FOP DIAGNOSIS

44% Saw a Pediatrician at Symptom Onset

53% Received an Incorrect Diagnosis

GENETICISTS are Playing a Greater Role in Correctly Diagnosing FOP

CLINICAL DRUG TRIALS

81% Have Never Participated in a Clinical Trial of an Investigational Drug Product

HOSPITALIZATIONS

24% Experienced a Hospital Admission in the 12 Months Prior to Completing the FOP Registry Enrollment Survey

Saw a Pediatrician
44%

First sought care from a pediatrician
44%

GENETICISTS saw the patient
20%

GENETICISTS werePlaying a Greater Role in Correctly Diagnosing FOP

Most Common Reasons for Hospital Admission

Acute respiratory infection
25%

Chronic respiratory condition
25%

Diabetic-related condition
16%

Infectious disease
16%

Surgery
16%

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

FOP REGISTRY

263 REGISTRANTS FROM 46 COUNTRIES

33% of all known individuals with FOP in the world

2017 Highlights on FOP Registry

Registration prevalence at FOP Meetings in Canada, France, Thailand and the United States, as well as at the Drug Development Forums in Italy

Translated the FOP Registry into French, German, Italian, Portuguese and Spanish

Prepared to do data requests from FOP researchers providing aggregate Registry data summaries to support their research efforts

An IFOPA Quality of Life Award could be used to assist with this expense.

More information at ifopa.org/quality_of_life_award

FOP REGISTRY

Celebrates Two Years of Research

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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 in conjunction with a related medical professional and is stored and analyzed for survey purposes.

The Registry is supported by the IFOPA and is open and available to all individuals and families living with FOP worldwide, regardless of whether you consider yourself a “member.”

The Registry provides a way for patients worldwide to report data on their own disease status in one database, which helps researchers develop more targeted drugs for FOP.

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