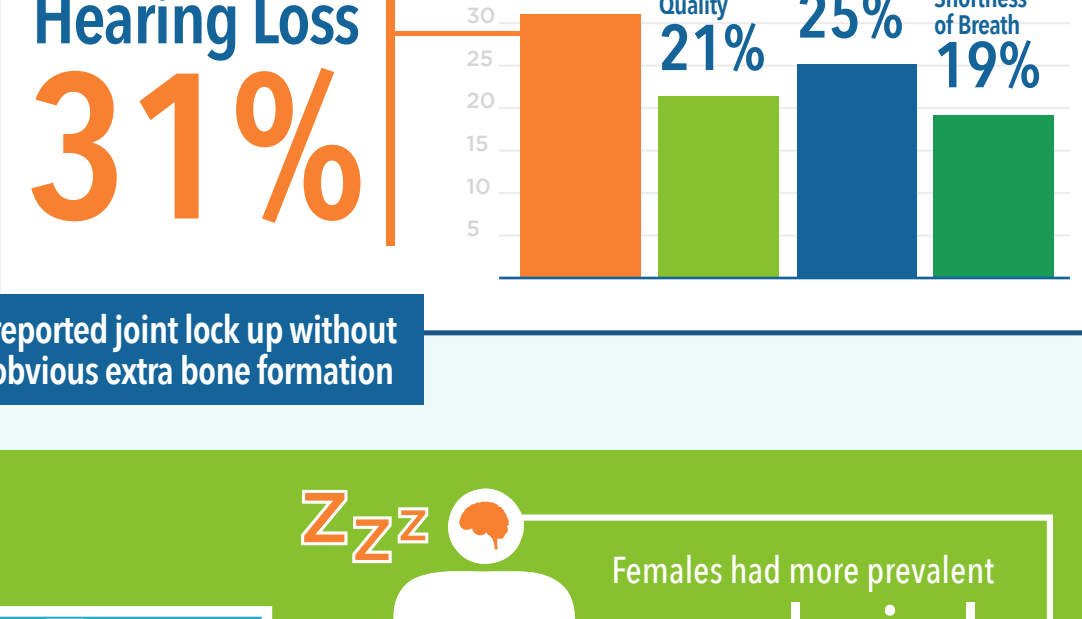
~96% reported the classic FOP R206H mutation*
~4% reported a variant mutation
*59% reported not knowing their mutation

What Symptoms Are People Experiencing?



Most common locations where participants experienced extra bone formation with partial movement.

Other key symptoms reported

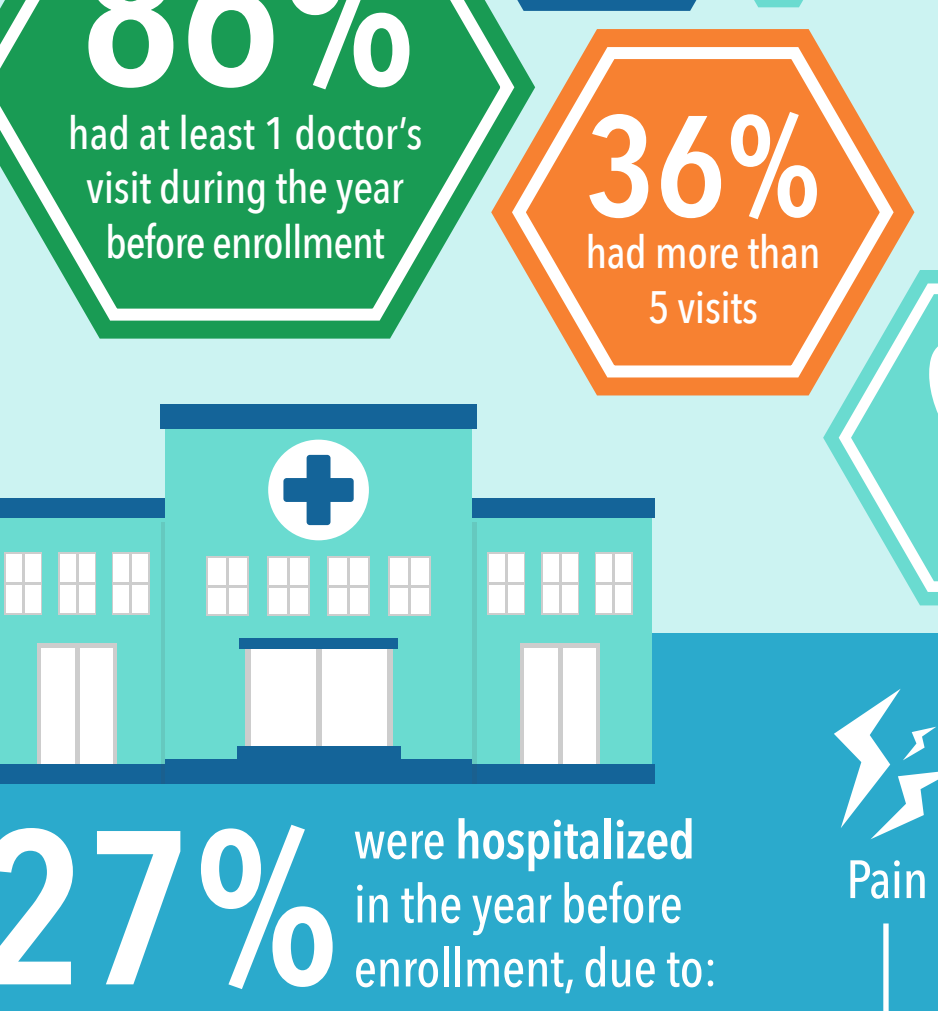


Stomach and Digestion



Females had more prevalent **neurological, gastrointestinal, and sleep** complaints compared to males.

Doctor Visits and Hospitalizations



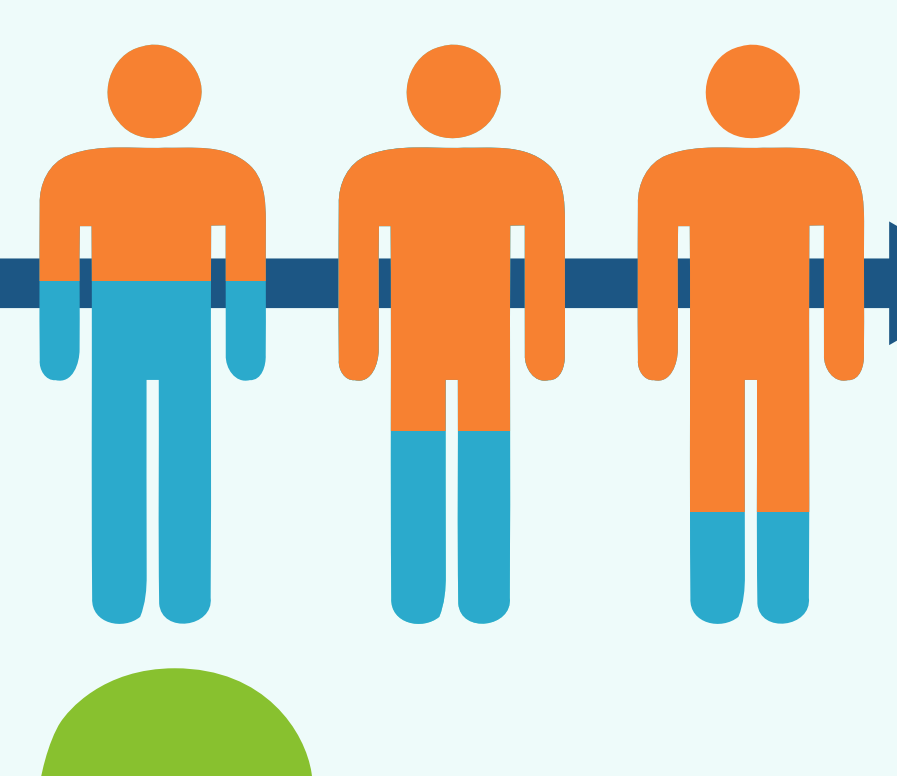
Emotional Health

21% visited their physician for emotional health issues (about 1/5 of all doctor visits)

Disability in FOP

Disability is Cumulative

Disability increases over the course of a person's life with FOP



Most Commonly Used Assistive Aides:

- FOP-specific care attendants
- Eating and personal care tools
- Bathroom and bedroom aids and devices
- Home, school and work environment adaptations
- Technology adaptations, sports and recreation adaptations
- Medical therapies for daily living

Craniofacial effects, such as jaw lock ups, are a significant cause of disability.

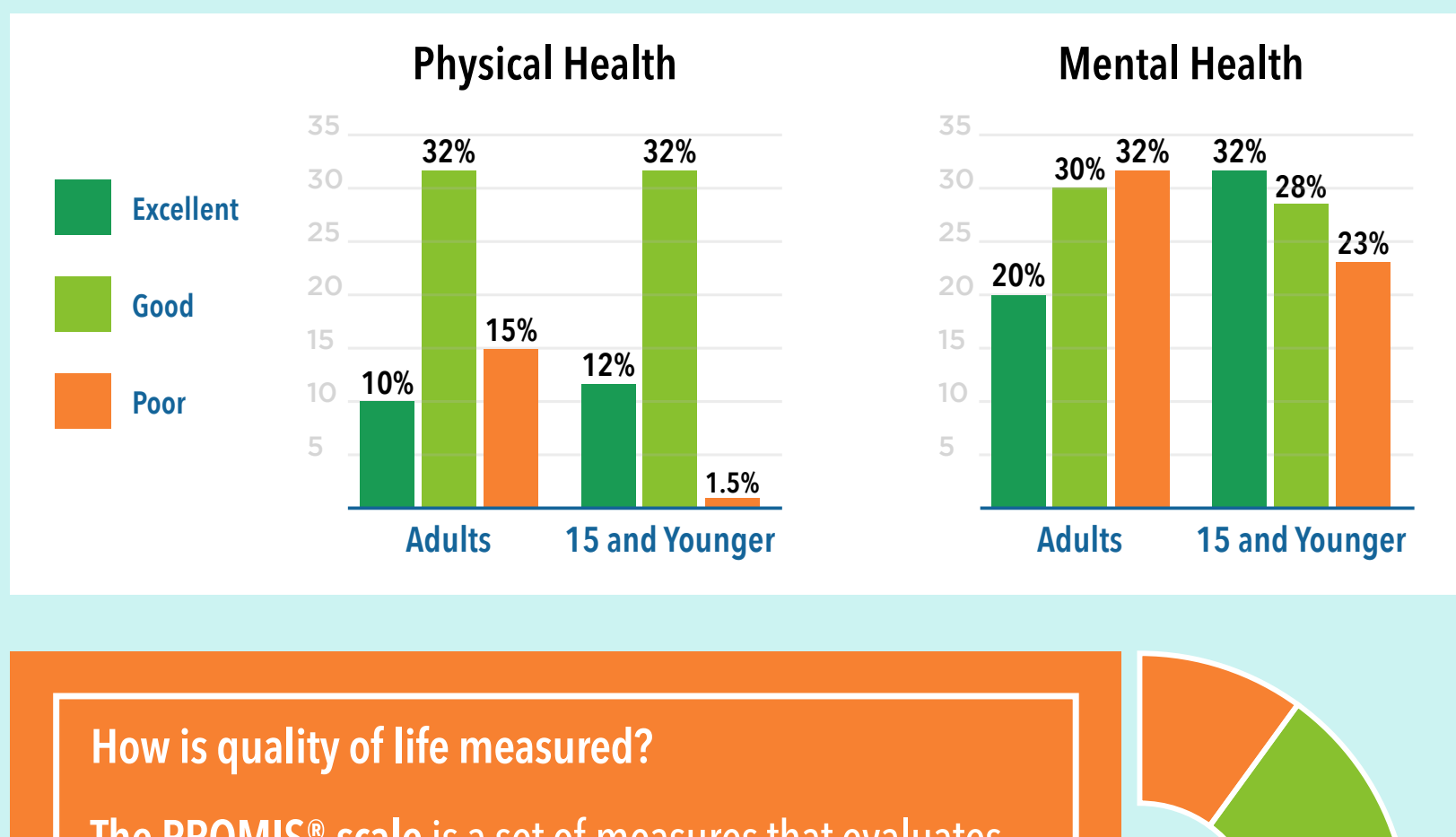
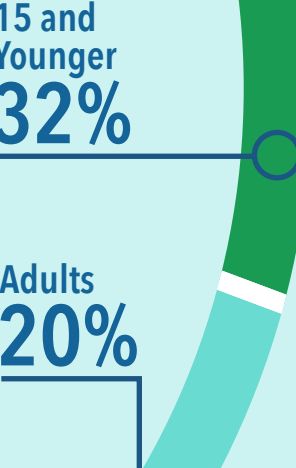
More than 40% of participants use:

- Bathing attendants
- Straws for drinking
- Reaching Sticks
- Memory Foam Bed Mattresses

Quality of Life with FOP

Overall, younger people with FOP have better physical, mental, and social health than those who are older than 15.

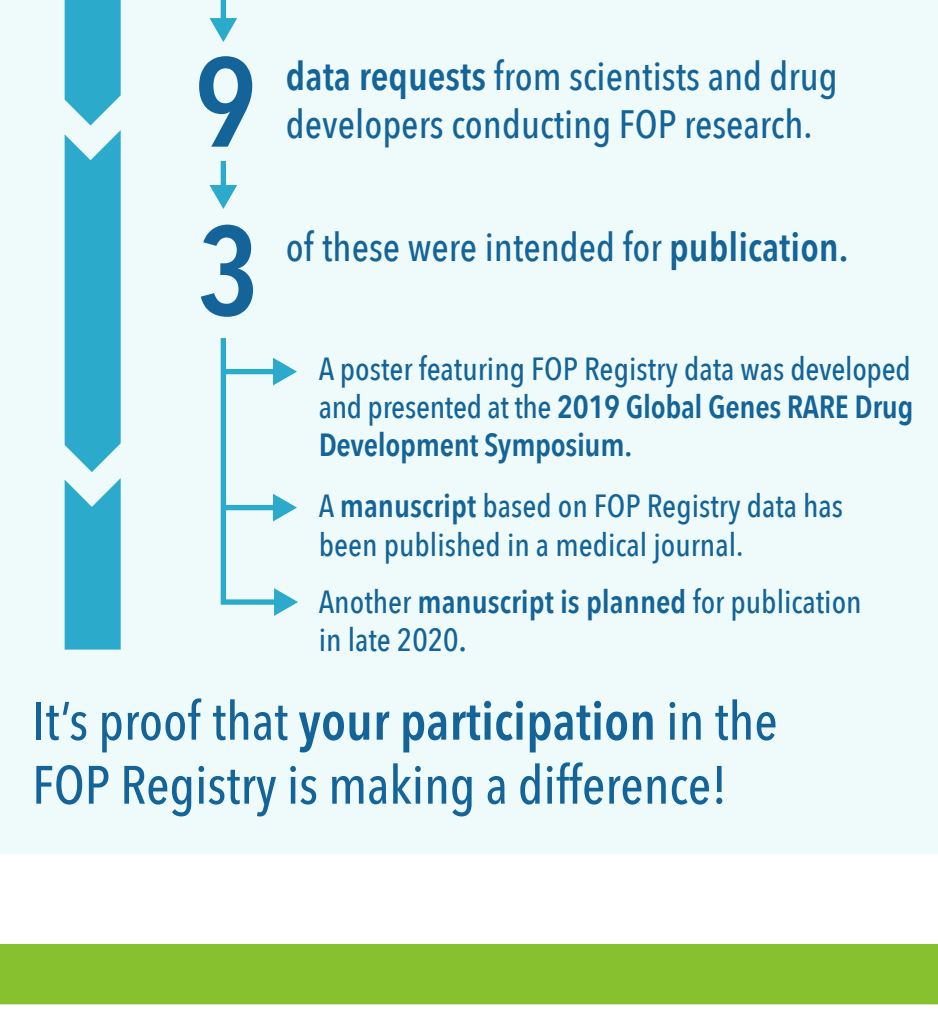
Percentage of People who Rate their Mental Health as Excellent:



How is quality of life measured?
The PROMIS® scale is a set of measures that evaluates and monitors physical, mental, and social health in adults and children.
The PROMIS scale is used with the general population and with individuals living with chronic conditions such as FOP.

PROMIS®: Patient-Reported Outcomes Measurement Information System

Sharing FOP Registry Data with the FOP Community



It's proof that your participation in the FOP Registry is making a difference!

What was new in 2019?

- Launch of Registry App for iOS
- Launch of the Medical Portal
- Transfer of Ipsen's non-imaging Natural History Study (NHS) data
- Launch of Registry incentive program
- Launch of new Registry website www.fopregistry.org

What's Next?

2020 will be an exciting time for the FOP community, as the promise for new treatments grows and as more people benefit from knowledge gained by participation in the FOP Registry.

Here's what you can look forward to:

- Daily Symptom Diary
- Expanding FOP Registry access to people around the world
- Android App
- More publications

Thank You

With funding support from Blueprint Medicines, Ipsen, and Regeneron Pharmaceuticals, the FOP Registry can continue to meet its goals in 2020 and beyond.

... AND none of this would be possible without our Medical Advisory Board, Participant Advisory Board, and our Registry participants.

Special Thanks To:

Robert J. Pignolo, MD, PhD for assistance with data interpretation for this annual report.

Amanda Cali and the Radiant Hope Foundation for the initial vision and funding support of the FOP Registry.