

# Newsletter

## Premier Edition!



### Welcome!

We cannot thank you enough for opening this document, reading it and hopefully gaining additional information to help you through the terrible disease of cirrhosis. With this newsletter we hope to provide informative articles tailored to the needs of all cirrhosis patients, with a little bit more emphasis on some of the underlying liver diseases and their own set of issues and treatments.

We are not an "officially sanctioned" part of the overall MDJunction website, rather we are part of a structure of information sources related to our specific support group. With the addition of this newsletter, we now have six different locations for liver disease, specifically cirrhosis, information:

1. Our MDJunction discussion group
2. Our website
4. Our website's email account
3. Our website's Facebook page
4. Our website's Twitter account
5. Our newsletter

Our plans are to produce a newsletter on a monthly basis. Each

newsletter will have one or two or maybe more articles within our "field of study". Our "Corners" section consists of articles written or compiled by members of our group. Let us know if there is any subject that you would like us to discuss or include on our website. Many of the articles that we envision including in this newsletter will probably eventually be included in our website.

You may have noticed that we speak in the "first person, plural" form. We do this because the information belongs to everyone, not the specific individuals that came up with the idea of the newsletter (Gail), puts all the information from our contributing editors (Mike, Marg, Susie, Paul, Mo and Nina) into the actual newsletter format (Dennis). If you have an article to include send it to our email inbox!

*Let us know your thoughts!*



PEOPLE HELPING PEOPLE

Visit or Contact us (please!) via:

[www.mdjunction.com/cirrhosis](http://www.mdjunction.com/cirrhosis)

[www.MySickLiver.weebly.com](http://www.MySickLiver.weebly.com)

E-mail: [MySickLiver@gmail.com](mailto:MySickLiver@gmail.com)

We're also on 

and 

as MySickLiver

### Disclaimer:

We are **not** doctors! Always consult with your own physicians before making any changes to your treatments.

We are **not** lawyers! Get appropriate legal advice when it is necessary.

We aren't even experts! We are patients and former patients that have been doing our own research on our common disease, trying to help other travelers on the roller coaster of dealing with cirrhosis.

### What's "weebly"?

Have you ever wondered why our website's address has an "extra part"? Remember those toddler toys that "wobbled but wouldn't fall down"—Weebles? No, we're not even remotely related to a child's toy and, if we were rich and famous or even had some sort of commercial sponsorship, maybe we wouldn't need the extra name.

The "weebly.com" portion of our web address (URL) is actually the address of a service that we use to bring you "My Sick Liver". Using the service allows us to not have the expense of actually running a website, which can be quite intensive in terms of computers and other devices, as well as an operating environment to always

be available when you, our visitors, want to find out something about liver disease.

Weebly also takes away a lot of the technical constraints of putting on a website. For those of you that don't know, each portion of a page that you view must be imbedded in special programming code to appear in a certain font, color and highlighting. Each "box" that you see on a page, whether it is for the "menu", footer, picture or text uses different coding. Even the overall page format has special coding requirements. Weebly gives the user the option to just "drag and drop" many of these otherwise tedious coding tasks to let the user concentrate on the content of their website. It also

allows more technical users the ability to further customize a site.

The best part of the service is that it is "FREE" (for the most part). You can get a few more bells and whistles if you pay a modest fee but very nice websites can be put together without any cost except your own time to put it together. For free, Weebly allows you to do everything we have just talked about as a "sub-domain" of their "domain name". Whenever you see more than two "dots" (they always called them periods when we were kids...) it usually means a subdomain is involved. It costs money to have your own domain name, maybe someday...



## April is National Donate Life Month

National Donate Life Month (NDLM) was instituted by Donate Life America and its partnering organizations in 2003 with the support of then Secretary of HHS, Tommy Thompson. Celebrated in April each year, NDLM features an entire month of local, regional and national activities to help encourage Americans to register as organ, eye and tissue donors and to celebrate those that have saved lives through the gift of donation.

Organ transplantation has become an accepted medical treatment for end-stage organ failure. The facts prove it. But only you can help make it happen.

- \* 18 people die each day while waiting for an organ to become available.
- \* 1 new person is added to the waiting list every 10 minutes.
- \* 79 people receive a transplant every day—that's over 3 per hour or 1 every 20 minutes.

Statistics can sometimes be overwhelming and difficult to understand. One thing to remember is that every number in the statistic you view is a person, a person who either: needs your help and is waiting for a lifesaving transplant; or a person who has left a lasting legacy through organ and tissue donation. Either way each number represents a life, a mom, a dad, a brother, a sister, a son or a daughter, someone who is important to someone else, maybe even you.

Statistics change. Some change day to day and some can even change minute to minute. So you may see different numbers each time you look for them. You may ask why this happens. There are several reasons. One of the most confusing statistics is the number of persons waiting for a transplant. Patients are allowed to register at multiple transplant centers so you may see a higher number if you count "registrations" rather than "candidates." Additionally, one of the great things that may happen is that donations and transplantations may be taking place at any time, so while the

waiting list might continue to grow the number of donors may also rise. The reality is that the number of candidates waiting continues to dwarf the number of donor organs available, and only you can change this.

Currently, more than 100 million people in the U.S. are signed up to be a donor—sign up and join them. The population of the United States was almost 312 million as of July of 2011, meaning that less than 1/3 of the population realizes the need for



registered donors. Right now, there are more than enough people waiting for an organ to fill a large football stadium...**twice over**. The goal for 2012 is to get 20 million more people to register their intent to donate their organs and tissue.

These facts may help you better understand organ, eye, and tissue donation:

**FACT:** Anyone, regardless of age or medical history, can sign up to be a donor.

**FACT:** Most major religions in the United States support organ donation and consider donation as the final act of love and generosity toward others.

**FACT:** There is no cost to donors or their families for organ or tissue donation.

The most important thing to do is to [sign up](#) as an organ and tissue donor in your state's donor registry.

**To cover all bases, it's also helpful to:**

- ✓ Designate your decision on your driver's license
- ✓ Tell your family about your donation decision
- ✓ Tell your physician, faith leader, and friends
- ✓ Include donation in your advance directives, will, and living will

All people regardless of age should consider themselves potential organ and tissue donors. There are few absolute exclusions (such as HIV infection, active cancer, systemic infection) and no strict upper or lower age limits. No one is too old or too young. Both newborns and senior citizens have been organ donors. Having other medical conditions also does not prevent someone from becoming a donor. Potential donors will be evaluated for suitability when the occasion arises. A decision will be based on a combination of factors such as your specific illness and your physical condition to determine which organs and tissues can be donated. Doctors will examine your organs and determine whether they are suitable for donation if the situation arises. If you are under 18, you may need the permission of a parent or guardian to donate.



Show us your **DONATE LIFE** Blue & Green!  
Friday April 20, 2012

**20 MILLION IN 2012** **DONATE LIFE**  
BE AN ORGAN, EYE AND TISSUE DONOR

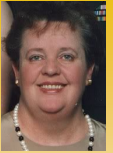
Help us save lives & register 20 million donors in 2012  
Create a unique look using the Donate Life colors  
Use fashion, accessories, makeup, baking, interior design...  
Post a photo to the Donate Life America Facebook page  
Post a photo to your personal page  
Tell friends to save lives at [DonateLifeAmerica.org](http://DonateLifeAmerica.org)

Top 10 looks win \$100

**Pass the word!**

# CORNER'S

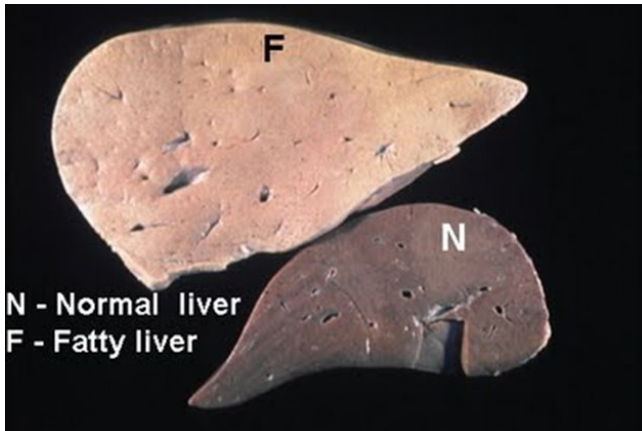
## Fatty Liver Disease



Gail "mpmom"  
Fatty Liver Disease

*I am a wife and mother who wants people to have information available in a simple and understandable format. My quest to find information when I was first diagnosed with cirrhosis led me to create the site that is now "My Sick Liver dot com". I have had numerous health issues over the years and was finally diagnosed with cirrhosis as the result of fatty liver disease. I also have diabetes and psoriatic arthritis. "My Liver may control my daily life but I am much more than my liver."*

Let's start with what Fatty Liver is. Fatty Liver Disease (FLD) is a reversible condition where large deposits of triglyceride fat accumulate in liver cells via the process of steatosis (abnormal retention of lipids within a cell). There



N - Normal liver  
F - Fatty liver

are 2 types of Fatty Liver.

In this picture the normal liver is viewed from the opposite side than the fatty liver. Which is to say the normal liver is positioned as it is in your body whereas the fatty liver is as if it were in someone else's body.

### Non Alcoholic Fatty Liver and Alcoholic Fatty Liver

Non-alcoholic fatty liver disease (NAFLD) is the buildup of extra fat in liver cells not caused by alcohol. It is normal for the liver to contain some fat. However, if more than 5% - 10% percent of the liver's weight is fat, then it is a fatty liver (steatosis).

#### ♦ Alcoholic Liver Disease (ALD)

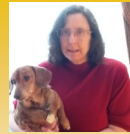
Alcohol consumed ends up in the liver where it is metabolized. Fat, along with carbon dioxide and water, is one of the end products of this metabolic process. Fatty liver disease, or fatty degeneration, is the storage and accumulation of fat in the liver, and is the

stage of alcoholic liver disease.

Each month we will look at Fatty Liver. Test, treatments and general discussion. Please keep checking in at the Fatty Liver Corner.

- <http://mysickliver.weebly.com/nonalcoholic-fatty-liver-disease.html>
- [http://en.wikipedia.org/wiki/Fatty\\_liver](http://en.wikipedia.org/wiki/Fatty_liver)
- <http://sharon-kirby.suite101.com/four-stages-of-alcoholic-liver-disease-a129360>

## My Diagnosis of Cryptogenic (Idiopathic) Hepatitis, Cirrhosis & End-Stage Liver Disease



Susie "dachsiefan"  
Cryptogenic (Idiopathic) Hepatitis

*I am a married woman who was first diagnosed in 1990 with giant cell hepatitis that had now evolved to cirrhosis. In 2008, I developed HE and edema. In 2011, I had the TIPS procedure to remove a portal vein clot and restore blood flow. I am currently on the UNOS waiting list for a liver.*

In the summer of 1990, while dog sitting my parent's dachshund in rural northwestern New Jersey, I came down with a circular rash on my neck and developed a slight fever. I went to the doctor who suspected I had contracted Lyme's Disease, as I had the telltale signs of a bull's-eye rash and fever. Blood tests confirmed Lyme's but also showed that my AST and ALT liver enzymes were about twice what they should be. The doctor asked if I ever had a history of liver problems. I vaguely remembered that as a freshman in college in 1979, I lost 40 pounds, was fatigued and had elevated liver enzymes. I had tested negative for all known hepatitis viruses back then. The next spring my enzymes had returned to normal levels.

Back to 1990, when my doctor learned of my history, I was immediately referred to a gastroenterologist (GI). The GI conducted additional blood tests, did an ultrasound of my liver and recommended a liver biopsy for diagnosis. I had the type of biopsy where they numb the skin and use what looks like a staple gun to pierce your skin to retrieve a tissue sample. The GI was baffled by my biopsy results and sent my slides to the National Institute of Health for their expert analysis.

An agonizing three weeks later, I was told that I had autoimmune hepatitis and was referred to the Liver Center at the University of Pennsylvania Hospital for care. I was put on prednisone, which they gradually reduced over time. In 1992, I moved to Chicago due to my job. The Liver Center referred me to a GI doc at Northwestern Memorial Hospital. He tried to put me on Imuran so he could get me off pred-

nisone, but the drug messed up my red blood count.

I had regular ultrasounds and blood labs and was relatively stable until 2004 when I developed edema in my calves and feet. I became "too complicated" for the GI and was referred to my first hepatologist. He put me on lasix to ease the edema. One day during an office visit, I mentioned my autoimmune hepatitis, and my Hepatologist responded "You don't have autoimmune hepatitis; you have a much rarer disease called **Giant Cell Hepatitis**".

My 1990 biopsy slides and NIH diagnosis indicated that I had multiple nuclei in my large liver cells similar to a disease common to infants named "Infantile Giant Cell Hepatitis". He also told me that I had already developed "some cirrhosis." I was floored! Like many, I thought cirrhosis was the result of alcoholism or hepatitis C. Since I was never much of a drinker and did not have the risk factors associated with hepatitis C, it did not occur to me I could develop cirrhosis.

I asked the Hepatologist what caused my liver disease. He told me that giant cell hepatitis was a form of cryptogenic or idiopathic disease. Doctors do not know if it is the result of genetics, an autoimmune disorder, a reaction to prescription drug or medication or caused by a virus. The cause remains unknown because it is so rare. I was the first patient he had ever treated who had this particular disease. Fortunately for me, my hepatitis was somewhat mild and probably was something that I had lived with most of my entire life.

Since I had lived forty years with hepatitis, I thought my health would remain relatively the same. Boy was I ever wrong in that assumption! Looking back at the end of my professional career, I had started to forget details and have trouble finding my words. I joked

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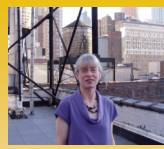
## Susie's Corner-continued

that I had developed "Sometime's Disease". Sometimes I would remember, and other times, I would not. I began to keep a legal pad of written reminders to help me with my work.

In late 2007, I lost my job and began the search for a new one. While interviewing with prospective employers over the phone, I had a terrible time maintaining my train of thought and was never contacted for a follow-up in person interview. During this time, I went to my internist for my annual visit, and she immediately sensed that I was "not my normal self". I chalked it up to depression over the inability to find a new job in the deteriorating economy. She thought it might be due to my liver disease and ordered an immediate ammonia test. Later the same day, she called me and told me to go to Northwestern Memorial's ER department. My ammonia level was over 400, which was potentially lethal.

That evening, my husband drove me downtown, where I was admitted with a diagnosis of Hepatic Encephalopathy and ESLD. Over the course of next several days, they gave me yucky syrup to drink to encourage bowel movements [lactulose]. I was then instructed to follow up with my Hepatologist. When I saw him in May, he told me my liver has decompensated, and it was time for me to be seen by the Transplant Center to be evaluated for transplant.

## Mo's Story



### Mo "IronCelt" Hemochromatosis

*Shortly after I got married and moved across country at the age of thirty-eight, I started getting lots of weird nonspecific, invisible symptoms. When my hair started falling out, I had something to show a doctor. I was soon diagnosed with severe hemochromatosis, at age forty, and cirrhosis six months later. I have now been dealing with these illnesses for ten years.*

### The Drama Queen of Early Stage and Screen

I was fortunate to receive the bombshell that I had liver cirrhosis when it was at an early stage. My reaction was to wail like an Irish banshee, but I felt vindicated. I had sensed something was wrong for at least two years, and my fears of lupus, MS, etc., were met with skepticism because I was a "drama queen." It was a label I may have deserved, given my dabbling in standup comedy and historical reenactment.

In the run-up to my initial diagnosis of severe hemochromatosis and then my subsequent search for a specialist to explain my elevated liver enzymes, I had hit the Internet hard. It was still somewhat new, and I spent hours glued to the computer screen. My circle of family and friends, frustrated that I had a diagnosis and yet remained obsessed with my disease (s), shook their heads: "Drama queen."

After some of my hair grew back and initially suspected hepatocellular carcinoma could not be verified or ruled out, I was just a clueless cirrhosis patient who didn't look sick. To my circle, early-stage cirrhosis may have seemed like a mental illness in which one imagines dire outcomes just over the horizon.

### Scary Potty and the Star of Topkapi

Shortly after my cirrhosis diagnosis, we went to an event six hours' drive from home. The second night, I put something very scary in the potty. It seemed black and in a purple haze that made me think of Jimi Hendrix. I assumed it was the infamous "black, tarry stools," so we bolted and drove four hours to the hospital where my

doctors were.

The ER did various tests but could find no blood evidence. I was frazzled, but I did hear the ER doc make three points: (1) I did not appear to have **melen**a (what? I dizzily wondered how this involved Melina Mercouri, the actress in that jewel heist movie *Topkapi*), which he said was the term for passing sticky, black, smelly stools due to moderate upper GI bleeding; (2) go to the **nearest** hospital if you do have this problem; and (3) **ambulance arrivals often get priority** in the ER. I was discharged without a diagnosis.

The next day, my mother diagnosed my problem over the phone. "Did you eat any beets?" she asked. That was the summer of my first-ever vegetable garden, and the week in which I had picked and eaten heartily of my first harvest: beets.

### Catching the Red Eye, not the Pinkeye

Several years before my diagnosis, I flew out to Nevada. Needing to look professional, I spent only a little time in the casino, didn't drink, and retreated to my room. I woke up next day with red zombie eyes. People must've thought I'd had a wild night. I thought it was the desert air.

But it kept happening, more and more often. And I'd wake up with my mouth glued shut. As I searched the Internet for clues to my rapidly lengthening list of nonspecific symptoms, I found a brief mention that liver cirrhosis could cause dry eye and dry mouth.

I soon had my official diagnosis but no solution to my zombie eye problem. Finally, on the day of my biannual ophthalmology appointment, I woke up with zombie eye and learned that my eyelids would no longer stay closed, perhaps due to a TIA [a Transient Ischemic Attack or "mini stroke"]. At first I tried eye ointment at night. When that failed, I also weighted my eyelid(s) with quarters sewn into flannel and taped in place. When that squished my eyeballs and altered my vision, the ophthalmologist said, "Swim goggles—every night." It's important to use drops, ointment, and, if necessary, swim goggles to keep the eyes moist because persistent dryness damages the cornea and irreversibly alters eyesight.

## My Inspiration



### Nina "prayer" Steve's Caregiver

*My name is Nina, I married my best friend Steve over 27 years ago, September 7th 2011 he was diagnosed with cirrhosis of the liver, caused from a genetic disorder called Alpha-1 antitrypsin deficiency, he has lost his Grandfather and his Father to this disease, our prayer is that this stops with Steve. We are blessed with one son, he and his wife have two boys. We are being carried on the wings of prayer.*

I have had a quote hanging on my wall at work for the past 3 years, "You gain strength, courage and confidence by every experience in which you really stop to look fear in the face You are able to say to yourself, 'I have lived through this horror. I can take the next thing that comes along'. You must do the thing you think you cannot do". Written by: Eleanor Roosevelt I have read this over the years and it seems that each time I go back to think on those words it is when I have to face something in my life that I feel is going to crush me, yes I have gained strength and courage over the years it is true. Each journey has been different, and this journey with Steve has been hard, but I must do the thing I think I cannot do! Philippians 4:13 I can do all things through Christ which strengtheneth me.

## AMA Isn't the Only Positive Thing About me!!!



Marg "sadyllstillsane"  
Primary Biliary Cirrhosis

*I am a wife and mother with Primary Biliary Cirrhosis. I have three kids; Kelsey is my daughter and Ryan and Linsey are my boy and girl twins. My husband Doug and I have been married since April 8, 2011. I worked with federal inmates who had been granted parole until taking disability leave in January of 2012. I live in sunny Saskatoon Saskatchewan, a beautiful city which I love. I have three great doctors and one bad liver. I have found over the last year or so that it is the little things, and the people I love that matter most, and I am not ready to let go anytime soon..... :)*

Hi everyone!

My name is Marg and I have Primary Biliary Cirrhosis (PBC). I was diagnosed in November of 2010 through a combination of factors. Blood work, family history, related disorders and physical examination convinced my doctor that I had PBC. Diagnosis and stage of the disease was confirmed with a biopsy in January of 2011. PBC has no curative therapy and the only way to prevent total liver failure is through liver transplantation. Due to the autoimmune nature of PBC, after liver transplant the new liver will be attacked in the same manner and PBC can potentially develop in the new liver although studies suggest it moves slower in the second liver.

Ninety five percent of people who have PBC test positive for something called "AMA", which are AntiMitochondrial Antibodies. AMA are antibodies found in the mitochondrial DNA. Those who test positive for this marker tend to develop or already have PBC. It is considered a significant histological marker for PBC, although some people do test negative for AMA and still have a confirmed PBC diagnosis.

Other blood work was done to assess my liver damage including ALT, AST and ALP tests. Since PBC is a biliary disease, ALP (alkaline phosphatase) is seen as significant in both detecting PBC and as a prognostic with regard to indicating bile duct destruction. Family history is important in the diagnosis of PBC because it tends to cluster in families. Those families who have PBC patients also tend to have other members who suffer from a wide array of other

autoimmune illnesses. My family history indicates the strong presence of autoimmune illness both paternally and maternally. We have PBC, lupus, multiple sclerosis, thyroid disease, Shilling Disease and rheumatoid arthritis in our family tree. Little wonder I tested positive for the AMA marker!

With PBC comes the possibility of other "overlap" illnesses that are also autoimmune in nature. Those with PBC generally are diagnosed with another autoimmune illness. The most common is low thyroid, known as Hashimoto's Syndrome. Well, I have that and a few others as well!

One less well-known autoimmune illness connected to PBC is called CREST syndrome. CREST is an acronym for the five most common symptoms in this connective tissue disease. Like a liver that becomes fibroid then cirrhotic, CREST is a scleroderma type progressive disease that causes the fibroid scarring seen in liver disease in many soft tissues and organs. Those who have CREST commonly have the following symptoms: Calcium deposits in soft tissue, Raynaud's Phenomenon, which is fingers and toes that turn completely white when cold or during times of stress; Esophageal dysmotility which is typically pervasive heartburn, Sclerodactyly which is a tightening of the skin on the face, hands, fingers and toes; and finally Telangiectasia, or small dilated blood vessels near the skin surface and mucous membranes, particularly the face. CREST causes uncomfortable symptoms and side effects in those who suffer from both PBC and CREST and is in its own right a scleroderma, or connective tissue degenerative disease.

So with these symptoms and side effects added to the more common symptoms and side effects of cirrhosis, how does a person suffering from this illness cope with the limits the illness places on them? Once the diagnosis has been made, what can be expected to happen down the road? What tests are necessary and what are the implications of this illness on one's ability to continue employment and day-to-day activities? How will I cope with this emotionally? Maybe most importantly,

when will liver failure occur and necessitate the need for a liver transplant?

The short answer to those very significant questions is this: every-one is different. For some, PBC moves so slowly that life is not shortened significantly, or at all. For others, the disease moves rapidly and liver failure happens quickly. For most, the disease has a steady progression toward the need for liver transplant. PBC is primarily a disease of middle-aged women, striking in the fourth to sixth decades of life in nine times more women than in men. Often PBC, like other causes of cirrhosis, is diagnosed accidentally, when some other illness is suspected. Like other forms of cirrhosis, PBC may not show significant symptoms until the disease is quite advanced. For me, a routine physical and blood work started a suspicion in my doctor that led to questions about family history that soon progressed to more specialized blood work (the AMA test) and then a diagnosis. It was only after the fact that some of the things that had been happening to me were recognized as symptoms. And some of those things affect the quality of my life and my ability to cope with this illness. My emotions are not caused by PBC but my disease certainly affects them. Some of these emotions are:

- ♦ **Fear:** Am I going to die? Will I be able to take care of myself as my illness progresses?
- ♦ **Guilt:** Do my children have this in their DNA too? Did I pass this on not even knowing I had it?
- ♦ **Anger:** Why me? I've lived an honest life, never consciously causing harm in this world!
- ♦ **Resentment:** Why do they get to live happily until they are 90, enjoying all life offers?
- ♦ **Jealousy:** I want to be able to do all the things other fifty-year-old women are doing!
- ♦ **Disappointment:** It's not fair I had to give up my career because of this.
- ♦ **Pity:** I have it pretty rough. I'm pretty sick and no one else has to go through this.
- ♦ **Hopelessness:** What is the point of getting a new liver, it's just going to come back again.

And an infinite range of other emotions, thoughts and feelings in between those above. Are any of the emotions positive? Well none of the ones I have mentioned so far. **But can something positive come from the news that you have a life threatening illness? My answer is YES!**

Oh it took a long time, a lot of work, a lot of thought, a lot of input from others and a lot of wading in the less pleasant emotions. Has it changed so much that now the only emotions are positive ones? Not on your life, or mine. Any type of cirrhosis, no matter how it is caused, is an illness that is silent until it screams....and its sufferer screams along with it! Nope, not all roses here!

Things are much better now because this illness has forced me to find good in the bad, hope in the despair, love in the hurt, pleasure in the pain. I had to! If I hadn't, PBC likely would not have been what killed me, my own emotions would have dragged me down and drowned me.

Today I can be grateful that PBC brought a wealth of new people into my life, which support me and care for me unconditionally. PBC brought closeness to my family that was lacking or under developed in the past. PBC brought out the best in my sometimes-wacky sense of humor. PBC forced me to realize just how much I have.....so much more than so many others. PBC allowed me to strive to be my best self.....because I no longer have time to put that off until another day, another birthday, another decade. PBC reminded me to be humble and to appreciate the small and the good. PBC forced me to look deep inside myself and examine what I found there. PBC allowed me the ability to change what I could about myself, accept what I cannot change in my life or anyone else's and the peace of understanding that I am all I can be, every day, imperfectly perfect.

AMA isn't the only positive thing about me, and I am positive that helps me deal with my illness!

## Inside Story Headline



**Dennis "dmanflan"**  
Alcoholic Liver Disease  
Liver Transplant Recipient

*I am a father, grandfather and husband for more than 38 years who will be eternally grateful to my family for sticking with me during my dark days. I have such a spark in me to try to return as much effort that I can to support many transplant related areas as possible. I love to give my opinion on these topics! I received a new liver in July of 2008. I developed cirrhosis with portal vein thrombosis (PVT) and eventually hepatocellular carcinoma*

I've had a long journey thru very deep depths of cirrhosis and end-stage liver disease. I spent a lot of time in the hospital or rehab due to various complications of the disease. I destroyed my native liver with alcohol. Only after experiencing the depths of negative health incidents did I really get serious about getting an organ transplant. I switched doctors as my old ones had seen me thru my drinking years and apparently did not think I would be alive long enough to go thru the process.

November 11<sup>th</sup>, 2006 is the date that I finally realized that abusing my body was no longer any fun. I don't know why it took me so long to realize this—it should have been obvious years ago! In any case, the sickness that I had experienced so many times finally became too much and I decided I would no longer partake of anything that altered my mind or body's "normal" operation with the exception of acetaminophen or other pain relievers but only under guidance from my medical teams.

At first it was extremely difficult to live with an unfulfilled dependency. After many years of counseling and trying various means of getting straight, including total immersion in AA and a 28-day program, it turned out the only method that really works is a self-commitment to experience life as it really is and not look for any "non-rational" means of escape. Somewhere in my journey I had heard about an

alternative recovery program called "[Rational Recovery®](#)" and later "[SMART Recovery®](#)".

As it turns out, both of these programs have an extensive online web presence. I spent many hours perusing these sites and came to agree with the premise that only I am responsible for my actions and only I can make any changes to my behavior. It does me no good to try to blame anyone or anything else for what I decide to do—I'm way too smart try to hide from myself.

As I write this journey years later, I find myself in an entirely different mental and physical place: my mind is clear and totally in control. I am post liver transplant and generally very healthy. I have absolutely no desire to return to using any substances. Even though I know my body will always have a physical dependency for bad things, my mind knows that there is no need for anything to aid my enjoyment of life. I hate labels of all kinds and like to think of myself as someone who used to have problems but now knows how to avoid them. Despite my dislike of labels, I am, and will always be, an alcoholic. I won't say that I don't think of using now and again, but I think of it in a way like it would be nice to jump in a lake on a hot summer's day when I'm really stuck somewhere in traffic—a passing thought that I would never act upon.

To this day I have the utmost guilt and shame for all of my "missed years" and wish there was some way to pay it all back to my family and friends. I know there is no way to change the past, but I now know that it is OK to have wishes but to be careful on how one acts upon them. My daily goal is to make sure I never let anyone doubt my compassion for life ever again.



## Recipe Corner

### Protein Drink

From Mike's post on our [Liver Friendly Recipes and Diet Tips](#) MDJ Forum:

A little background on this. My son is an athlete, and wants to grow. As he is only 16 I'm against a lot of these drinks targeted for muscle builders. He wanted something for energy pre-workout. I searched online and found this targeted for morning work out on an empty stomach.

- 8 oz unsweetened tea (green, oolong, white, yerba)
- 8 oz pure (natural) fruit juice ([simple](#) carbs to burn, and anti-oxidants)
- 1 serving whey protein powder (make up for protein losses overnight)
- ½ tbsp coconut milk (easy to digest fats for energy)

Makes 1 serving.

Make your own tea for low salt. Don't use pomegranate or grapefruit juice without checking with your doctor as it may be contraindicated with the meds you take. Use "light" or "diet" juice to reduce the overall carbs if you need to watch your carb intake.

### A word about salt (sodium):

**1 Tsp of salt averages  
2,300mg of sodium!**

Use with caution as 2,000 mg or less of sodium constitutes a low sodium diet.

### Nutrition Facts

#### Mike's Protein Drink

1 Serving

#### Amount Per Serving

Calories .....	226.9
<b>Total Fat</b> .....	<b>1.4g</b>
Saturated Fat .....	0.5g
Polyunsaturated Fat.....	0.1g
Monounsaturated Fat .....	0.1g
<b>Cholesterol</b> .....	<b>17.0mg</b>
<b>Sodium</b> .....	<b>64.0mg</b>
<b>Potassium</b> .....	<b>62.0mg</b>
<b>Total Carbohydrate</b> .....	<b>38.6g</b>
Dietary Fiber .....	0.3g
Sugars .....	34.2g
<b>Protein</b> .....	<b>16.2g</b>

#### Percent Daily Values\*

Vitamin A .....	0.2%
<b>Vitamin B-12</b> .....	<b>0.0%</b>
Vitamin B-6 .....	2.5%
<b>Vitamin C</b> .....	<b>249.4%</b>
Vitamin D .....	0.0%
<b>Vitamin E</b> .....	<b>0.0%</b>
Calcium .....	6.9%
<b>Copper</b> .....	<b>3.1%</b>
Folate .....	0.3%
<b>Iron</b> .....	<b>3.5%</b>
Magnesium .....	2.1%
<b>Manganese</b> .....	<b>27.3%</b>
Niacin .....	0.7%
<b>Pantothenic Acid</b> .....	<b>1.5%</b>
Phosphorus .....	1.2%
<b>Riboflavin</b> .....	<b>1.3%</b>
Selenium .....	0.0%
<b>Thiamin</b> .....	<b>1.6%</b>
Zinc .....	1.5%

\*Percent Daily Values based on a 2,000-calorie diet. Your daily values may be higher or lower depending on your calorie needs.

## Tips & Tricks

- ⚡ Always tell your doctor everything!
- ⚡ Only take the meds and supplements your doctor tells you to take.
- ⚡ Always clear new meds & supplements from other docs with your hepatologist.
- ⚡ Eat a balanced diet.
- ⚡ Get any extra exercise you can.



## Events this Month



April 1



April 6 – Good Friday



April 8



April 1



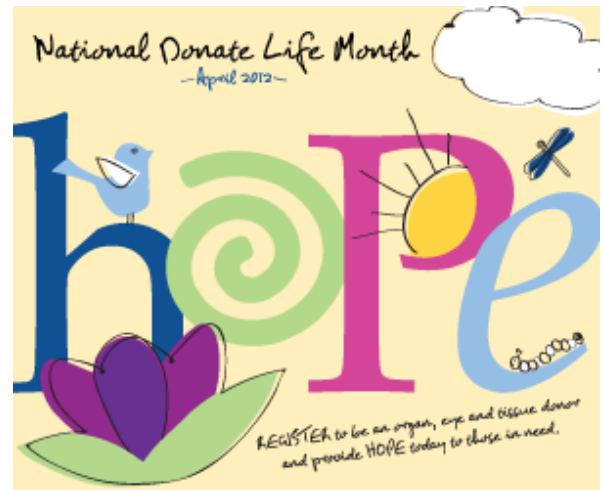
April 17 - Income Tax "Day", instead of April 15, because Fed gov't will celebrate Emancipation Day on April 16.



April 7 Passover (begins at sunset April 6)



April 27 Arbor Day usually the last Friday in April, but many states observe Arbor Day on different days.



### Phrases of the Month:

- ☘ Got your donor dot (heart, sticker)?
- ☘ April Fools!
- ☘ Doh!
- ☘ "Chag Sameach" (Happy Holiday) (Passover)
- ☘ Groooan! (on Tax Day and April Fools Day?)
- ☘ Save our planet, we only have one!
- ☘ Think Green!!!
- ☘ Plant a Tree—Make some air!

*Do not abandon yourselves to despair. We are the Easter people and hallelujah is our song.*

**Pope John Paul II**

*Please let us know if there is a date that we should be commemorating or celebrating so we can add it to our calendar.*



© Apr 8 "sadlystillsane" Marg & Doug Wedding Anniversary



**Transplant Anniversaries**

⌘ Apr 1 "vanekiki" dad's  
⌘ Apr 10 "sldg514" mom

### UNOS Waiting List Livers (Nov 30, 2011)

Status 1A	2
Status 1B	10
Status 7 (Inactive)	3,252
MELD / PELD <10	4,905
MELD / PELD 11-18	5,144
MELD / PELD 19-24	1,701
MELD / PELD 25+	1,175
<b>Total Waiting</b>	<b>16,189</b>

Courtesy OPTN reports



- ☘ Apr 14 "mikeny1132" partner Cliff
- ☘ Apr 21 "heatherm10" Heather's dad
- ☘ Apr 26 "letsdance" Meg's husband Jerry
- ☘ Apr 27 "Italian1022" dad

5,840 liver transplants performed  
6,392 livers donated/recovered