WORLDWIDE FOP PATIENT REGISTRY CELEBRATES TWO YEARS OF RESEARCH

ABOUT THE FOP REGISTRY
35 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 participant in an intelligent interview tool and is sent directly to a secure survey database.
36 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."
37 FOP patients worldwide are eager to take data to their own disease state in one database, which helps researchers develop more targeted drugs for FOP.

GENERICISTS are Playing a Greater Role in Correctly Diagnosing FOP By 44% kids sought care from a hematologist, only 17% received a correct diagnosis from a hematologist.

CLINICAL DRUG TRIALS
81% Have Never Participated in a Clinical Trial of an Investigational Drug Product When 6% of FOP patients could only think of one drug that may be effective for FOP, 81% of FOP Registry participants are open to participating in an Investigational Drug Product Clinical Trial.

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 between adults and children are more pronounced in the shoulders, elbows, and hips.

Symptoms in Other Body Systems May Also Significantly Impact Daily Function and Quality of Life for FOP Patients** Participants of all ages reported symptoms related to the ears, skin, stomach, kidneys, and the respiratory/pulmonary system.

Customers
Article
Mentioned
FOP
27%
7%
N = 77
N = 56
What type of mobility aids do FOP Registry participants use?

FOP DIAGNOSIS
53% Received an Incorrect Diagnosis Between 44% of women and 16% of men were found to have an incorrect diagnosis.

HOSPITALIZATIONS
24% Experienced a Hospital Admission in the 12 Months Prior to Completing the FOP Registry Enrollment Survey Those reporting a hospital admission experienced an average of 2.8 hospitalizations, with a range of 1 to 15 admissions.

SHARING FOP REGISTRY DATA
2017 Highlights on FOP Registry
• Registrations GREW in the second year +38% growth in Year 2
• 264 Registrants from 46 countries (97% of all known individuals with FOP in the world)

These activities, as well as the ongoing contributions of disease information that every FOP Registry participant makes to the Registry, are helping the IFOPA achieve its overarching goal of stewarding participation to the Registry and beyond.

ABOUT THE FOP REGISTRY
• The Registry can be found at fopregistry.org
• Registrants can be found at fopregistry.org
• 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."
• 100% of all coordinated and shared registry program that will benefit all people living with FOP: clinicians, researchers, 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!