

Berkeley



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Working Group Update PSC Patient Databases

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Mission of Working Group

- Locate and define purpose of each of the existing PSC patient databases
- Highlight strengths of each registry
- Determine gaps in information
- Identify other fields that should be included in the PSC databases



European National Registries

- Dutch PSC – prospective (C. Ponsioen)
- UK-PSC – prospective (G. Hirschfield)



Rare Disease Registry - Europe

- European Reference Network (ERN) – all rare diseases in EU – prospective
 - Rare-Liver (branch of ERN) - includes PSC (C. Schramm)



International Registries

- International PSC Study Group (IPSCSG) – retrospective, largest PSC database (Tom Karlsen, Norway)
- Mayo Clinic, PROGRESS (PSC Resource Of Genetic Risk Environment & Synergy Studies) – prospective, multicenter (K. Lazaridis)



North American PSC Registries

- North American PSC Registry - in planning stages - retrospective and prospective components (C. Bowlus, D. Assis)
- Pediatric PSC Registry - retrospective (M. Deneau)
- Canadian PSC Registry – new - prospective (B. Eksteen)



Patient-Driven Registry

- PSC Partners Patient Registry
 - Created in collaboration with NIH
 - IRB reviewed, HIPAA compliant, proof of diagnosis required
 - Retrospective to date, currently longitudinal





Advantages of Patient-Driven PSC Partners Patient Registry

- Flexibility – multi-purpose
- Easy access to community of participants
- Availability to patients outside specialized centers
- No national and institutional boundaries
- Can complement academic research
- Advocacy tool for unmet needs





Next Steps

- Identifying criteria to investigate each database
- Creating a webpage of PSC databases



Thank You!

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