



Your Liver. Your Life.

Primary Biliary Cholangitis (PBC) Resources

PBC is a chronic liver disease caused by damage of the bile ducts in the liver

- The most common symptoms include fatigue and itching of the skin
 - Women consist of 90% of PBC cases
 - Most diagnosed cases occur during the ages of 35-60
 - There appears to be a genetic component
 - There is no cure for PBC, however treatments are available for symptoms and disease progression
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Interested in learning more about PBC?

Visit the following resources,

PBC Facebook Support Group

Live facebook discussions and chats occur every Wednesday from 9am -10am & 7pm – 8pm

<https://www.facebook.com/groups/1881641552083412/>

PBC Overview Webinar by Dr. Sonali Paul, University of Chicago

[https://www.youtube.com/watch?v=8Wr3k9nJ -Y&t=3s](https://www.youtube.com/watch?v=8Wr3k9nJ-Y&t=3s)

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<http://www.liverfoundation.org/chapters/illinois/>

<http://www.liverfoundation.org/chapters/missouri/>

Meet Donna Boll

PBC Facebook Group and St. Louis Support Group Leader



“Hi! My name is Donna. I want to share my story with you.”

Having been diagnosed with Primary Biliary Cirrhosis (now called Primary Biliary Cholangitis) at the age of 35, I know firsthand what it’s like to hear these words and know nothing about it. I can remember not even knowing if I should be scared, what does it even mean, or more importantly am I going to die? Over the next few years with repeated lab work every 3 months and several liver biopsies confirming the diagnosis, my life still seemed unchanged. I was working full time as an RN without any symptoms, raising 2 daughters, living life as I always had. I often recall the doctors asking me during my visits “how’s the fatigue” or “how’s the itching”. My answers were always the same – “I feel fine”. Even after nearly 10 years with this diagnosis my life seemed unchanged. On or around 2000 things began to decline rapidly. One day I couldn’t push the lawn mower. I couldn’t walk any distance. I found myself sleeping until 3 or 4 in the afternoon, not being able to get out of bed. The itching consumed my life. I vividly remember sitting on the side of my bed at night rocking back and forth, crying, asking God to make it stop. Quickly I found out what made the itching even worse as well as a very small amount of things that seemed to help. Becoming jaundiced was perhaps the worst of all for me because everyone could see this. Everyone could tell something was very wrong. In January of 2005, at the age of 54, I heard the words “ I think it’s time to think about a transplant”. This was a world I knew nothing about but it would instantly become my world, as well as my family’s and my colleagues. I was listed on the transplant list mid March of 2005. By the grace of God I received my phone call telling me they had a liver for me only 3 weeks later. On April 13, 2005, I received my gift of life from a total stranger who forever changed me. I am writing this to say I hope you know you are not alone in your journey with PBC. I know how you feel – how alone, how hopeless, how scared, and even how tired you are. If I can share one thing that helped me, my efforts with not be in vain. Know I am here to help you even if I can’t change anything.

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