Women's Health: PSC & IBD

Presenter: Whitney Jackson, MD, UCHealth

For women living with PSC, questions about contraception, family planning, and menopause can feel complex and overwhelming. In a recent session at the PSC Partners conference, Dr. Whitney Jackson, a transplant hepatologist at UC Health, offered a reassuring and practical guide to navigating these critical life stages. Using a case-based approach, Dr. Jackson demystified common concerns, emphasizing that with careful planning and open communication with a medical team, most women with PSC can lead full lives and have healthy families. The core message was one of empowerment: understanding your specific situation allows you to make informed, safe choices for your body and your future.

Contraception: Making Safe Choices

A common question is whether hormonal birth control is safe for people with liver disease. Dr. Jackson clarified that for most women with PSC who do not have cirrhosis, both estrogen and progesterone are generally safe.

However, there are important exceptions. Estrogen-containing products—like many combination pills—should be avoided by those with specific conditions such as decompensated cirrhosis, Budd-Chiari syndrome, or hepatic adenomas.

Fortunately, there are many excellent and safe alternatives. Progesterone-only birth control options are safe for all liver diseases. These include pills, injections, and intrauterine devices (IUDs). The copper IUD is another highly effective choice, as it contains no hormones at all. In fact, IUDs and hormonal implants are the most effective forms of birth control, with pregnancy rates of less than 1%. It is also important to note that emergency contraception is considered safe for all types of liver disease.

Planning a Healthy Pregnancy

Many patients with PSC have healthy children and healthy pregnancies. The key to success is proactive planning with your hepatologist and a maternal-fetal medicine (MFM) specialist, who is an expert in higher-risk pregnancies.

Here are some key takeaways on pregnancy with PSC:



- Fertility and PSC: For both men and women, PSC itself does not typically affect fertility.
 The primary exception is in cases of advanced PSC with cirrhosis, where hormonal changes can make conception more difficult and higher risk.
- Pregnancy's effect on PSC: In general, pregnancy does not worsen PSC, and most
 patients have stable labs throughout. The most common issue that may arise is
 worsening itch (pruritus), which occurred in about a third of patients in one small study.
 Thankfully, most itching medications, including Ursodiol, are safe to use during
 pregnancy.
- Pregnancy outcomes: Overall outcomes for mothers and babies are excellent. There is
 no increased risk for major maternal complications, stillbirths, or birth defects. There is a
 slight possibility of pre-term delivery or a C-section, but a C-section is not required simply
 because you have PSC.
- Inheritance: PSC is not caused by a single gene and cannot be passed directly to a child in the way some genetic disorders are. While some genetic risk factors for autoimmune diseases may be inherited, there is no direct heritability for PSC itself.

Special Considerations: Cirrhosis and Post-Transplant

The conversation becomes more nuanced for those with cirrhosis or who have had a liver transplant.

For women with PSC-related cirrhosis, pregnancy carries a higher risk. The level of risk is directly related to the severity of the cirrhosis, often measured by a MELD score, and the presence of portal hypertension. To minimize risks like variceal bleeding, doctors will typically perform an upper endoscopy during the second trimester to check for enlarged blood vessels. This is not to say pregnancy is impossible, but it requires meticulous planning and management with your medical team.

For post-transplant patients, fertility can return very quickly. Because of this, the most critical piece of advice from Dr. Jackson is to avoid pregnancy for the first year after a liver transplant. The risk of organ rejection is significantly higher if pregnancy occurs within that first year (46% vs. 11% after the first year). Effective contraception is essential, especially because mycophenolate—a common anti-rejection drug associated with birth defects—is often used during this period. After the one-year mark, and with stable liver function, and after transitioning to safe immunosuppression regimen for fetal development, pregnancy outcomes are excellent for over 75% of liver transplant recipients.



Questions from the Community

The session wrapped up with questions addressing other areas of women's health.

A question was raised about menopause and PSC. Dr. Jackson noted that bone density is a key concern, as cholestasis (impaired bile flow) can affect the absorption of fat-soluble vitamins like Vitamin D, which is crucial for bone health. She recommended that PSC patients have their bone density screened. Regarding hormone replacement therapy (HRT), she explained that for women without cirrhosis, low-dose options like a transdermal patch are likely safe and can significantly improve quality of life.

Finally, an attendee shared her story of being diagnosed with PSC after a pregnancy, wondering if the two were linked. Dr. Jackson acknowledged that this was possible, explaining that pregnancy creates an "immune-tolerant" state in the body, and the rebound of the immune system postpartum could theoretically trigger or unmask an autoimmune condition like PSC.

