

A Snapshot of 2022

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

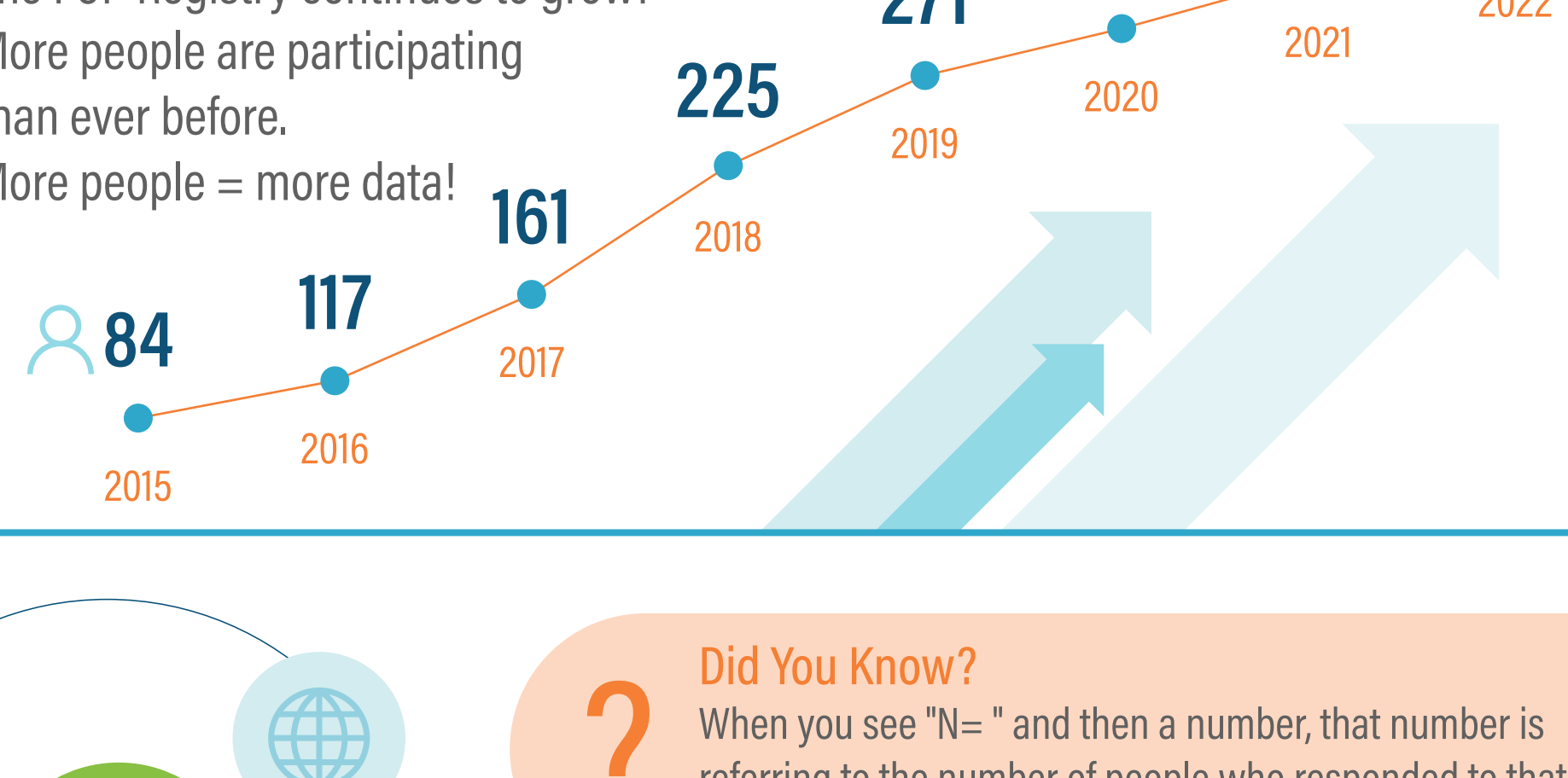
living with FOP. Information from the FOP Registry is used to increase our understanding of FOP, improve clinical care, and speed the development of treatments.

Here's a snapshot of what we learned in 2022!



Demographics

The FOP Registry continues to grow! More people are participating than ever before. More people = more data!



Did You Know?
When you see "N=" and then a number, that number is referring to the number of people who responded to that question and are included in that data set.

Number Enrolled by Country*

- United States: **33.1%**
- Brasil: **9.6%**
- United Kingdom: **5.5%**
- France: **5.2%**
- Canada: **3.5%**
- India: **3.5%**
- Italy: **3.2%**
- Spain: **2.9%**
- Poland: **2.6%**
- Australia: **2.0%**
- Germany: **2.0%**
- Russia: **1.7%**
- Colombia: **1.5%**
- Other countries in Europe: **9.3%**
- Other countries in Asia: **4.4%**
- Other countries in South America: **4.4%**
- Other countries in Africa: **2.3%**
- Other countries in North America: **2.3%**
- South Pacific Ocean: **0.6%**

New Enrollments in 2022 by Country

In 2022, we had 19 new enrollments. Here's where they were from:

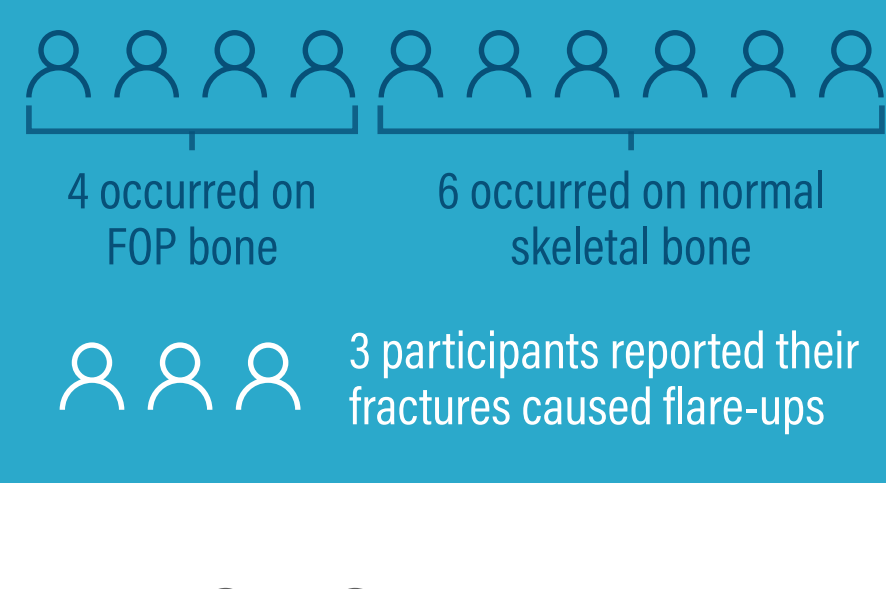
- United States: **21.1%**
- India: **15.8%**
- Brasil: **5.3%**
- France: **5.3%**
- Germany: **5.3%**
- Poland: **5.3%**
- Other countries in North America: **10.5%**
- Other countries in South America: **10.5%**
- Other countries in Africa: **5.3%**
- Other countries in Europe: **5.3%**

*To adhere to privacy expectations and ensure patient identity is anonymized, the FOP Registry does not report on specific countries with less than 5 patients. Therefore, those countries with less than 5 patients are 'rolled up' into regions, such as the continents listed above.

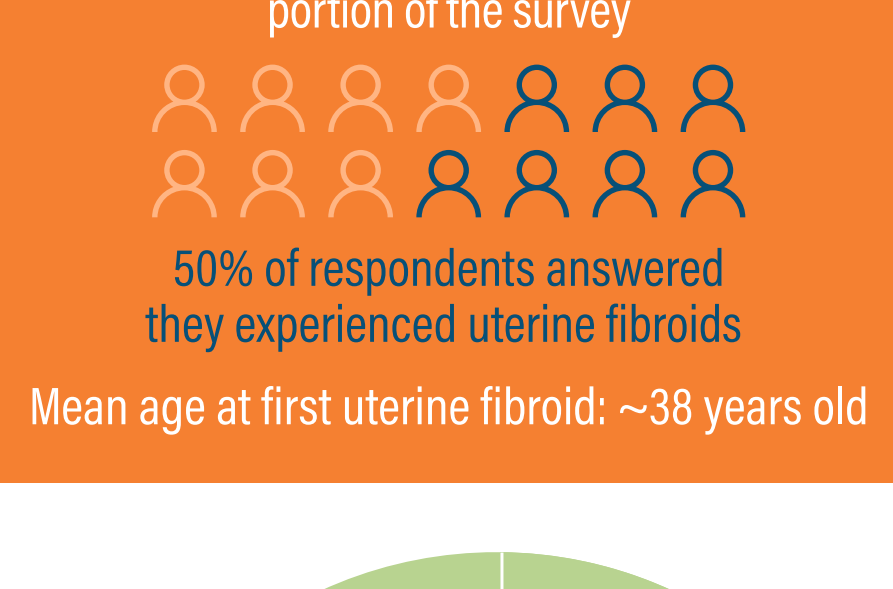
New FOP Registry Data Fields

New data fields were added to the Registry in early 2022. Here is a look at the preliminary data we have collected!

Fractures N=10

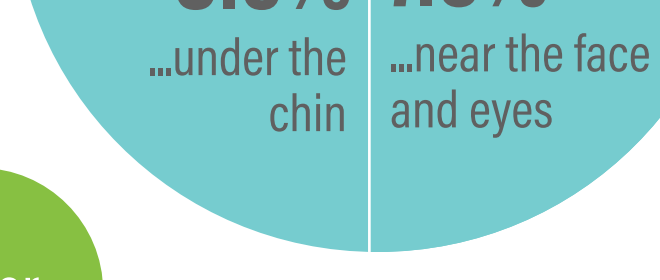
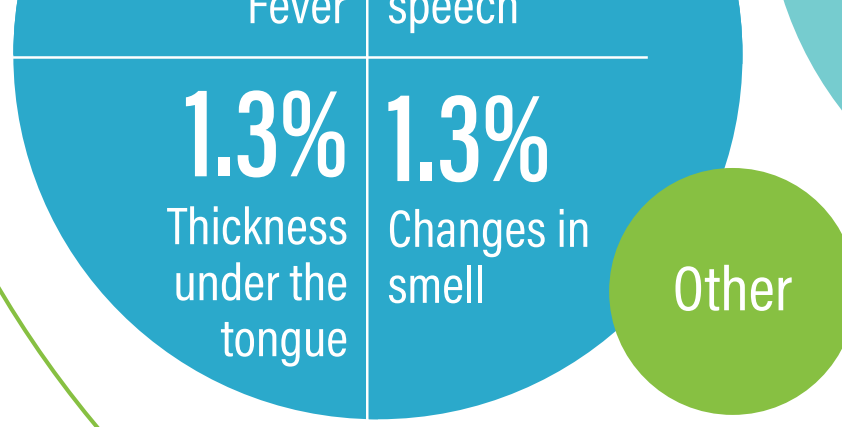
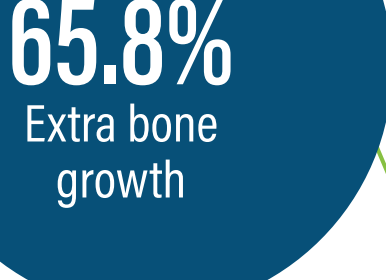
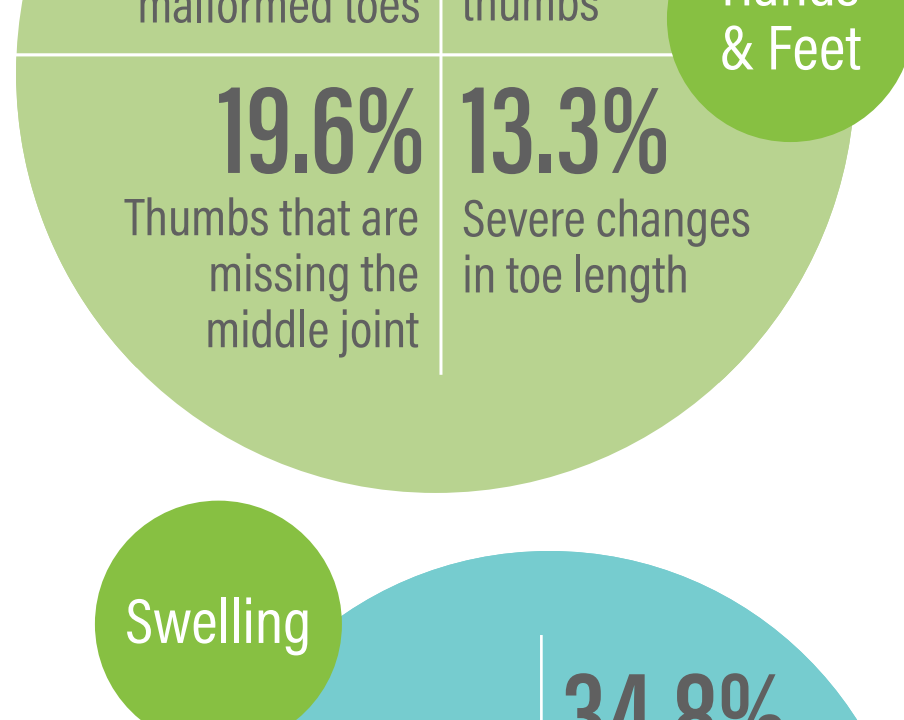
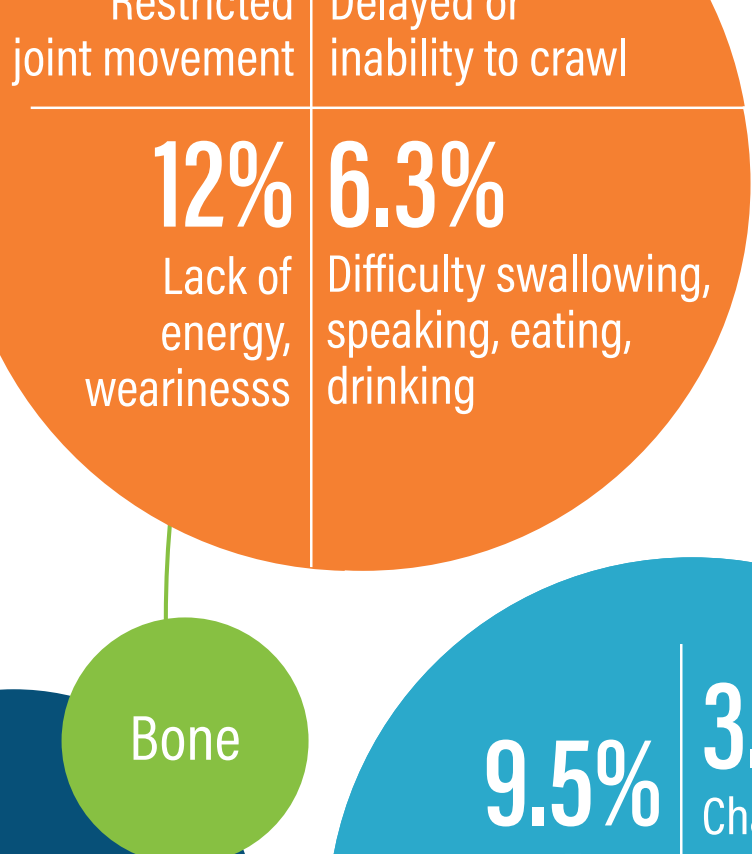


Uterine Fibroids N=14



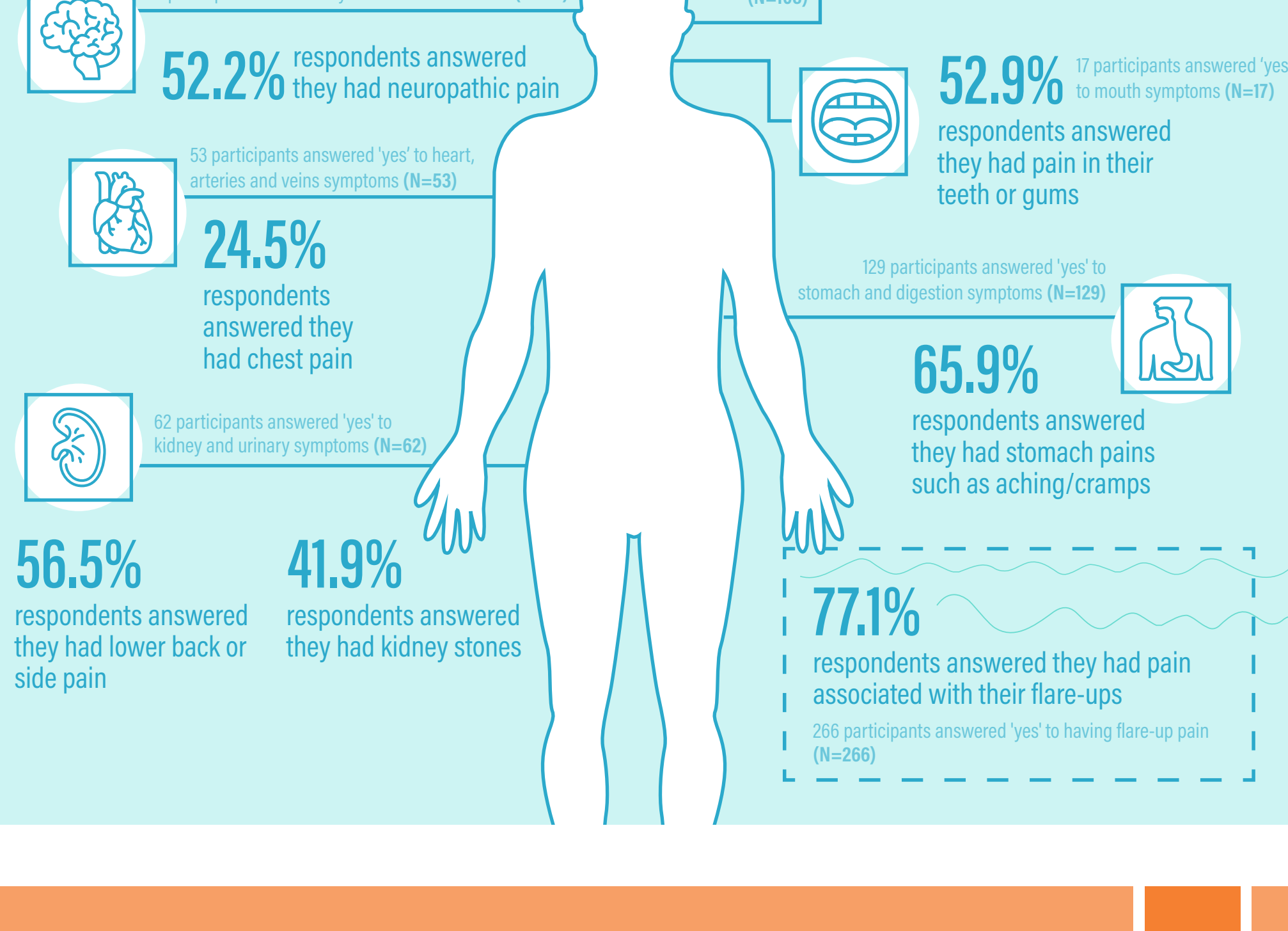
First FOP Symptoms

as Reported by Participants N=158



Body Systems Affected by FOP

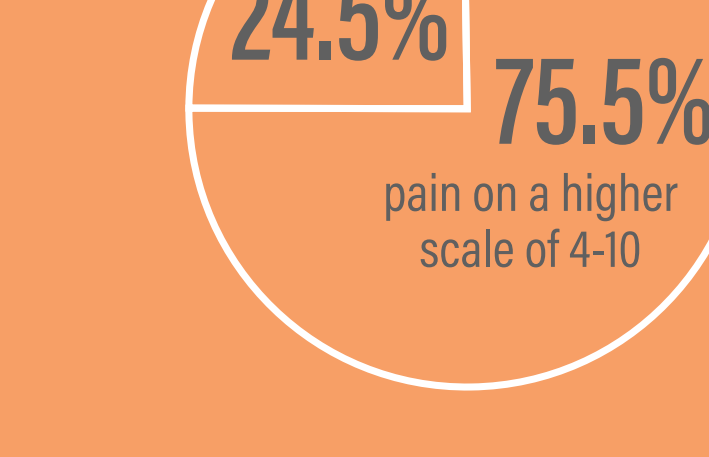
We asked participants new questions about body systems.



PROMIS Global Health (Pain) N=184

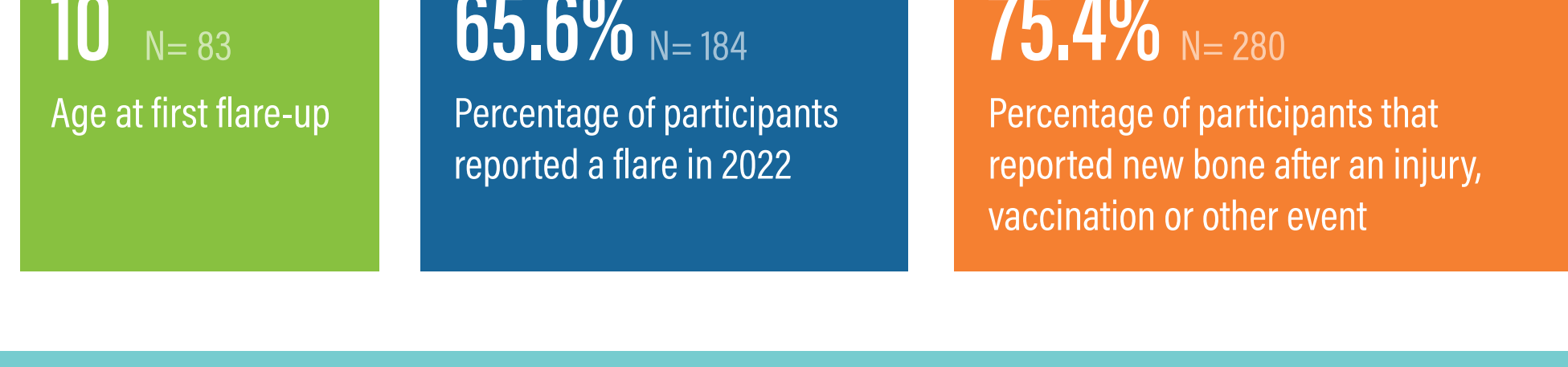
PROMIS stands for Patient-Reported Outcomes Measurement Information System, and it is a global health scale scoring system we use for scoring pain.

On a scale of 1-10, respondents reported...



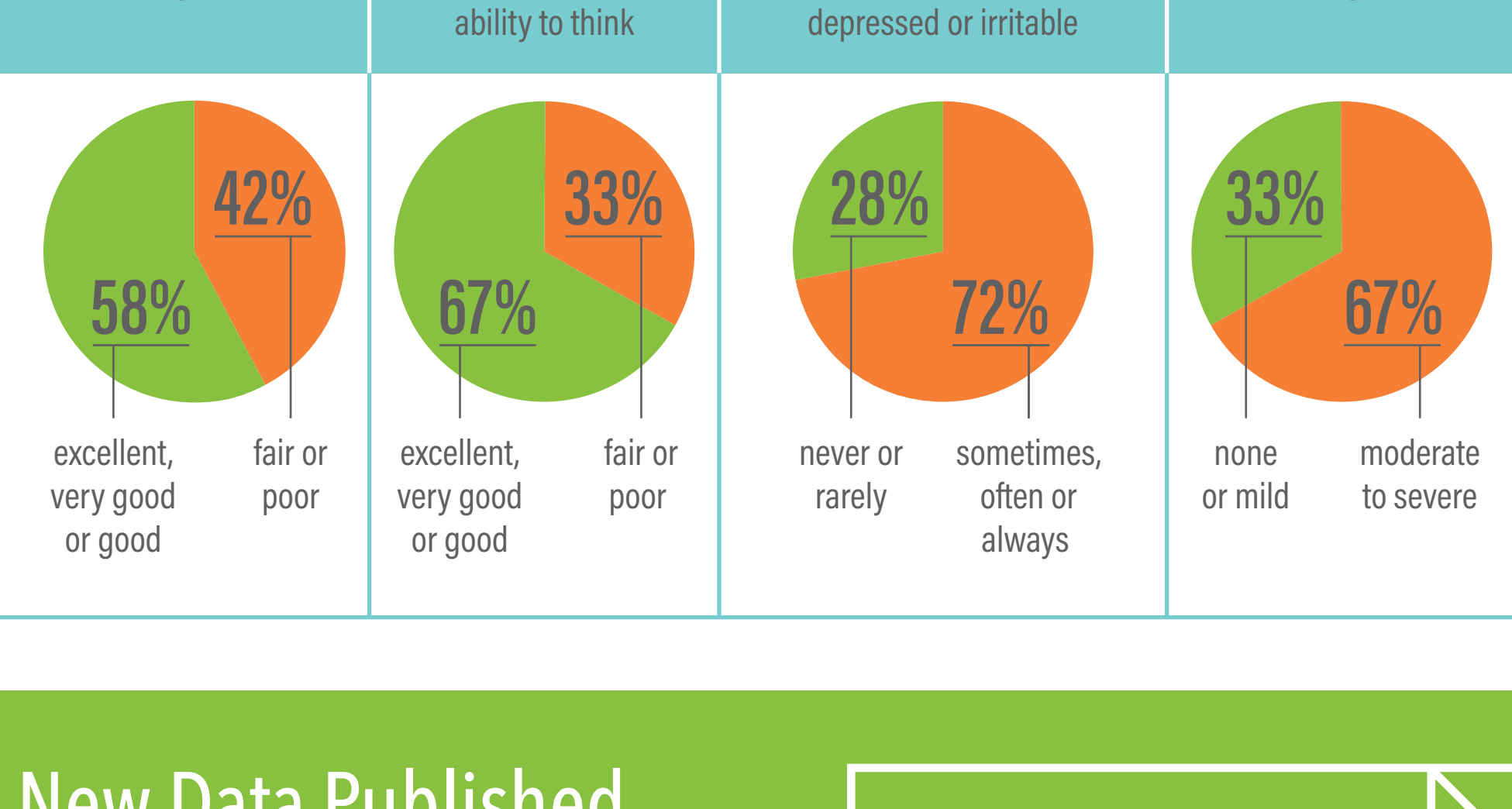
Flare-Up Data

Flares remain a key symptom of FOP. This data remains consistent over the years.



Mental and Emotional Well-Being N=114

Here's a look at how participants view their overall well-being.



New Data Published

Registry data was incorporated into a publication on neuropathic pain in the *Journal of International Association for the Study of Pain*.

ACVR1-Activating Mutation Causes Neuropathic Pain and Sensory Neuron Hyperexcitability in Humans

[Link to article](#)

Thank You to Our Registry Sponsors

Thanks to funding support from our sponsors, the FOP Registry has continued to serve the FOP community.

Visionary Partner: Incyte Pharmaceuticals
Leadership Partner: Regeneron Pharmaceuticals

Collaborating Partners: BioCryst Pharmaceuticals, Ipsen
Sponsor: Keros Therapeutics

The FOP Registry would not be possible without our Medical Advisory Board members, Participant Advisory Board members, and our Registry participants.

Special Thanks To:

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

