

Patient Perspective

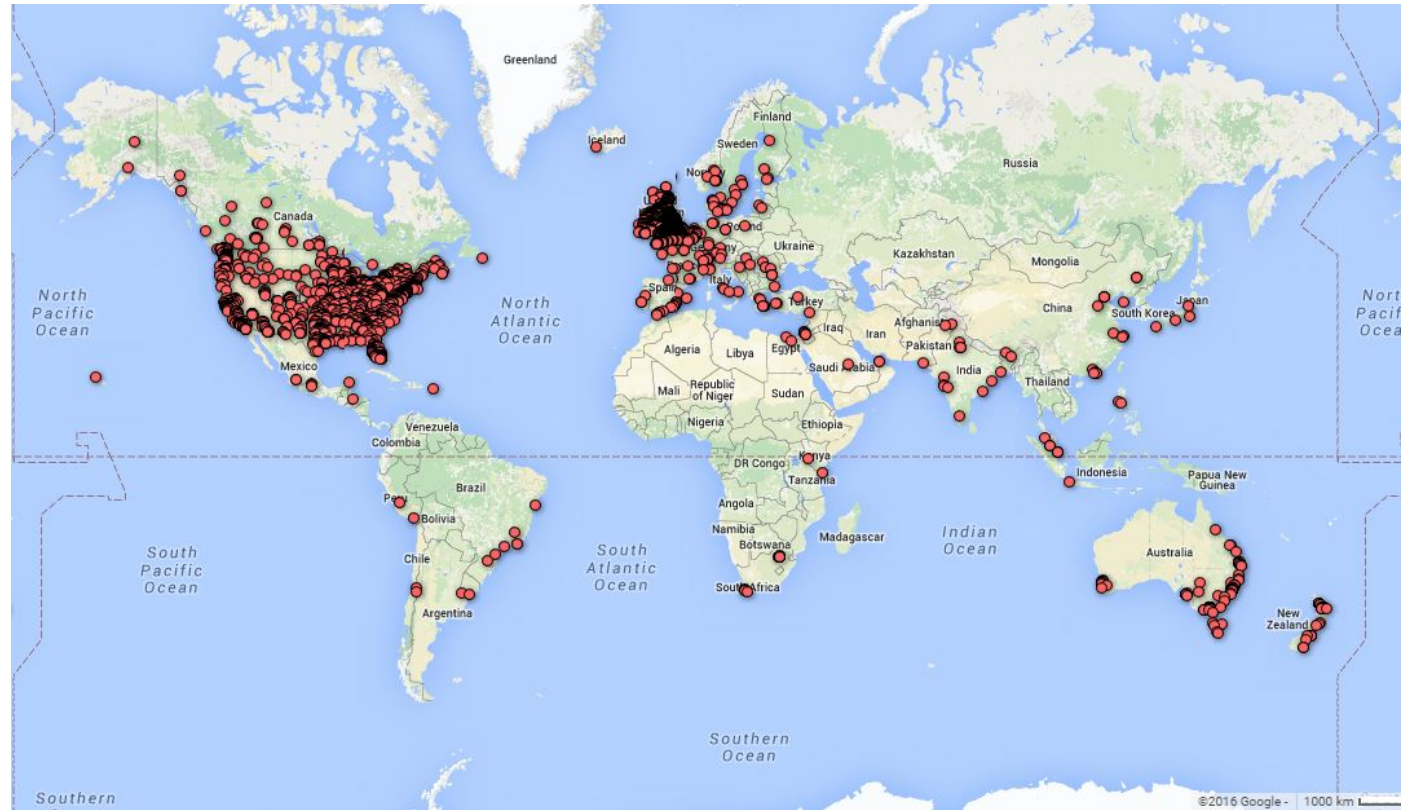
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PBC Foundation



PBC Foundation

- 13,000 patients registered
- 76 countries
- 19 languages on website
- 9 languages on app



Patient Voice

- Volunteer Network
- RSU surveys
- Face-to-face consultations
- Helpline calls

Patient Priorities: Urso

- Urso is good, is it good enough?
- Symptom management
- Response risk: age, sex, time of diagnosis in PBC journey
- 6/12 month wait for response confirmation

Patient Priorities: Histology

- “Stage 2 PBC”
- Histology not compulsory
- If histology **is to be** measured, side by side validity study incorporated

Patient Priorities: Unmet Need

- AIH/Overlap Syndrome
- Cure
- Symptom Management
- Itch
- Fatigue

Patient Priorities: Taking Part

- Obstacles
 - Travel ~10%
 - Biopsy ~1%
- Incentives
 - Cure ~19%
 - Symptoms ~ 22%

Patient survey 2017 n=1089
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