

MDJunction Cirrhosis Support Group Newsletter



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PEOPLE
HELPING PEOPLE

Anybody Else Like Numbers?

Someone once told me (Dennis) that computer programmers and engineers should not be allowed to spend too much time with numbers and to *never* be allowed to use spread sheets without supervision! Well, no one was watching when I went to get updates for our regular feature listing how many people were waiting for a transplant based on MELD values.

Did you know the US Health Resources and Services Administration (HRSA) [Organ Procurement and Transplantation Network \(OPTN\)](#) compiles all kinds of information about all types of organ transplants? That at their [website](#) has tools to analyze all of this information in various reports that are pretty much just limited to your imagination on how it is presented?

Well, in case you don't appreciate numbers in the same way that I do, or numbers don't really fire up your imagination, I spent a little time putting together a couple of tables that I thought others might also find interesting.

The first table shows the number of people on the waiting list based on the underlying (causal) liver disease. It is easy to see that half of all people on the waiting list are due to hepatitis or alcohol. It is just as

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, former patients and caregivers that have been doing our own research on our common disease, trying to help other travelers on the roller coaster of dealing with cirrhosis.

important to understand that hepatitis can be due to many different causes.

Transplants 2011 by Causal Disease	Count	% All
All Diagnosis	16,811	
Hepatitis all types	4,998	29.7%
Alcoholic Liver Disease (ALD)	3,523	21.0%
Other	1,697	10.1%
Primary Sclerosing Cholangitis (PSC)	1,340	8.0%
Fatty Liver (NASH)	1,165	6.9%
Cryptogenic	996	5.9%
HCC	800	4.8%
Autoimmune	612	3.6%
Necrosis Drug/Other	417	2.5%
Biliary Arteresia	232	1.4%
Budd-Chiari Syndrome	107	0.6%
Alpha-1-Antitrypsin Deficiency	87	0.5%
Benign Tumor	86	0.5%
Hemochromatosis	63	0.4%
Cystic Fibrosis	31	0.2%

Next up, I wanted to see how long patients have been on the list.

Waiting Time on the List (current)	
All Time	16,811
< 30 Days	830
30 to < 90 Days	1,391
90 Days to < 6 Months	1,581
6 Months to < 1 Year	2,451
1 Year to < 2 Years	3,111
2 Years to < 3 Years	1,902
3 Years to < 5 Years	2,370
5 or More Years	3,175

The third table I put together (next column) shows the status of patients on the waiting list and the last couple of years. Status 1A and 1B patients, who are the sickest, are allocated first, regionally then nationally, before consideration of MELD.

Transplants by Status				
	To Date	2012	2011	2010
All Types	113,930	500	6,341	6,291
Liver Status 1A	2,176	24	281	306
Liver Status 1B	434	7	76	79
Liver MELD / PELD <10	1,617	6	72	76
Liver MELD / PELD 11-18	9,254	25	558	588
Liver MELD / PELD 19-24	17,900	123	1,440	1,773
Liver MELD / PELD 25+	25,604	295	3,667	3,187
Liver Status - Living Donor	4,554	20	247	282

I included a few years worth of data so that you can see the trends over time appear to be similar—the sickest patients get treated first. The “to date” column is since the first transplant was performed.

There is one more table on the following page. It shows the number of transplants for each of the 11 UNOS regions, broken down by status like the chart above.

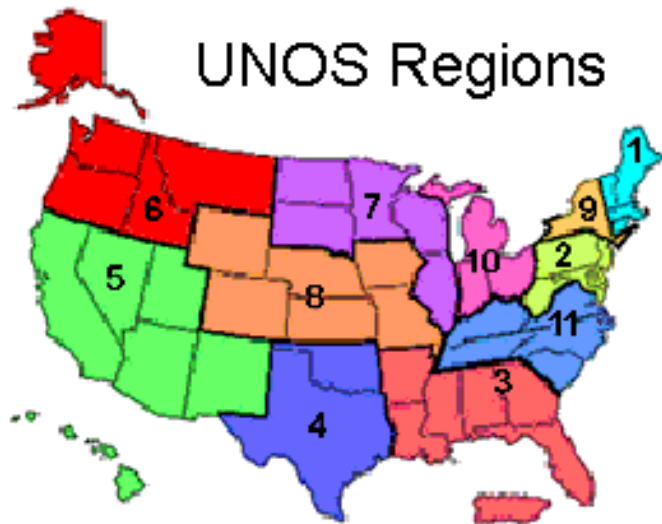
	All Regions	Region 1	Region 2	Region 3	Region 4	Region 5	Region 6	Region 7	Region 8	Region 9	Region 10	Region 11
All Types	6,341	283	737	1,018	557	944	176	602	463	378	531	652
Liver Status 1A	281	12	32	21	19	62	6	35	22	20	23	29
Liver Status 1B	76	4	17	7	9	19	4	3	4	0	9	0
Liver Status - Living Donor	247	32	42	1	3	39	0	60	7	36	11	16
Liver MELD / PELD <10	72	9	3	3	11	17	0	6	2	5	10	6
Liver MELD / PELD 11-18	558	32	59	130	15	29	14	25	44	21	93	96
Liver MELD / PELD 19-24	1,440	27	165	426	75	54	42	74	81	33	191	272
Liver MELD / PELD 25+	3,667	167	419	430	425	724	110	399	303	263	194	233

UNOS Review

According to the [UNOS website](#): "The United Network for Organ Sharing (UNOS) coordinates the nation's organ transplant system, providing vital services to meet the needs of men, women and children awaiting lifesaving organ transplants. Based in Richmond, Va., UNOS is a private, nonprofit membership organization."

UNOS members encompass every transplant hospital, tissue matching laboratory and organ procurement organization in the United States, as well as voluntary health and professional societies, ethicists, transplant patients and organ donor advocates."

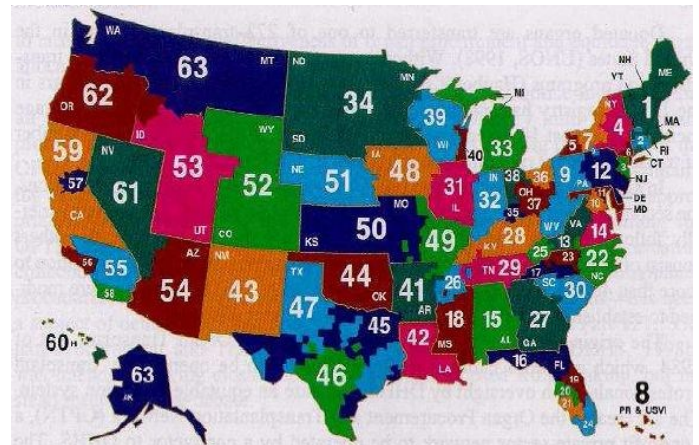
The United States are divided into 11 geographic UNOS regions. Each of these regions provide for efficient communication between UNOS members, the UNOS Board of Directors and the transplant community. Further, each region provides a "local" forum to facilitate consensus building for the overall UNOS policy development and maintenance.



Organ Procurement & Transplantation Network (OPTN) Review

The OPTN is a private, not-for-profit entity with an expertise in organ procurement and transplantation. Each OPTN member agrees to comply with all applicable provisions of the National Organ Transplant Act (NOTA). The OPTN conducts ongoing and periodic reviews and evaluations of each member Organ Procurement Organization (OPO) and transplant hospital for compliance with the OPTN Final Rule and OPTN Policies.

Organ procurement organizations (OPOs) are private non-profit organizations that are responsible for increasing donor registration in their service areas and for coordinating the donation process in their service area hospitals. To promote donor registration, OPOs implement a variety of community outreach initiatives and strategies to motivate the public to sign up for donation. When notified of a potential donor in a hospital in their area, OPOs verify or obtain consent for donation to take place, determine whether the deceased is medically suitable to donate, obtain a list of potential recipients from the OPTN, and organize the recovery, preservation, and transportation of the organs to the appropriate transplant centers.



CORNER'S



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 by looking at **Alcoholic Fatty Liver**

When alcohol is consumed, it 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 first stage of alcoholic liver disease. Fatty liver disease does not cause serious damage to liver function. In its early stages it is reversible by abstaining from heavy drinking or, better still, not drinking at all. If heavy drinking continues, the damage to the liver will get worse. Continued drinking with a fatty liver can lead to alcoholic hepatitis.

There is no way to know if you will develop alcoholic Fatty Liver. The risk levels are controlled by many different things including genetic factors (e.g., predilection to alcohol abuse, gender) and environmental factors (e.g., availability of alcohol, social acceptability of alcohol use, concomitant hepatotoxic insults); Fatty Liver is almost universal in heavy drinkers. But only one in five heavy drinkers develops alcoholic hepatitis and one in four develops cirrhosis.

Patients with fatty liver typically either are asymptomatic (no symptoms) or present with non-specific symptoms that do not suggest acute liver disease. Sup-

porting features on physical examination include an enlarged and smooth, but rarely tender, liver.

Fatty liver is usually diagnosed in the asymptomatic patient who is undergoing evaluation for abnormal liver function tests, which are typically: aminotransferase (AST) levels are less than twice the upper limit of normal; and no laboratory test is diagnostic of fatty liver. Characteristic ultrasonographic findings include a hyperechoic liver with or without hepatomegaly. Liver biopsy is rarely needed to diagnose fatty liver in the appropriate clinical setting, but it may be useful in excluding steatohepatitis or fibrosis. In severe fatty liver, however, fat is distributed throughout the acinus (the smallest functional unit of the liver) Attribution of fatty liver to alcohol use therefore requires a detailed and accurate patient history.

The foundation of therapy for alcoholic liver disease is abstinence.

Only once fatty Liver advances to the more serious alcoholic hepatitis will you see more symptoms and lab changes. The fatty liver stage is the point to make a difference in your life. Be honest with your Dr. Avoid Alcohol, Eat a healthy diet and exercise. Give yourself and your Liver time to heal. Living a healthy life can reverse the Fatty liver and you can go on to live a normal life. See Dennis' Corner for a continuing discussion of alcoholic liver disease progression.

Now let's look at **Non Alcoholic Fatty Liver (NAFLD)** is very much the same as alcoholic fatty liver, in fact slides from a biopsy of each look exactly the same. Diagnosis is made by a complete medical exam and history. Excluding excessive alcohol leaves you with a diagnosis of NAFLD.

Here again simple fatty liver can be reversed and may never advance to the more serious non-alcoholic steatohepatitis. (**steato = fat hepatitis = inflammation**) About 18% of fatty liver patients will progress to NASH.

NASH like alcoholic hepatitis can progress to cirrhosis. About 10 to 20% of NASH patients will develop cirrhosis. Inflammation destroys liver cells over time. The scar tissue (fibrosis) if not stopped can eventually encompass enough of the liver to be diagnosed as cirrhosis.

In the case of NAFLD the fat accumulation is often linked to obesity, diabetes, insulin resistance & high triglycerides. As more research is done however they are starting a connection to family history. Many of our ancestors may have never known they had fatty liver so it is hard to trace. We are also seeing more NON-overweight patients with Fatty Liver. This also points to a likely family connection. Perhaps the saddest reflection on our society is the sharp increase in the cases of fatty liver diagnosed among children.

Fatty Liver and NASH are usually diagnosed by ultrasound and confirmed by biopsy (where they will be able to tell if cirrhosis is present). Many patients receive their diagnosis after surgery for gallbladder disease. After diagnosis the most important thing you can do is to live as healthy a life as possible.

Lose weight (But slowly) Rapid weight loss is hard on a healthy liver and can be devastating to an injured liver. Also remember that almost all pills are processed by the liver. Diet pills run the risk of undoing any benefit you may get from losing weight. Weight gain is not only caused by over eating. Inactivity is just as much of a problem. Being a couch potato or in this day and age, an Internet junkie contributes to weight gain as much as overeating.

Exercise is important to all of us. I know it's not easy especially when you are sick. But there is usually something we can do. I walk; maybe you have more difficulty walking than I do. Regardless there are many web site, books and programs that offer ideas for exercise for all

levels of abilities.

Control your Diabetes (if you have it) elevated blood sugar is extremely hard on your liver. Ask for a referral to a dietitian to help you set up a proper diabetic diet. Did you know a simple 3-minute walk could reduce your blood sugar by 20 points or more? So think what you can do.

Insulin Resistance can be helped but often medication is needed. "Metformin is usually the drug of choice" It carries less liver risk.

Reducing Triglycerides is usually helped as we cut the fat from our diets but you may need your doctor's help.

We can't change our family history but by living as healthy as possible we achieve a few important things.

First we may REVERSE our disease

Second we may STOP the progression of our disease

Third we may SLOW DOWN development of cirrhosis COMPLICATIONS

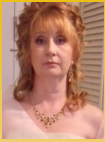
Fourth and most important if we progress to the point of needing a transplant we have done all we can to be certain that we are in the BEST PHYSICAL CONDITION to handle such a major surgery.

<http://www.clevelandclinicmeded.com/medicalpubs/diseasemanagement/hepatology/alcoholic-liver-disease/>

<http://sharon-kirby.suite101.com/four-stages-of-alcoholic-liver-disease-a129360>

[United Network for Organ Sharing](#)





Marg "sadlystillsane"
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..... :)

AND SO, THESE WERE SYMPTOMS!?

For many years prior to my diagnosis of Primary Biliary Cirrhosis, my doctor had investigated and tried unsuccessfully to diagnose the cause for a group of seemingly unrelated symptoms. This began in the mid 1990's and it was not until 2010 that a confirmed diagnosis of PBC emerged. Were all these past issues leading toward the ultimate diagnosis of PBC? Could other autoimmune illness or 'overlap' illness and syndromes associated with PBC have been the cause of these other issues? Can it be that I have had PBC since the mid 90's? So it seems today.

I have seen a dearth of specialists: a neurologist for headaches; a cardiologist for heart palpitations; a rheumatologist for pain in my joints; and a sleep clinic for my exhaustion. I was starting to think there was nothing and everything wrong with me! My friends were starting to wonder if I was a hypochondriac. My doctor was mystified. She always believed me when I went to her with a symptom, never telling me it was just in my head, but like me, became frustrated with partial diagnoses or no diagnosis at all.

I seem to have always been tired. So tired that at times I fell asleep in University classes, or so tired that my kids would ask me questions and I would answer while asleep. So tired that in my thirties I felt like I was ninety. So, ruling out the obvious like thyroid disorder (which I have and was taking medication for) off I went to the sleep disorder clinic. Maybe they could find out why I was so exhausted. After a night of being asked to sleep and then not to fall asleep with a million wires attached to my head I was told there was some disturbance of the alpha waves. Okay, but what did *that* mean? Well, apparently nothing!

I have had joint pain for years. My wrists, my hands, my elbows, my

hips... So off I went to the rheumatologist. With a family history that includes Lupus in a first-degree relative, my doctor wanted to be sure that I didn't have it. So I was poked, prodded, had my blood tested. The rheumatologist said I had some of the symptoms of Lupus, but that I did not in fact have Lupus. There was definitely something wrong with me: I did have sore joints but no one could put a finger on why. Maybe arthritis? Take Tylenol. Maybe from doing a physical job? Take Tylenol. No real diagnosis and no answer.

Heart palpitations, headaches, exhaustion, sore joints, bruising, a general feeling of not being well... I went over this with my doctor a million times. I researched what could be wrong with me. I thought we had it with Lupus. I thought we had it with Hashimoto's Syndrome (thyroid). I thought we had it with Mitral Valve Prolapse. I thought we had it with migraines. I thought we had it with clinical depression. I thought we had it with arthritis. I thought at several points that I was crazy. Earlier in my life we had run the gamut with irritable bowel syndrome and possible colitis. They eventually decided it was my nerves. No one knew it was all connected and that there was a bigger picture and that picture was Primary Biliary Cirrhosis. No one knew because PBC is not, and was not then, well known; no one looked at my liver as the source of the problems. My doctor tried to treat what she could and sent me to specialists she thought would figure out the cause of my discomfort. Eventually I just learned to live with being tired and sore and put it down to depression (which is real for me) and to stress from my career, my family and from living in a busy crazy world! I thought I was just one of those people who would never really feel well but never really know why. The aches and pains came and went; the depression was managed with anti-depressants. And life went on and I managed and I occasionally had good days, even months, that were interspersed with not feeling well and wondering if it was always going to be like this, if other people felt like this or if I was crazy.

When my annual physical came in 2007 my doctor decided to do liver enzymes tests. I don't know why she did, I had not complained about my liver. The pain in my side was due to scar tissue from a gallbladder removal some eighteen years earlier and that was clear to both of us. I occasionally worried about contracting

hepatitis from my work in the prison system but had never been clearly exposed so not a big concern. The tests showed a little elevation of the enzymes but nothing really to worry about. So, we didn't. The physical that I had in 2010 caused alarm bells to ring with my doctor. The liver enzymes were crazy and she was worried enough to do an emergency referral to a gastroenterologist. He told me I likely had PBC. He told me to go home and research the illness. He told me to talk to my general physician and learn about the illness and to come back in six months. I left that appointment wondering what my doctor had made such a fuss about, obviously this PBC was no big deal....sort of like the heart palpitations. A little leaky valve that really wasn't concerning, just take a pill....well now it was just another pill, a little pill called Urso. No big deal. Certainly nothing that tied together that exhaustion, and pain in my side, the sore joints and the bruising. Nothing that related to my itchy and sensitive skin. Just something else wrong with me—no big deal—I'm used to it by now! I have a lot of things wrong with me but none of them are a big deal, just a lot of annoying little unrelated problems with my skin, my joints, and my scar tissue....and on and on.

The internet can be a curse and a savior. I decided to search PBC and went to the Canadian Liver Foundation website and the Mayo Clinic website. No 'liver cleanse' sites for me—just good, reliable sites. And what I found floored me! I will never forget the first two things I realized. My carry all bag of little health issues were almost ALL related to PBC or overlap disorders like CREST and osteoporosis. And second, this was very, very serious and potentially fatal disease. I felt relief that finally I knew—these were real symptoms of a real illness and terror. **These were real symptoms of a real illness.** I will remember for the rest of my life reading about the common symptoms of PBC and the line that said, "There is no curative therapy for PBC and a liver transplant is the only option when the disease progresses to cirrhosis". I sat there in my chair at work, minutes prior to conducting a problem-solving group with a bunch of gang members out on parole and thinking "this cannot be real. A liver transplant? A ten year time frame on average?" I look back now it still seems surreal!!!

I had a close friend in high school

that lost her father in 1979 at the age of 56. He was a second dad to me. He died from a combination of liver cancer and cirrhosis attributed to hepatitis contracted in WWII and alcohol consumption. I remember the yellow skin and the big belly. I remember how quickly he died. I remember the family saying, "well you can't transplant a liver"... because in Alberta, Canada, in 1979 you couldn't transplant a liver. It was my first experience with the death of someone close to me and close to my family. At the time I was mystified at how a liver could quit, how alcohol could cause a problem and how an illness from years earlier could cause such a quick death. I was 17 and clueless. Now I understand how the illness was left unfound and untreated in him until it was too late and he was in liver failure. Now I understand how a bunch of unrelated and unimportant issues can end up being a significant set of findings with regard to the symptomology of liver disease. Now I know that in my own DNA at age 17 I was already heading toward cirrhosis myself.

Today I know that if someone had put it all together years ago, the PBC would have been found in stage one or two, not stage three or four. Awareness of liver disease and the myriad of causes of cirrhosis remain problematic. Many people are still diagnosed by accident or when the disease has progressed to the critical stage. Most people don't know you can get cirrhosis from many genetic and environmental causes. Many doctors do not think liver enzyme tests should be standard blood work. More education and awareness is needed in the medical community and the general population. If you are tired there is a reason and stress may not be the only cause. The most pervasive symptom of liver disease is exhaustion. In Canada alone, over 700 people will die each year waiting for a liver transplant. That means a lot of people have issues with liver disease. So how can it still be such a mystifying illness to diagnose early? And so, it took fifteen years for me to discover that these were symptoms, and for a Hepatologist to tie together all the things from irritable bowel to thyroid to itchy skin. For a cause to be found that explained my various ailments and tied the ribbon around the endless doctoring and endless feeling of being unwell. For the word CIRRHOSIS to become foremost in my life. And so, these were all symptoms, all this time!



**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 starting 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

Welcome to My Zoo

From the very beginning of my medical odyssey, I've felt like I was in a zoo, the old-fashioned kind with jailhouse bars. Sometimes it was interesting, being a spectacle, watching the reactions of others. Sometimes I wanted to rebel, like an angry primate. I always wanted to escape, but no animal is clever enough to get out of here. But I have always felt that I should at least be treated decently and properly, considering that, despite the fact that I produce hoof-beats when in motion, I am not your ordinary horse. I am the Zebra.

When I married and moved, my new family doctor struck me as a fast-talking Captain Kangaroo. I have to be careful with my first impressions, because they *are* impressionistic and I need to wait for solid evidence of medical expertise before judging. The Kangaroo proved admirably practical. He allowed for the possibility of serious reasons for my nonspecific symptoms and suspected hemochromatosis after a single round of blood work.

Things went downhill from there. Due to a nurse's error, my spouse abruptly shifted me to a family doctor in an even smaller town. My first impression that he was Reptilian was followed by evidence of his less-than-evolved medical skills and bedside manner. And then there was the hematologist, who gave a positively Rodent-like first impression, followed up with the opening statement that he knew next to nothing about hemochromatosis, and further proved his lack of qualifications by ignoring the liver issues I specifi-

cally pointed out.

Over these 10 years, I have seen 2 family doctors, 1 hematologist, 1 endocrinologist, 2 dermatologists, 1 rheumatologist, 1 internist, 4 gynecologists, 2 oncologists, 1 psychiatrist, 1 pulmonologist, 2 cardiologists, 1 gastroenterologist, 5 ER physicians, and 2 hepatologists. Some of them preferred to see me not as the Zebra with its unique pattern of stripes but as a bland beast from central casting. In such cases, I had to be the Cobra. (Footnote: the "Cobra" is the hand gesture "the Donald" Trump used on *The Apprentice* as he intoned, "You're fired!") It was against my nature, but sometimes I had to do it.

Early on, after galloping past a gang of useless doctors, I finally arrived at a big university hospital where there was a hepatologist with a subspecialty in hemochromatosis. I waited three months for an appointment with him. When he came in I could practically see a six-foot glowing aura highlighting his starched shirt, creased pants and shining leather shoes. A string quartet wouldn't have been out of place either. My first impression was that he was a mighty Centaur, from the zoo of the Greek gods of Olympus. He listened and affirmed my concerns, ordered appropriate tests and then called me personally to tell me the bad news.

Alas, but who has not seen their infatuations dull with time and change? The Centaur was of course destined to move on and up and new insurance restrictions limit my ability to be the Cobra and move on myself. Now I am the patient of Dr. Meerkat, from whom I struggle to extract clear information. I try to remember my father's eternal advice: "Be the Bulldog—keep at it!" It's advice that has always been hard for me to follow; with cirrhosis, there are many days when I am not the Zebra, the Bulldog, or the Cobra but the Pekingese.



Recipe Corner

Gail's Barley Corn Salad

- 2 cups medium pearl barley (cooked per package directions)
- 2 cups frozen corn, thawed
- ½ cup sweet red pepper, chopped
- ½ cup sweet green pepper, chopped
- 3 green onions, chopped
- 1 Tbls fresh cilantro, minced
- 2 Tbls lemon Juice
- 2 Tbls canola oil
- ½ tsp salt
- ½ tsp dried thyme
- 1/8 tsp pepper

1. Combine in a large bowl: barley, corn, red and green peppers, cilantro & onions. Set aside.
2. In a jar or bowl combine lemon juice, oil, salt, thyme and pepper. Mix well.
3. Pour mix over salad and toss to coat.
4. Cover and refrigerate for at least 2 hours before serving.

Serves 6

Nutrition Facts	
Amount Per Serving	
Calories	450
Total Fat	37.1 g
Saturated	2.7 g
Polyunsaturated	11.1 g
Monounsaturated	21.6 g
Cholesterol	0.0 mg
Sodium	199.5 mg
Potassium	273.8 mg
Total Carbohydrate	30.3 g
Dietary Fiber	4.4 g
Sugars	2.4 g
Protein	3.3 g
Vitamin A	19.6 %
Vitamin B-6	11.4 %
Vitamin C	69.7 %
Vitamin E	39.0 %
Calcium	2.6 %
Copper	5.5 %
Folate	10.0 %
Iron	11.8 %
Magnesium	8.5 %
Manganese	15.8 %
Niacin	10.9 %
Pantothenic Acid	2.6 %
Phosphorus	8.3 %
Riboflavin	5.5 %
Selenium	7.2 %
Thiamin	8.2 %
Zinc	6.0 %

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

Want to write for this newsletter?

Do you like to write? Do you like to research, particularly subjects related to liver disease, liver transplant, providing care to your loved one or raising awareness of the need to register organ donors? Do you have any liver friendly recipes or tips for coping with liver disease? Do you have any ideas for articles that you would like to see in future newsletters?

If you answered "yes" to any of these questions, we would love to hear from you. All you have to do is send us an [email to our Gmail](#) account with your idea for what you would like to contribute. Its just that simple! You would not only be helping us bring a quality newsletter to our members but probably help other members with their understanding of liver disease!



**Paul "tabbtech"
Idiopathic Liver Disease**

I am a 61-year-old sheet metal worker, welder and ironworker. I have been married to my beautiful wife for over 40 years. We are the very proud parents of our beautiful adult daughter. I started having pains in my right side and I was really moving slow sometimes. Some friends at work noticed that too. It eventually started affecting my work. My doctors were no real help, so I found new ones who determined I have advanced cirrhosis and will need a transplant to get well again! Needless to say, my wife and I were thoroughly shocked!!! Fortunately we had come to belief in our Lord and Savior Jesus Christ just a few years before this diagnosis, and this has made us depend on him all the more.

I'm a sheet metal worker, welder and iron worker. I joined the Sheet Metal Workers Union in 1978 at 27, finally some direction in my life. I had been married in 1971 and we had a beautiful little girl who was 4 when I started apprenticeship. It was a bit tough, 40 hours plus 3 hours a night 2 nights a week in school. I had to take a pay cut as I had been working in a tire plant the previous 4 years. My wife and daughter said it was worth it since I didn't smell like rubber all the time!

I did well as a journeyman and was in charge of a few jobs and after three years as journeyman I had an opportunity to start my own small shop. I did very well for 4 years, took my wife to Hawaii, what a beautiful place, then came the lawsuits. I got sued for poor construction that the developers had done, not even my own work, but the liability insurance people said it was easier to just settle instead of fight, easier for them maybe!

Anyway the lawsuits and a bad housing market soon broke me and we lost our home, ended up managing apartments. If you ever have the choice of managing apartments and starvation, go with the starvation it's quicker and much less stress! That was a painful time!

I was finally able to get back into the Sheet Metal Workers Union in 2005 when I was 54. I figured I could work for maybe 10 years to build up my pension. The Union has a very good pension plan, so I thought I would be way better off than just being on Social Security. Then someone, (I'm a Republican so I figure it was a Democrat 😊😊😊) decided to ruin the economy. I was still doing pretty well since I'm pretty good at a

job that few sheet metal workers are willing to do.

Then I got ambushed! I started having pains in my right side and I was really moving slow sometimes. Some friends at work noticed that too. At my pay rate, the boss wants see some production each day. So I went to the doctor and complained about chronic fatigue syndrome, I had been complaining about this for years but now it wasn't just a bothersome little problem, it was really affecting work.

This doctor told me that I was just getting older and that I couldn't expect to get around as I did in my 30's. Besides there is really no such thing as chronic fatigue syndrome—that fatigue is caused by something. He didn't do anything to find out what though. This was the same doctor who 14 years earlier had put me on some medications because of elevated liver enzymes. Back then he hadn't done anything to find out why the enzymes were elevated. Now that I have been diagnosed with cirrhosis this all really makes me say "Hmmm". I wonder how many people who are complaining about chronic fatigue syndrome don't find out what the cause of it is until it's about to kill them, or never!!!

So I got real tired of all this non-care I tried to find a new doctor. His first blood test shows my platelets are down to 70,000. So I'm sent for a bone marrow biopsy in case it's a marrow problem. Then of course to the GI doctor who looks at my blood work and then examines me. I have a super-sized liver and spleen, both very sore so he tells me that he is sending me to have an ultrasound to confirm his diagnosis that I have advanced cirrhosis and that I will need a transplant. Then he runs out of the room leaving my wife and I totally stunned!!!

Until this time, I thought I was handling things pretty well. Getting back into the union was the right thing to do we were doing very well. So now I have

something that I haven't a clue as to what to do. I'm not getting much help from the doctors, they just treat you they don't tell you how to react to it.

To be fair to my GI doctor as I look back on it, I don't think the guy knew what I was there for before he looked at my chart when I got there, he hadn't looked ahead of time. So it had to have been a bit of a shock to him too, to be going "Oh my, this guy has cirrhosis". I don't think that doctors deal with terminal diseases and death any better than the rest of us. You would think that they could give you a pamphlet or some direction to a helpful web site or something.

So we went home, got on the web sites, read about cirrhosis and scared the heck out of ourselves! Fortunately we had come to believe in our Lord and Savior Jesus Christ just a few years before this diagnosis and this has made us depend on him all the more. He has blessed us and strengthened us in so many ways, so that now we can get through this trial and anything else that comes along. And you can always be sure in this life that something else will come along. Jesus said, "In this world you will have tribulation, but fear not for I have overcome the world."

My wife has been a great blessing to me throughout our forty plus years together but she is even stronger now in spite of her own painful back and sciatica problems. It is such a blessing to see our daughter also grow in her faith in the Lord.

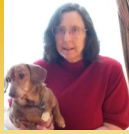
I haven't had major complications to speak of yet—just one episode of being very sick for four days and coughing up a small of blood from a stomach ulcer. That was early on and we had read just enough to be really scared. I thought I was dying! Fortunately I was nowhere near death. Though I have not had major complications, I do have portal-hypertension, low platelets 55,000 and a slightly elevated INR of 1.2, which scares me a little since I do occasionally have minor bleeding.

I'm just now learning about the importance of seeing a hepatolo-

gist. I believe my PCP, and GI doctor are good doctors, but they do not specialize in diseases of the liver. If I'm going to make the old broken down liver that I have last as long as possible, I believe that I must be seen by a liver specialist.

I have a number of questions I believe need answers. For example I take an iron supplement that my PCP started me on before the diagnosis of cirrhosis. Low platelets, red blood cells and iron call for an iron supplement, that's standard procedure. However, with a cirrhosis patient you sometimes have a concentration of iron as the cause—most often a high concentration of iron in several of the organs, primarily the liver. You may also have a high concentration of iron in the blood, but sometimes you won't have this high blood concentration, so your body plays a cruel trick on you and your doctor.

We are all learning to cope with this disease at my house as well as with my wife's back pain and sciatica problems. I was hoping, like most people I suppose, to be strong and healthy until sometime after I turned 80 and then pass quietly in my sleep. I suppose that doesn't happen for everybody. I suppose that I understand now that I really am going to die someday, a fact that I hadn't come to terms with before. I'm not so much afraid of it as when I was first diagnosed, but I must admit that I am still a bit afraid of any pain that might come up. When that time comes though, the Lord will strengthen me for it. When it comes time for a transplant, if the Lord intends for me to continue serving him here, then there will be a good surgeon and a liver for me. If he wants me to come home to him, then I'll go with joy. Either way, it's in the Lord's hands.



**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.

Living with Transplantation

Since joining the MDJunction Cirrhosis Group last year, I have learned quite a bit about End-stage Liver Disease from the wonderful people who share their stories online every day. Even though I get a lot of support from the web, I have often yearned for other opportunities to learn about cirrhosis and transplantation. One such opportunity became available to me last Saturday with the *Living with Transplantation* conference I attended in Chicago. I'd like to share with you my experience.

The one-day conference was sponsored by the National Kidney Foundation of Illinois. Although it was geared primarily to kidney candidates and recipients, it was open to people interested in heart, lung, liver, pancreas and small bowel transplants. Approximately, three hundred people attended.

The seminar opened with Dr. Juan-Carlos Caicedo, transplant surgeon at Northwestern Memorial Hospital, discussing the current trends in transplantation. Basically, we all know the statistics. The need for organs is steadily rising, but the number of donor organs is not. He stressed the critical need to encourage and utilize living donors for liver transplantation.

The keynote speaker of the conference was Rich Ramirez. Ramirez is a professional actor and stand-up comedian who had a liver transplant in the mid 1990's. Rich recounted his journey to transplant in his unique comedy style and had us chuckling throughout his presentation. Check out some of his story online and his comedy routines on [YouTube](#).

The keynote was followed by a breakout session. Transplant recipi-

ents attended support groups organized by organ type. Candidates were asked to attend the "How to Get Listed for a Transplant and Financial Preparation". Since I am on the UNOS waiting list, the first talk did not really pertain to me. However, the transplant professionals did stress the need to constantly update your center on your current contact information, insurance changes and medical testing. They described instances where they could not reach a candidate and had to offer the organ to someone else. Make sure your medical testing is up-to-date. I learned I needed an annual pap smear not one every two years as recommended by my internist.

Open seating at the luncheon was organized by organ type. I saw the graphic of the liver on a table in the center of the room and headed for it. At my table, everyone had already had their transplant except for me. The two people I sat next to actually had their transplants done at Northwestern Memorial Hospital where I am listed. It was great to get their perspectives on the doctors, nurses and hospital. Both of them stressed to me that their conditions had been relatively stable but then suddenly worsened so they were transplanted. One had her transplant in 2006 and the gentleman in 2011. They also told me that they both had speed bumps along the way, especially problems with fluid retention and draining. However they are eternally grateful and blessed to be alive with their new livers.

After lunch, I attended the "Immunosuppressive Medications Update", where a transplant pharmacist reviewed all the types and side effects of the drugs currently used. I was never a science major, but I came to these basic conclusions:

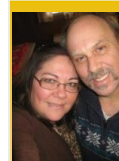
- The drugs have to be taken as prescribed
- Blood testing has to be done on a regular basis
- all side effects need to be re-

ported to your doctor

The doctor mentioned a new drug that has been recently approved by the FDA, but a single 600 mg dose cost is a staggering \$12,000!!!

My last session was "Intimacy and Transplant". Only 50 percent of candidates report problems with intimacy pre-transplant and between 50-80 percent of recipients report problems with intimacy post-transplant. The speaker indicated that problems are greatly under reported because doctors do not ask their patients if they having intimacy problems and many patients do not feel comfortable volunteering this information. She stressed the need to be open with your doctor about these problems so that they can be adequately addressed.

What are some of my thoughts on the day? It was sad to see the need is so great for transplants in the Chicago Metro area. It was inspiring to be in the same room with recipients who received their gifts of life over twenty years ago. It was interesting to speak with kidney candidates and compare wait list times for transplants. It was fun to peruse an exhibit hall featuring displays from area transplant centers, pharmaceutical companies, medical services companies and our state procurement center. It was an exhausting, exhilarating day I wanted to share with all of you!



**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

Caregiver....more than just a word to me!

I was talking with a friend who recently lost her husband to cancer, he fought a 6-month battle

and she was by his side the whole time. I ask her what was one of the hardest things for her other than the obvious. Her answer was that she had to take over everything. I too have found that to be a challenge, I have relied on my husband so very much through the years and when I started noticing that he was having issues with his health I had to step up and take over a lot of things. I found it very hard at first.

I never drove very far in all the 27 years of our marriage, I never paid the bills, I didn't even have to do the grocery shopping by myself, but things have certainly changed in the last year. We bought a GPS, I drive him to all his appointments, most of which are in a big city and I have always been a country girl. I have, over the course of the year, slowly taken over paying all the bills and they are even paid on time! I also have been going to the grocery without him.

Nothing is as fun without him by my side! We have always been a team. We will continue to be because my husband would do this for me and, in fact, has for many years. I am thankful for our journey, for what we have learned and for the friends we have made. In saying that, it doesn't mean that I don't have bad days. It just means that I chose to be positive! I know fear can and will cause me stress but I chose not to let fear control me. Knowledge is power! I won't allow this disease to consume my life with worry or fear!

Caregiver.... this word means a lot of things to me, I took vows 27 years ago, through sickness and in health, richer or poorer, until death do us part! This is only a chapter in our book of life, we take one page (day) at a time, together!





Dennis "dmanflan"
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!

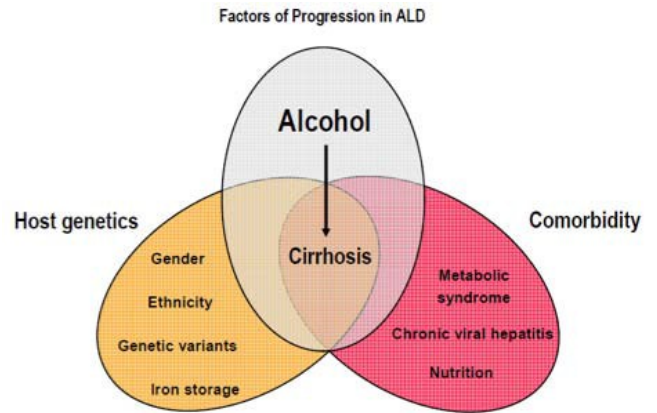
I received a new liver in July of 2008. I destroyed my native liver with alcohol developing cirrhosis with portal vein thrombosis (PVT) and eventually hepatocellular carcinoma (HCC). I had been completely sober for almost 2 years before my transplant.

Alcoholic Liver Disease (ALD) Progression

Your liver performs many jobs in your body. It process what you eat

Gail explained in her corner. The second stage of ALD is **Alcoholic Hepatitis**. Alcoholic hepatitis causes the liver to swell and become damaged. Symptoms may include loss of appetite, nausea, vomiting, abdominal pain, fever and jaundice. Up to 35 percent of heavy drinkers develop alcoholic hepatitis. Alcoholic hepatitis can be mild or severe. If it is mild, liver damage may be reversed. If it is severe, it may occur suddenly and quickly lead to serious complications including liver failure and death.

Finally, the third stage of ALD is **Alcoholic Cirrhosis**. Alcoholic cirrhosis is the scarring of the liver—hard scar tissue replaces



ALD is a complex disease and accounts for the majority of chronic liver diseases in Western countries. Development and progression of ALD drinking alcohol and other environmental or individually acquired factors that interact over time. While many environmental factors are now well-recognized by scientific studies, recent advances in our understanding of the role of genetics in the development of diseases in man called for additional research activities for genetic factors that influence ALD.

ing daily vs. binge drinkers showed that the former had a higher risk of cirrhosis.

An unequivocal risk factor for fibrosis progression in ALD is obesity, with numerous studies demonstrating that being overweight is the most important single risk factor of cirrhosis and tissue death in drinkers. Gender also plays a role in determining the likelihood of ALD cirrhosis with women being more susceptible than men for the same amount of alcohol.

Whether the type of alcoholic drink consumed, e.g. wine as opposed to beer or hard liquor, impacts the risk of ALD is still controversial, however, consensus among scientists is the content of actual alcohol likely outweighs all other ingredients in different drinks that may potentially control the effects of alcohol to the body's systems. Patterns of drinking also influence the risk of ALD and usually vary substantially among patients. There are conflicting data on this issue, but several recent studies compar-

The bottom line still comes back to the fact that ALD cannot be predicted based on the amount or type of alcohol intake. The only sure way for someone with liver disease to have a long term possibility for life is to abstain from alcohol in totality. The liquor industry in the US uses the phrase "Think before you drink!" not only to prevent people from drinking and driving but, in a feeble way, to warn people about the dangers of drinking!



and drink into energy and nutrients your body can use. The liver also removes harmful substances from you blood. Alcohol can be a harmful substance to your body. It doesn't matter what type of alcohol that you drink: beer, wine or spirits. It doesn't necessarily matter how much you drink either, just as how many years you've been drinking. Liver injury or serious damage occurs when you drink more alcohol than your liver can process. Alcohol can affect other organs of the body as well.

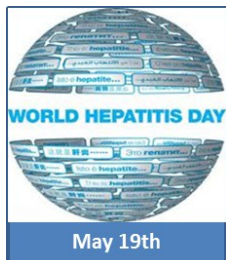
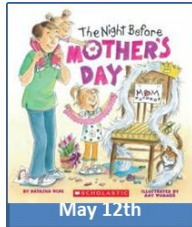
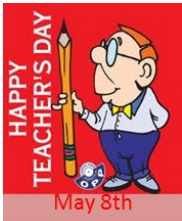
soft healthy tissue. It is the most serious type of alcohol-related liver disease. Symptoms of cirrhosis are similar to those of alcoholic hepatitis. Between 10 and 20 percent of heavy drinkers develop cirrhosis. The damage from cirrhosis cannot be reversed and can cause liver failure. Not drinking alcohol helps prevent further damage.

Once alcohol begins to exceed the liver's processing capabilities, Alcoholic Liver Disease (ALD) begins to occur. There are three main stages of ALD although progression through each stage does not occur at the same rate for everyone. The first stage is **Alcoholic Fatty Liver** disease, which

Many heavy drinkers will progress from fatty liver disease to alcoholic hepatitis to alcoholic cirrhosis over time. However, some heavy drinkers may develop cirrhosis without having alcoholic hepatitis first. Others may have alcoholic hepatitis but never have symptoms. Heavy drinkers who also have a chronic liver disease such as hepatitis C are at high risk for developing cirrhosis.



[®] This month, the national list of all patients waiting for an organ transplant rose to 114,267 and is only going up! It only takes a few moments to register to possibly save up to 7 lives or improve the quality of life for more than 100 people in need of tissue, cornea or bone donation, which area not currently on any waiting list.
Go to www.DonateLife.net to find out how to register in your state. It is just as important to talk about your decision with your loved ones so they know your intentions.



Events this Month



Phrases of the Month:

- ☛ "Isn't it appropriate that the month of the tax begins with April Fool's Day and ends with cries of "May Day !
- ☛ I have been driven many times to my knees by the overwhelming conviction that I had absolutely no other place to go." Abraham Lincoln
- ☛ "Cinco de Mayo has come to represent a celebration of the contributions that Mexican Americans and all Hispanics have made to America." ~ Joe Baca.
- ☛ Nurses dispense comfort, compassion and caring without even a prescription. ~Val Saintsbury
- ☛ Nurses are I.V. leaguers. ~Author Unknown
- ☛ "A good teacher is like a candle - it consumes itself to light the way for others." -Anonymous
- ☛ Being a full-time mother is one of the highest salaried jobs... since the payment is pure love. ~Mildred B. Vermont
- ☛ "Today let us, as Americans, honor the American fighting man. For it is he—the soldier, the sailor, the Airman, the Marine—who has fought to preserve freedom. It is his valor that has given renewed hope to the free world that by working together in discipline and faith our ideals of freedom will always prevail." Admiral Forrest P. Sherman
- ☛ "No duty is more urgent than that of returning thanks." James Allen
- ☛ And hail their queen, fair regent of the night. Erasmus Darwin
- ☛ "We often take for granted the very things that most deserve our gratitude." Cynthia Ozick

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



© None reported



Transplant Anniversaries

⚭ None reported

UNOS Waiting List Livers (April 13, 2012)

Status 1A	4
Status 1B	7
Status 7 (Inactive)	3,293
MELD / PELD <10	5,019
MELD / PELD 11-18	5,489
MELD / PELD 19-24	1,758
MELD / PELD 25+	1,241
Total Waiting	16,811

Courtesy OPTN reports

500 liver transplants performed
500 livers donated/recovered



☛ May 15 "lisel" Lisa's husband Jamie

☛ May 16 "scottswife's" husband Scott