

House Bill 537 – Proponent Testimony Ohio Senate Health Committee Bassam Estfan, M.D. & Alok Khorana, M.D. Taussig Cancer Institute, Cleveland Clinic

Chair Huffman, Vice Chair Antani, Ranking Member Antonio, and members of the Ohio Senate Health Committee, thank you for the opportunity for Cleveland Clinic to provide proponent testimony for House Bill 537, which would designate February 12 as Cholangiocarcinoma Awareness Day in the state of Ohio. Our names are Bassam Estfan and Alok Khorana, and we are oncologists at the Taussig Cancer Institute at the Cleveland Clinic.

Cleveland Clinic Cancer Center provides complete cancer care enhanced by internationallyrecognized research efforts, offering the most effective techniques to achieve long-term survival and improve patients' quality of life. More than 700 physicians, researchers, nurses and technicians care for thousands of patients each year, providing access to a wide range of clinical trials as well as support programs to help patients navigate the challenges associated with a cancer diagnosis. Cleveland Clinic Cancer Center unites clinicians and researchers based in Taussig Cancer Institute and in Cleveland Clinic's 25 other clinical and special expertise institutes, as well as cancer specialists at our regional hospitals and health centers.

At Cleveland Clinic, we provide care for patients with a rare form of cancer known as cholangiocarcinoma, which is a cancer that starts in your bile ducts. Bile ducts are thin tubes that bring bile (a fluid that helps you digest food) from your liver and gallbladder to your small intestine. Most people receive a cholangiocarcinoma diagnosis after the cancer has already spread outside of their bile ducts. The chance of recovery is usually poor. The five-year survival rate for bile duct cancer that hasn't spread outside of the bile ducts is 10% to 15%. This rate drops to 2% if the cancer spreads to areas of the body that are far from the bile ducts, such as the lungs. However, a growing number of targeted therapies and clinical trials are starting to change that, meaning these rates will improve over time.

Cholangiocarcinoma is difficult to cure, and many cases are sporadic with no identifiable etiology or cause. This is why House Bill 537 is so important: creating Cholangiocarcinoma Awareness Day will educate Ohioans about this rare cancer, which about 8,000 people in the U.S. will develop each year.

Experts don't know exactly what causes cholangiocarcinoma. Risk factors include bile duct stones or cysts, chronic ulcerative colitis, cirrhosis of the liver, Hepatitis B or C, HIV, inflammatory bowel disease, non-alcoholic fatty liver disease, abnormalities where the bile duct and the pancreatic duct meet, alcohol and tobacco use, diabetes, exposure to toxins, and obesity. These risk factors suggest that health conditions that cause chronic inflammation in the bile ducts may play a role in the development of this cancer. In the United States, Hispanic Americans are at a higher risk of cholangiocarcinoma, and it is most common in older people around age 70.

There are three types of cholangiocarcinoma: extrahepatic (bile duct cancer outside the liver), intrahepatic (bile duct cancer inside the liver), and gallbladder cancer (which is cholangiocarcinoma that starts in the gallbladder). A subset within extrahepatic cholangiocarcinoma is hilar cholangiocarcinoma, meaning a bile duct cancer that is outside the

Cleveland Clinic

liver, but starts in the hilum, which is the area where the bile ducts and important blood vessels connect with the liver.

Symptoms of this cancer include: abdominal pain, dark urine, fever, itchy skin, jaundice, lightcolored stool, nausea and vomiting, and unexplained weight loss. As healthcare providers, we evaluate symptoms, review medical history and perform tests in order to reach a diagnosis. Treatment depends on the location of the cancer and if it has spread. Surgery can treat early bile duct cancers that haven't spread. But most bile duct cancers have spread by the time they're diagnosed.

The designation of Cholangiocarcinoma Awareness Day will bring statewide attention to this disease. Again, Cleveland Clinic supports House Bill 537 and urges the committee to be supportive as well. We thank the sponsor, Rep. Abrams, for introducing this important bill. Thank you, and we can be contacted with any questions you may have.