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Welcoming Remarks from a PSC Patient

"You have Primary Sclerosing Cholangitis. You will need a liver transplant."

These were the first words I heard from a gastroenterologist, after waking up from my first experience with Endoscopic Retrograde Cholangiopancreatography (for some reason <u>that</u> is abbreviated to ERCP). This was in April of 2000. Trust me; I never expected to hear something like that after 48 years of good health and a day's worth of stomach pain. I now know that pain was upper right quadrant, or URQ pain.

I'm an engineer by trade. Anyone who says engineers have a monopoly on acronyms has no experience with PSC. In this brief little speech, I will use at least 5 – there are a <u>lot</u> more.

As you might guess, and many of you know from your own experience, the diagnosis of PSC was a devastating pronouncement for me. I've lead a fairly active recreational life, including mountain climbing, bicycling, running, cross-country skiing, backpacking, wilderness canoeing and farming (although most people would not consider farming recreational, of course). Now I'm told I have a serious, chronic disease that will almost certainly require a liver transplant. How could that be?

I've had ulcerative colitis (which of course, is affectionately known as UC) since 1977, but I've been fairly lucky in that it has never resulted in hospitalization, and has never really limited my chosen lifestyle. I know others have been less fortunate. PSC is one of the more unlikely extra-intestinal manifestations of ulcerative colitis.

After initial diagnosis, I spent about six months surfing the internet, looking for answers – I thought surely it could not be as bad as the gastroenterologist said (there's another acronym for you - GI). Nothing I found would corroborate my optimism, but I eventually found a site called PSC-Support on the World Wide Web at www.e-groups.com (now http://health.groups.yahoo.com/group/psc-support/). This was in October of 2000.

Stumbling onto PSC-Support was a tremendous stroke of luck. I found people just like me, suffering from the same apprehension and fear that I felt. Many were much worse off, and a few had already been transplanted. The support group was formed in 1998 by our founding visionary, Tiffany. It has grown from 12 in '98 to 150 in 2000 when I joined, to over 700 now.

Knowledge is power, and that's one of the most important benefits I've gained from this group, along with outstanding support. I'm a <u>far</u> better patient now - I frequently surprise my hepatologist with questions on current developments. There <u>is</u> hope, from advances in cadaveric, living donor and xeno transplantation, to stem cell research (which, by the way, includes my <u>own</u> stem cells).

Five years post-diagnosis, I'm still optimistic, especially after the formation of the PSC Partners Seeking a Cure foundation. There have been several attempts at a foundation since the support group was formed. <u>This</u> is the one that will succeed. I applaud those who have made it happen.