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An Uncured Disease

By: Katie Farley

A disease so prominent, so recently discovered and so deadly has infected an estimated 5.3 million Americans. A process to test an individual only was discovered 1987 and perfected in 1989.

It is found in the blood, and can only be transmitted through blood. In California in the late 1980's, research scientists tested this disease, finding it to be similar to Hepatitis A and Hepatitis B, but also different from each one of them. There were other characteristics present in the DNA strands, and different effects the virus had on a person, so it was named Hepatitis C.

One of the main symptoms for this virus is fatigue. Bill Remak found this out the hard way when he was only 15 years old. At the time he was diagnosed with chronic liver disease, and then later, more specifically with Hepatitis C. Collapsing with a high fever and extreme weakness, Remak was taken to the hospital by ambulance. The teen was then quarantined because no one really knew what was wrong with him, and they figured whatever he had was rare. An acute attack of Hepatitis C, then known as infectious hepatitis, causing the patient in acute distress to be placed in a hospital, was not uncommon.

After spending a number of days in the hospital and enduring many needle sticks for blood samples and tests, there was not a clear result produced.

Antibiotics were administered to help the boy feel better. Researchers did not know much about the disease at the time, so they told his family and the boy they would get back with them if they found anything helpful. Remak was released and returned to his normal teenage life.

“You feel different.” Remak then said, “I was still focusing on the same thing as my friends at that age though. I was not thinking I am liver boy!”

This was not the last time Remak would deal with this though, both in his life and others.

The disease was only discovered some years ago, but it has been found in the blood of the remains of civil war soldiers. Researchers think it is much older than some of the common diseases present today.

Remak has now devoted his life to helping others with this disease. He is a national figure and speaks all over the country about Hepatitis C. He is an advocate and a supporter of both the research involved with hepatitis C and to those with the disease. Remak is based in Northern California, about 50 miles north of San Francisco. He is an Honorary member of the Board of Directors of the American Liver Foundation, the president of a clinic in Modesto, California that deals with alcohol and drug/substance abuse treatment and recovery and the hepatitis medical clinic called the Nirvana Institute. He is the Chairman of the California Hepatitis C Task Force, and is on the National Community Advisory

Committee for Hepatitis C of the Veterans Administration's Hepatitis C Resource Centers.

Being involved in so many aspects of the disease and the search for a cure has consumed Remak's life. He knew as soon as he was old enough to realize the extent of this disease that he wanted to work towards its advocacy.

He attended College of Marin, San Francisco State University, University of Copenhagen, and University of California San Francisco. While in attendance, he worked to receive a Bachelor's in Science and Public Health Administration, a Bachelor's degree in Medical Technology, and became a Medical Technologist. He dealt with certain aspects of lab data, and advanced his knowledge of the disease he had while not knowing it was slowly killing him.

In 1992, a bio-technical process to see if a person's blood had the antibodies that try to fight off the virus were present and was put to work to clear infected blood from our nations blood supply through the blood banks. This revealed if the person was exposed to the disease, but not if they had it. Some people's immune system can actually fight off the disease. This was useful to see if one in the medical field was actually exposed to it because these workers were at risk to being exposed to patient's blood. One can now be tested for the disease as early as three weeks after exposure.

Hepatitis C has a higher risk of being contracted than other diseases. One has a .2 percent chance of being transmitted with AIDS, and a 7.6 percent chance of exposure to Hepatitis C. Medical experts do not even know how long the virus can exist in dried blood. The recent time it is thought to be able to live

for is four to five days, however. Since it is a blood borne disease, Hepatitis C can be carried through shared needles such as those used for injecting drugs, steroids, IVs and piercing. Any blood to blood contact can transfer the virus from one person to the next, even simple means that no one would suspect. Razors and toothbrushes are a way of disease transmission as well. Bleach and boiling water do not kill the disease, but surgical sterilization such as autoclave works effectively to terminate it.

This spread of the disease has not however, helped our medical professionals burdened with demands to focus on helping patients, get the funding to find even more effective treatments to produce a cure for all those infected. The governmental institution that oversees disease research funding, the National Institution of Health (NIH) is spending \$3,053 in research money on each AIDS patient versus the \$20 on each Hepatitis C patient. The mortality rate of the two diseases is very similar and the frequency of Hepatitis C infection is 4 or 5 times greater.

A form of Chemotherapy called Interferon is used at times with some encouraging results for some, with slowing down the disease progression and in other cases eradicating it for an undetermined length of time. Some experts say diabetes will be cured before Hepatitis C because not enough funding is dedicated to its research. A person living with this virus can go 20 to 30 years with out having any symptoms, but other diseases enter the body and compound the health problems, it can be trouble. If discovered in the blood, vaccines for Hepatitis A and Hepatitis B are strongly recommended. If the body contracts

Hepatitis A or B in addition to Hepatitis C it is very hard on the person and further breaks down the immune system and may cause dire circumstances in some cases. People who contract another form of Hepatitis besides Hepatitis C can become even more ill than with a single form of the disease.

Hepatitis C mainly effects the liver cells and will cause reactions in the body that cause the organ to deteriorate. The liver tissue first turns into fiber-like cells, called fibrosis. The fibrous cells then turn to a stage called cirrhosis, where the formerly pink cells turn into module and strand-like clumps. The liver grows or swells in size and then shrinks and ultimately shuts down. There are five stages of liver disease, stage zero through four. By the time the disease is at stage two or three, doctors get serious and the patient is considered for treatment or is placed on a liver transplant list. By stage four, the liver may progress to Cancer and/or End Stage Liver Disease and stops working.

In 1995, Bill was referred to a transplant center, and was officially put on a transplant list one year later. In 1998, he had full liver cancer and his liver was failing.

The morning of January 4, 1998, Remak was awoken from his hospital bed and informed that a liver was found that would match. With less then 60 days to live at the time, he went into surgery January 5 at 1:30 am, and woke up feeling like a new person only six and one half-hours later. He was only hospitalized for seven days following the surgery; he would have been released in five days but was kept over the weekend due to a mild fever for observation purposes. Remak said, "It was the first time I had felt actually well in 35 years."

The man received the liver of a 58 year-old woman who suffered from a stroke. Cynthia Raymond, a retired government employee from Alameda, California, is Remak's self-proclaimed "hero". He has a portrait of the woman who saved his life when hers ended on his fireplace mantle.

Remak took this to the next level. He met the woman's family—her husband and her two daughters—in Texas, where they now reside.

Remak is an advocate of organ donation. There are not enough livers donated for transplant. Around 2800 people die each year, waiting for a transplant. "You can't take your organs to heaven, so you might as well keep them here with people who need them," he said.

In his home state of California, Remak has formed grassroots-style support groups for those who suffer from Hepatitis C. The group is a support system, but is also socially orientated. It offers a positive atmosphere for patients to discuss how the disease has effected their lives, as well as how they have overcome certain obstacles that have been thrown in their way. "No one wants to sit in a room full of depressed, complaining people," Remak said.

Type-two diabetes is one concern arising from liver failure that has affected Remak. Although many hurdles have stood in his way, Remak has challenged them all and helped many others over them as well. He has devoted his life to those with this disease and turned many negative aspects into positive reinforcements for change.

Now at a stage three and approaching stage four of liver disease again, Remak will need another liver within two years unless treatments are developed

that will reverse his disease. He says the only thing he can think of as a source to his disease, was having his ears pierced when he was 14 with his friends but it is a debatable point with him now. Turning personal misfortune into hope for others have consumed Bill Remak's heart and compassion to help others. This, he says, is a family tradition. This can be seen in his smile and his devotion to the cause-- he knows he is lucky to be alive.

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