

THE GLOBAL FOP POPULATION PROJECT

Established within the IFOPA to describe the population of our known international FOP community, comprising the net of FOP patients and families connected either by themselves or through FOP national leaders/organizations. A major goal of the project is to have reliable and updated data about the number of FOP patients along with a set of demographic information which also allows avoidance of duplicated cases. Encoded data collected by the IFOPA and national leaders among other sources, is aggregated at the global level and processed.

Along with the IFOPA, International President's Council members taking part of this project are: Fundación FOP (Argentina); FOP Brazil; Canadian FOP Network, South African FOP Association; AEFOP (Spain), FOP Italia, Friends of FOP (UK), FOP Stichting Nederland, FOP Skandinaviska, Russian FOP Community, FOP Australia, Poland, Serbia, China and Malaysia. Outcomes are presented at three levels: i) global description of the universe of known FOP cases; ii) regional, to show the distribution of FOP cases and prevalence; iii) country, showing and example of those countries for which FOP prevalence is higher than the theoretical one of 1:2,000,000 people.

GLOBAL LEVEL

TOTAL RESULTS¹

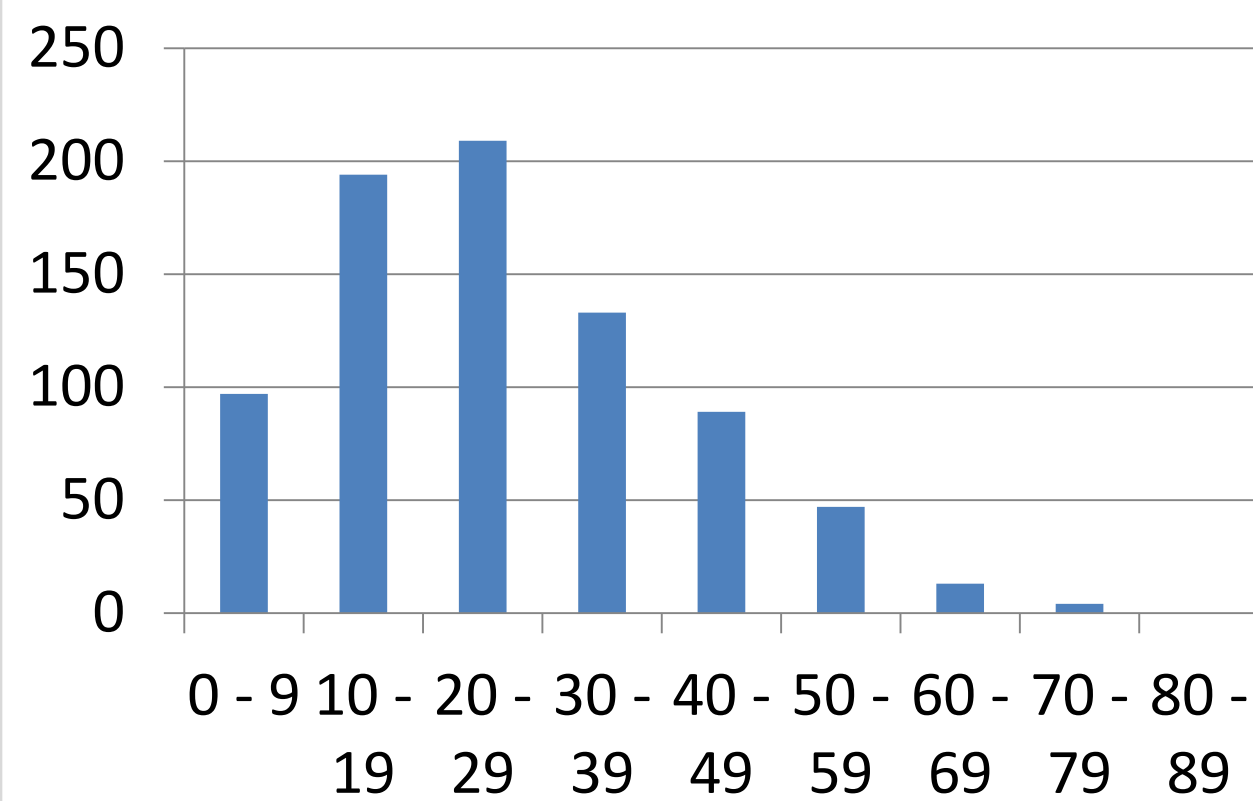
Number of countries: 67 (colored in the map) Number of data providers: 18
Number of FOP cases: 1072²

Number of living FOP cases: 834 Number of deceased FOP cases: 147
No data about living or deceased: 91

LIVING POPULATION

Total female: 445 (53%)
Total male: 387 (47%)
No data: 2

LIVING AGE GROUPS

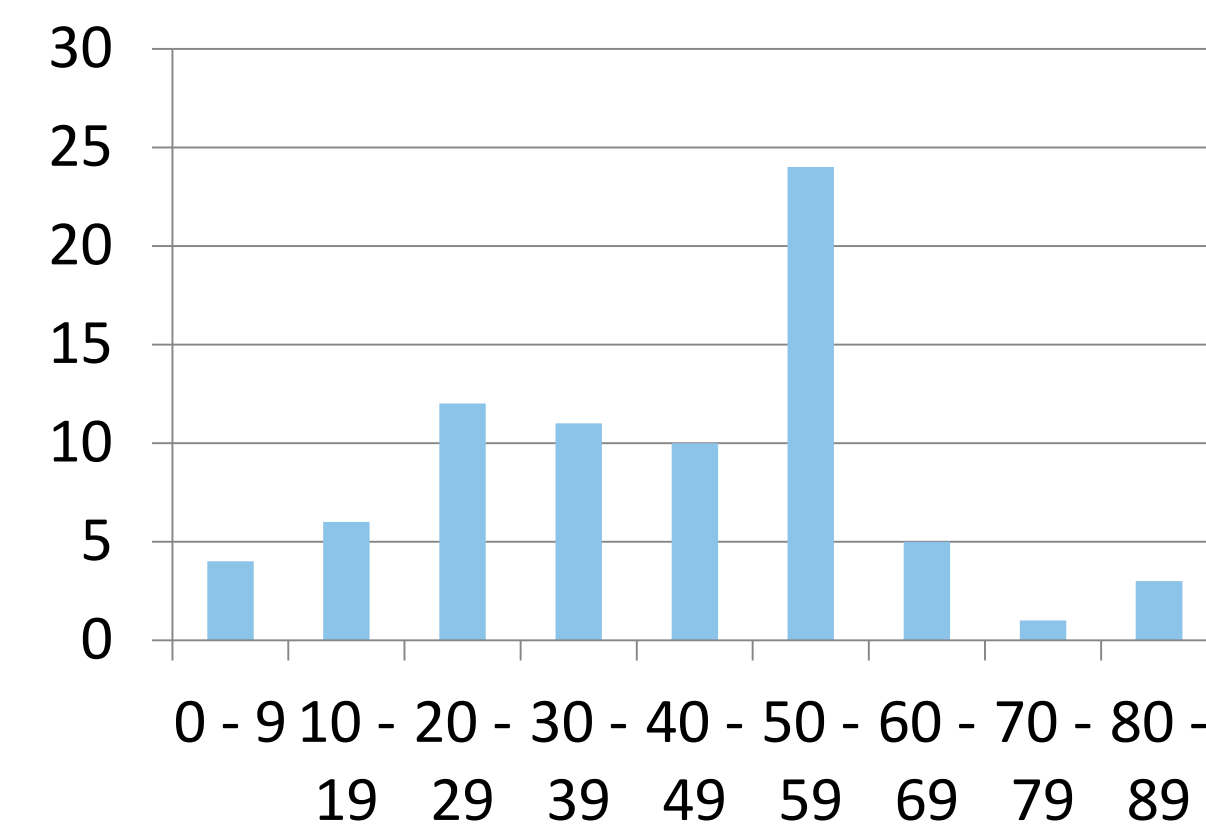


The 60 % of the known international FOP population is in the range between 0 to 29 years old. The 34% is in the range of 30 to 79 years old, and for the 6% remaining there is no data.

DECEASED POPULATION

Total female: 69 (47%)
Total male: 74 (50%)
No data: 4 (2%)

DECEASED AGE GROUPS



Median age of life: 44 years old
Average age of life: 41 years old
Quartile 25: 26 years old
Quartile 75: 56 years old

The smaller number of FOP patients within the interval of 0 to 9 years old could be read as an underreporting due to late onset of FOP acute symptoms, delayed diagnosis, and /or delay reaching the international FOP community.

¹Updated June-September 2016

²Comprise by patients with FOP diagnosis that are connected with the FOP community either directly or through national FOP leaders

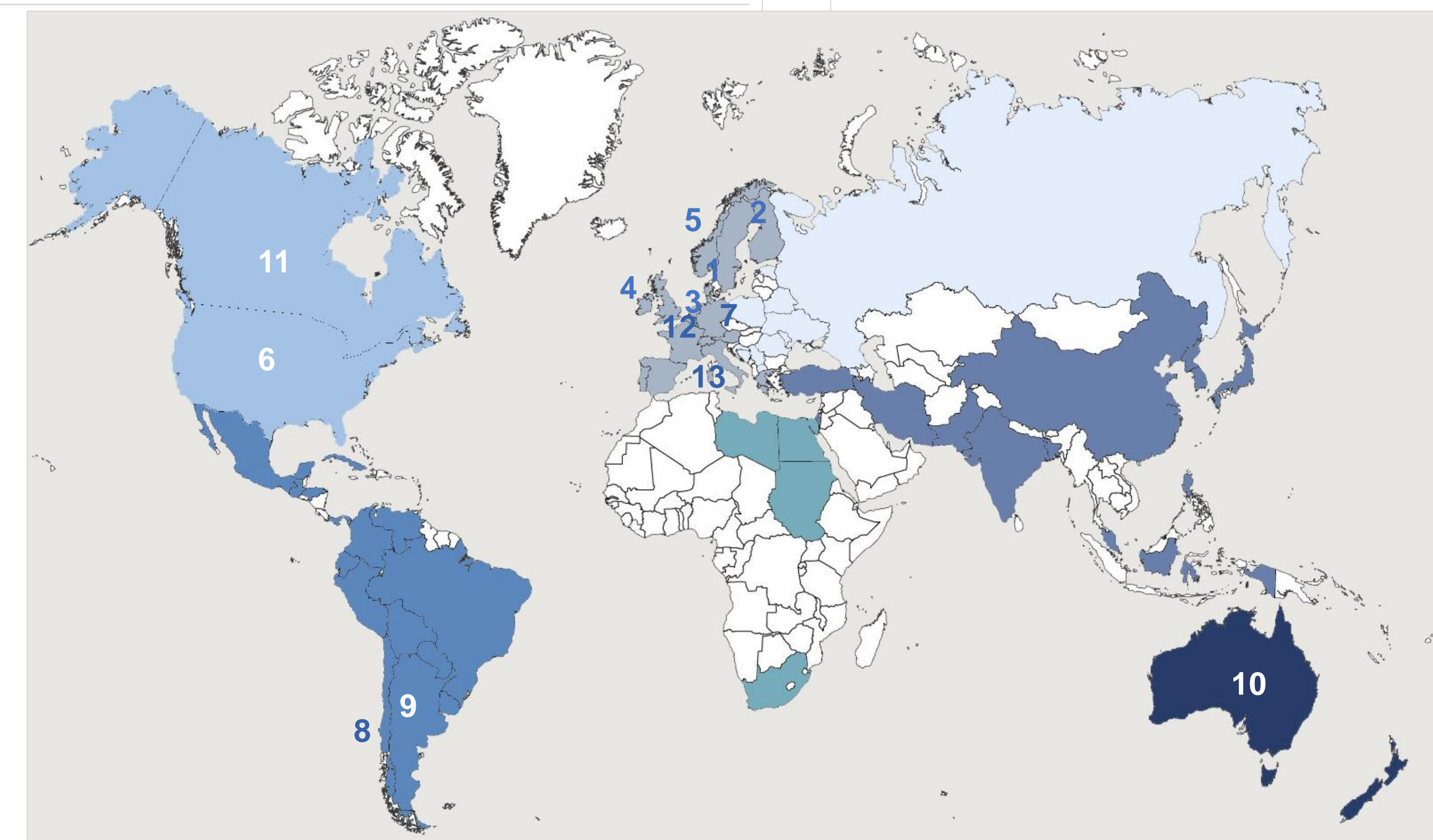
³Estimated based on 2015 population data worldbank.org rounded to tens of thousands

⁴Countries where prevalence might be higher as there are FOP lost cases for which there is no updated information.

REGIONAL LEVEL

NUMBER OF FOP PATIENTS PER REGION AND PREVALENCES

Region	Number of countries	Total living FOP cases	Prevalence
North America	2	231	1:3,620,000
Latin America	15	161	1:3,620,000
West Europa	17	198	1:1,580,000
East Europa	13	86	1:3,320,000
Africa	4	10	1:19,210,000
Asia	14	133	1:27,920,000
Oceania	2	15	1:1,890,000



71% of known and connected FOP cases worldwide are in the Americas and West Europe. Early developed health systems that help to achieve FOP diagnosis along with active FOP community leaders who search for patients, seem to be major factors for showing higher ratios of FOP patients.

COUNTRY LEVEL

PREVALENCE IN GROUP OF COUNTRIES HIGHER THAN 1:2,000,000³

Countries	FOP prevalence
1 Sweden	1:700,000
2 Finland	1:910,000
3 Denmark	1:1,140,000
4 UK	1:1,140,000
5 Norway	1:1,300,000
6 USA ⁴	1:1,520,000
7 Poland	1:1,580,000
8 Chile ⁴	1:1,630,000
9 Argentina ⁴	1:1,670,000
10 Australia ⁴	1:1,700,000
11 Canada ⁴	1:1,790,000
12 Netherlands	1:1,880,000
13 Italy	1:1,900,000

In addition, several countries that meet one or both mentioned issues have FOP prevalences from 1:700,000 to 1:1,900,000. This data suggests that FOP prevalence might be higher than the theoretical 1:2,000,000. Based on the West European, North America and the US prevalence, and that there maybe more FOP patients that we don't know, FOP prevalence might be 1:1,500,000 or higher.