

Poland Syndrome Community Register



Pulse Infotrame collaborated with PIP- UK to create a patient registry for Poland Syndrome. We reached our goal of 100 participants across 13 countries in only 21 days!

PATIENT COMMUNITY INSIGHTS

Age Of Diagnosis



- Half of participants who responded were diagnosed between ages 0-10
- 64% diagnosed before age 21



Specialists Making Diagnoses



- Pediatricians and Surgeons each make 35% of the diagnoses
- General Practitioners, Specialists and Geneticists account for the remaining 30% of participants

Most Common Symptoms



- Most common symptom participants reported was an underdeveloped right pectoral muscle (28%)
- The 2nd most common symptom was a lack of fatty tissue below the skin (18% Left and 12% Right)



- 80% of respondents provided complete medical history
- 70% of respondents are based in the U.K

Register Objective

This patient register has been established to understand the natural history of Poland Syndrome, characterize symptom presentation and diagnosis, as well as to better understand treatments and their outcomes

Learn More:

PIP Foundation: www.pip-uk.org

Pulse Infotrame: www.pulseinfotrame.com/