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HOUSE RESOLUTION

2           WHEREAS, The National Institutes of Health reports that an  
3           estimated 50,000 to 100,000 people in the United States have  
4           primary biliary cholangitis (PBC), a chronic progressive liver  
5           disease in which the bile ducts become inflamed and damaged;  
6           and

7           WHEREAS, PBC is a rare, chronic autoimmune liver condition  
8           in which the small ducts in the liver are inflamed and damaged,  
9           causing bile and toxins to build up and cause problems,  
10          including scarring, cirrhosis (scarring and poor liver  
11          function), and eventual liver failure; the disease has no  
12          cure; and

13          WHEREAS, PBC is more common in women, and researchers  
14          estimate that in the U.S. approximately 65 out of every  
15          100,000 women have PBC; and

16          WHEREAS, Many people do not have symptoms when they are  
17          first diagnosed and may not develop symptoms for several  
18          years; early symptoms may include fatigue or lethargy, which  
19          is the most common symptom, itchy skin (pruitus), dry  
20          eyes/mouth, and abdominal pain; and

21          WHEREAS, More people are being diagnosed with PBC,

1 impacting people of varied ages, gender, race and ethnicity;  
2 those living with PBC share common symptoms, including  
3 debilitating fatigue and incessant itching or skin-crawling  
4 sensations that is made worse at night; and

5 WHEREAS, A GI specialist can screen a patient for primary  
6 biliary cholangitis by checking certain indicators in the  
7 blood that determine how well the liver is functioning;  
8 elevated quantities of the enzyme alkaline phosphatase (ALP)  
9 and AMA's (antimitochondrial antibodies) in the blood stream  
10 could point to PBC; diagnostic imaging tests could also be  
11 conducted to get a closer look at the bile ducts and the liver  
12 to screen for signs of scarring; and

13 WHEREAS, There is no cure for PBC, but treatment can help  
14 delay the condition's progression and manage complications; a  
15 liver transplant may be required in severe cases; in addition  
16 to the most common symptoms of fatigue and itchy skin, other  
17 symptoms may include darkening of the skin, small yellow or  
18 white bumps under the skin or around the eyes, and bone,  
19 muscle, and joint pain; as the disease progresses, symptoms of  
20 cirrhosis can develop, including jaundice, swelling of the  
21 legs and feet (edema), enlarged abdomen from fluid  
22 accumulation (ascites), or internal bleeding in the upper  
23 stomach and esophagus from enlarged veins (varices); and

1           WHEREAS, People living with PBC have been waiting for  
2 treatment advancements for many years; the Orphan Drug Act has  
3 encouraged and promoted the discovery and development of  
4 biopharmaceuticals designed to treat and potentially cure rare  
5 diseases; and

6           WHEREAS, Many of the world's leading academic  
7 institutions, academic medical centers, biotech companies, and  
8 pharmaceutical companies that are conducting research and  
9 seeking cures for rare diseases are doing so in this State;  
10 therefore, be it

11           RESOLVED, BY THE HOUSE OF REPRESENTATIVES OF THE ONE  
12 HUNDRED THIRD GENERAL ASSEMBLY OF THE STATE OF ILLINOIS, that  
13 we declare September 2024 as PBC Awareness Month and September  
14 8, 2024 as PBC Day in the State of Illinois in order to raise  
15 awareness of primary biliary cholangitis (PBC) and provide an  
16 opportunity for patient organizations to help connect  
17 individuals and families who struggle with PBC, bring  
18 attention to the need for research and funding to support the  
19 discovery and development of therapies designed to treat and  
20 potentially cure PBC, and support the continued work of the  
21 Friends of the PBC Foundation; and be it further

22           RESOLVED, That suitable copies of this resolution be  
23 presented to the Illinois Biotechnology Innovation

1 Organization (iBIO), the chairperson of the Illinois Rare  
2 Disease Commission, and the Illinois Department of Public  
3 Health.