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Public Health



FORUM
for Collaborative
RESEARCH

Call to Action for a PSC-Specific ICD-10 Code

An urgent need for PSC research

Ricky Safer

CEO – PSC Partners Seeking a Cure

www.forumresearch.org



Letter of Request to the CDC

“As a practicing hepatologist in an academic center specializing in this disease, I have experienced the frustrations attempting to handle administrative data related to PSC and have no doubts that these frustrations are shared by other investigators in this field. PSC is a rare disease with many challenges to overcome, but a simple change in coding would remove many barriers we have to understanding the epidemiology, natural history, and practice patterns related to PSC.”

Chris Bowlus



Rationale for Needing a PSC-Specific Code

- To facilitate robust epidemiological and natural history studies
- To select the correct cohort of patients
- To enable early and better identification and assessment of therapeutic outcomes
- To obtain better information on comorbidities and adverse effects
- To bring to light the multifactorial nature of PSC and to identify the burdens on patients



Progress to Date

- Proposal submission by PSC Partners to the ICD Coordination and Maintenance Committee
- Input and guidance from Chris Bowlus and Gideon Hirschfield
- Invited to testify at the September 13th meeting – video online
- Comment period until November 13th



Call to Action

Request for Comment Letters from Medical Professionals

- Briefly focus on reasons for your support for a specific PSC code: K83.01
- Topics to avoid:
 - PBC and possible confusion with PSC
 - PSC sub-codes
- Send letters by November 13th to Donna Pickett at the CDC
Nchsicd10cm@cdc.gov



**Thank you for your support.
Your comments really do
make a difference!**