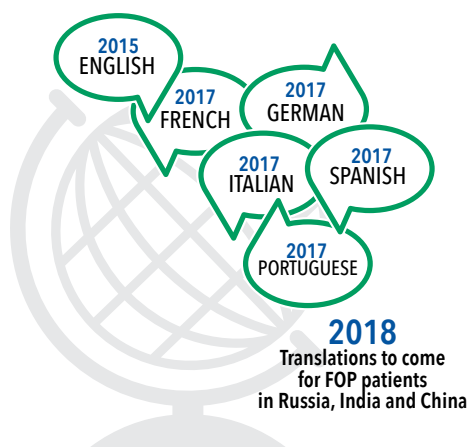
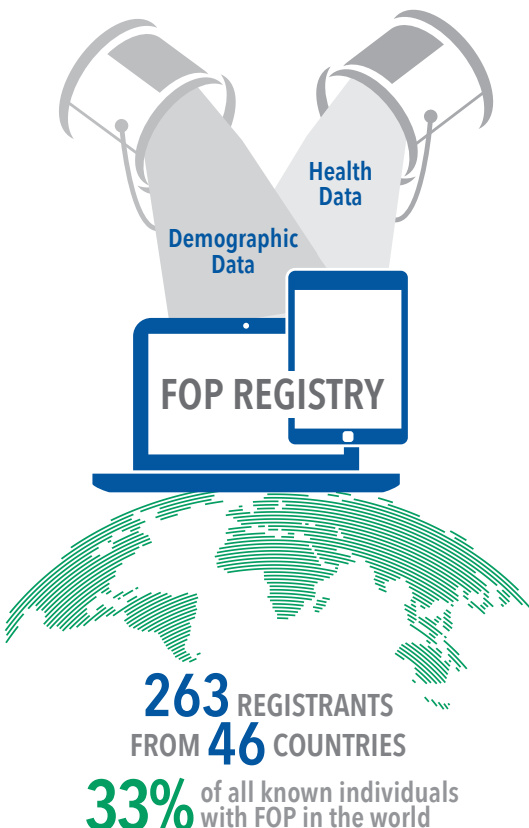


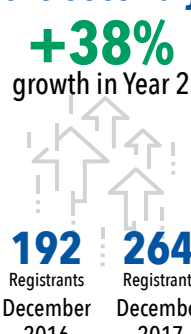
# WORLDWIDE FOP PATIENT REGISTRY Celebrates Two Years of Research

## ABOUT THE FOP REGISTRY

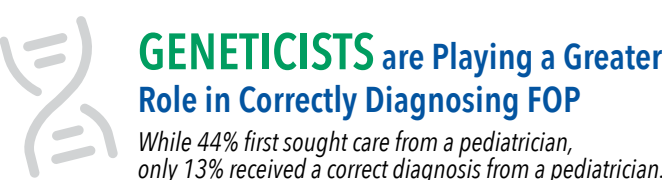
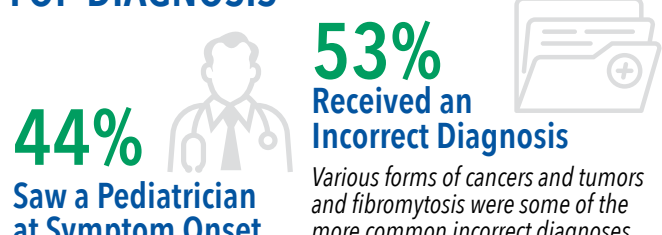
- >> The Registry is an international database that collects demographic and health data from individuals living with FOP worldwide using a secure web-based survey tool. Data is entered by the patient or a caregiver in an initial enrollment survey and six-month follow-up surveys.
- >> The Registry is sponsored by the IFOPA and is open and available to all individuals and families living with FOP worldwide, regardless of whether you consider yourself an "IFOPA member."
- >> Enables FOP patients worldwide to report data on their own disease state in one database, which helps researchers develop more targeted drugs for FOP.



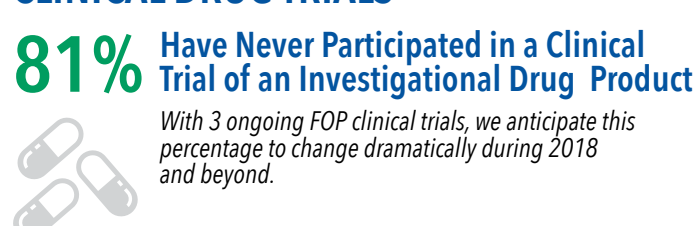
## Registrations GREW in the second year



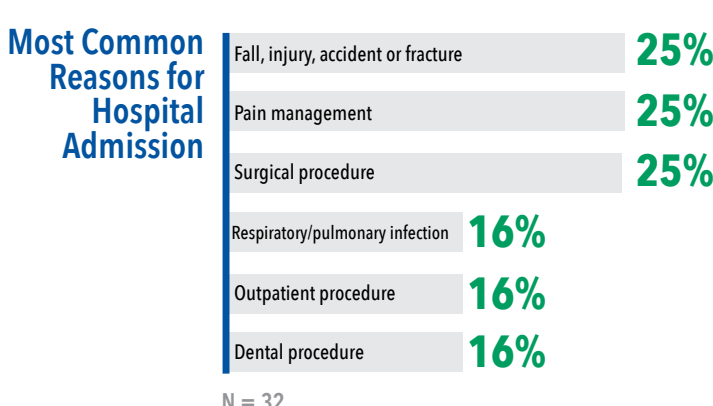
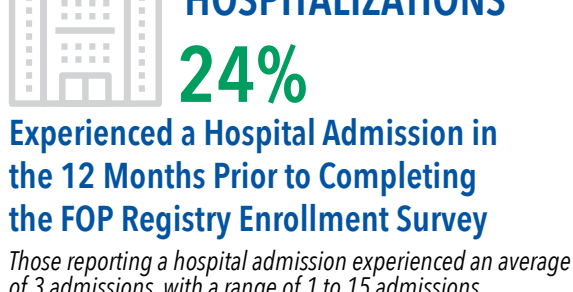
## FOP DIAGNOSIS



## CLINICAL DRUG TRIALS



## HOSPITALIZATIONS

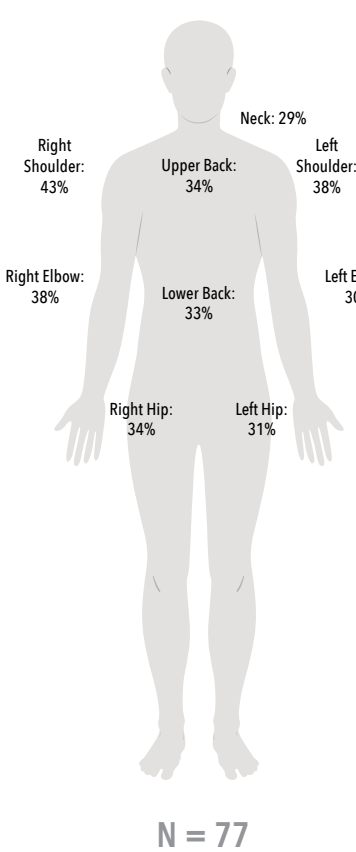


## HEALTH IMPACT OF FOP

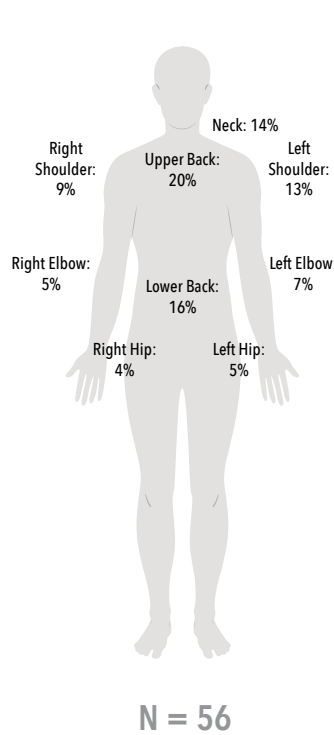
**Most Frequent Loss of Mobility is in the Neck, Upper and Lower Back, Shoulders, Elbows, and Hips**

The differences in total loss of mobility reports between adults and children are most pronounced in the shoulders, elbows, and hips

### ADULTS

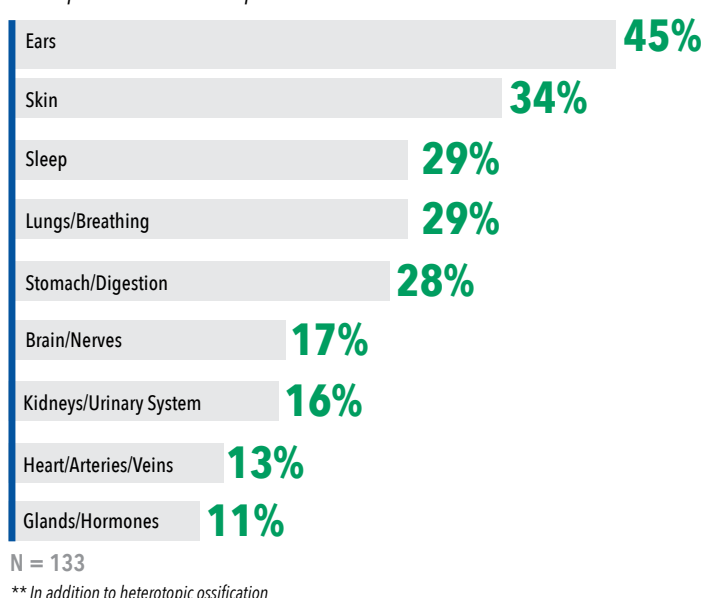


### CHILDREN



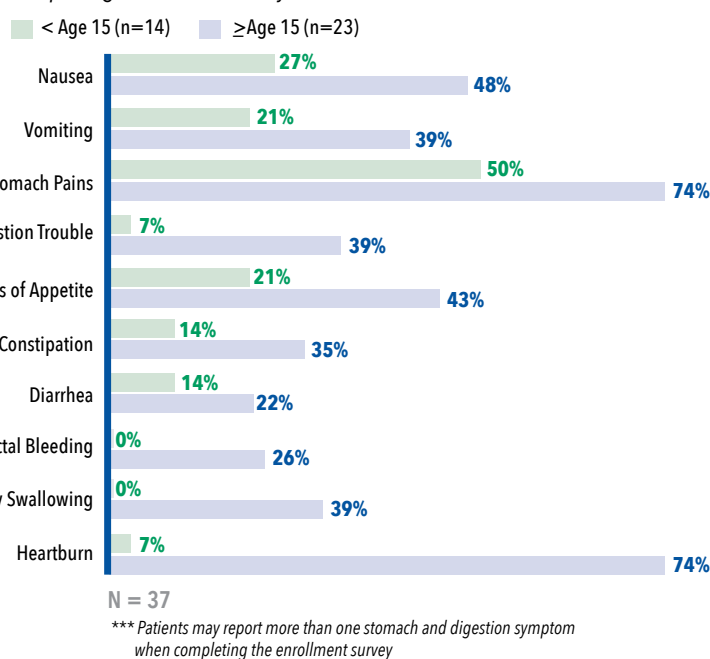
## Symptoms in Other Body Systems May Also Significantly Impact Daily Function and Quality of Life for FOP Patients\*\*

Participants most often reported health issues related to the ears



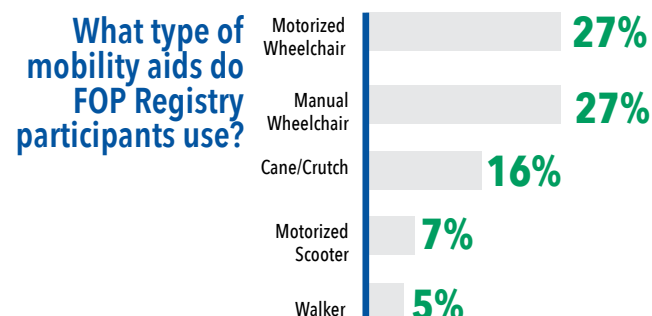
## Patients Experience a Broad Range of Stomach and Digestion Symptoms\*\*\*

Larger proportion of older patients reported symptoms when completing enrollment survey



## 27% Use Motorized and Manual Wheelchairs as the Most Common Mobility Aids\*

Mobility aids may represent a significant financial investment for individuals with FOP and their families.



An IFOPA Quality of L.I.F.E. Award could be used to assist with this expense. More information at [ifopa.org/quality\\_of\\_life\\_award](http://ifopa.org/quality_of_life_award)

## SHARING FOP REGISTRY DATA

### 2017 Highlights on FOP Registry

- Registry presentations at FOP Meetings in Canada, France, Russia and the United States, as well as at the Drug Development Forum in Italy
- Translated the FOP Registry into French, German, Italian, Portuguese and Spanish
- Responded to 6 data requests from FOP researchers providing aggregate Registry data summaries to support their research efforts
- Authored the first peer-reviewed manuscript for a special edition of the journal *Bone* published in September 2017 – *The FOP Connection Registry: Design of an international patient-sponsored registry for fibrodysplasia ossificans progressiva*
- Supported the IFOPA's ongoing collaborations with several biopharmaceutical companies as they work towards developing an effective treatment for FOP

These activities, as well as the ongoing contributions of disease information that every FOP Registry participant made to the Registry, are helping the IFOPA achieve its overarching goal of stewarding one coordinated and shared registry program that will benefit all people living with FOP: clinicians, researchers, regulators, and the bio-pharmaceutical industry.

We would like to acknowledge and show a heartfelt appreciation to our Registry participants and [Medical Advisory Board and Patient Advisory Board members](#) for setting the FOP Registry on trajectory to achieve its critical research mission!