



Patient Registry 2016 Conference

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Video From the FDA PSC Workshop is Now Available to Stream Online

The FDA hosted a PSC Workshop on March 3rd - 4th, 2016, in Silver Spring, Maryland. The topic of the conference was Trial Design and Endpoints for Clinical Trial in Adults and Children with Primary Sclerosing Cholangitis. The FDA workshop was also sponsored by AASLD, ACG, AGA and NASPGHAN.

Video of the workshop is now available to stream online. If you were unable to attend the workshop in person, or missed part of the live webcast, there are two ways to view the material. [The AASLD website](#) has posted the entire workshop in separate segments, which is easier to navigate, whereas [the FDA website](#) allows viewers to stream the workshop in its entirety.

Presentations explaining the patient perspective were made by Ricky Safer, CEO of PSC Partners, and Martine Walmsley, Chair of PSC Support in the UK, and can be found in Session III: Patient Experience. The workshop demonstrates the dynamic state of PSC research: as collaboration increases among stakeholders who search for a cure for PSC, the patient voice is more important now than ever before.

Important Considerations for PSC Patients to Keep In Mind Before Enrolling in a Clinical

Study

Clinical trials are an essential component in the fight to find better treatments and a cure for PSC. While it is very exciting to have more trials for PSC patients to participate in, it is very important for patients to carefully assess whether a specific clinical trial is appropriate for them or not. There is a lot for each patient to evaluate in this process; thankfully, Dr. Chris Bowlus, Co-Chair of our Scientific/Medical Advisory Committee, has prepared an article that presents some of the criteria to consider when evaluating participation in a clinical trial. Please visit our website for [the complete article](#) and to [learn more about clinical trials](#).

Important Video: Best of Cholestatic and Autoimmune Liver Diseases at the 2016 International Liver Congress.

Find out the latest in autoimmune and cholestatic liver disease research and patient management by watching Giorgina Mieli-Vergani and Diego Vergani, professors at King's College London, in debriefing the best of these topics at the 2016 International Liver Congress. Click [HERE](#) to access the video on the EASL website. You will need to register for an account with your contact information in order to view the video. You may need to click on "DESCRIPTION" to view the video. It is worth watching the whole 24 minute video because it places PSC within the context of three other biliary diseases. The actual discussion of PSC appears in the second half of the video.

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