Knowledge is power
Q&A with Dr. Jon McCone Jr.

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Patient resources across the country

Congressman Henry “Hank” Johnson (GA-04) shares his inspiring story of overcoming the odds

If you were born between 1945 and 1965, ask your healthcare provider today for an OraQuick® HCV test.

CDC recommends all Baby Boomers get a one-time Hepatitis C Test

If you were born between 1945 and 1965, ask your healthcare provider today for an OraQuick® HCV test.

Get tested today!
Viral hepatitis claims the lives of **12,000 to 15,000** Americans each year.

**IT IS TIME TO SPEAK UP**

The need to invest resources to overcome these barriers is pressing. We can’t afford to remain indifferent to the suffering and death associated with chronic viral hepatitis, nor will we be able to bear the future cost. Our leaders must support increased diagnosis and improved systems of care for persons with viral hepatitis. Solid science supports the need to act. Identifying the millions of Americans who do not know that they have viral hepatitis is not only the moral thing to do; it is the fiscally responsible approach to this burgeoning epidemic. Rather than cutting lives short, many at the peak of their productivity, and robbing families of their loved ones, we need to act before it is too late.

The challenges we face

Ironically, many of the challenges related to hepatitis are not due to a lack of science, but to the lack of infrastructure to support the science. Because our health care system does a poor job of viral hepatitis screening and testing, the majority of infected Americans remain undiagnosed until advanced liver damage has developed. Without knowledge of status, an individual cannot receive timely treatment or make life changes—such as cessation of alcohol, a healthy diet, and regular exercise—to stem the transmission and progression of liver disease and prolong a high quality of life.

**Looking to the future**

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**RESOURCES AND PATIENT SUPPORT GROUPS**

**Hepatitis C Association**  
Provides information for patients, clinicians, and caregivers, as well as emotional support.  
Call 1-877-437-4377

**Hepatitis Education Project**  
HBV and HCV testing / HBV vaccination for underserved populations in the Seattle/Tacoma, WA areas. Call: 1-800-218-6932

**The Hepatitis C Support Project**  
Call: 415-286-0993.  
http://www.hcvadvocate.org;  
http://hbvadvocate.org

**HELP-4-HEP**  
A national helpline for the hepatitis C community. Call 1-877-435-7443 from 9 am to 7 pm EST; Email: info@help4hep.org."HELP-4-HEP is a project of The Support Partnership, which includes HealthPro, FL; Hepatitis C Association, NJ; Hepatitis Education Project, WA; Hep C Connection, CO; and Project Inform, CA.

**The Hepatitis B Foundation/Association of Asian Pacific Community Health Organizations (AAPCHO)**  
http://www.hepbunited.org  
a national campaign to address the public health challenge of hepatitis B among Asian Americans.
The American Liver Foundation is often asked, “Who gets liver disease?” and the answer surprises people. Liver disease strikes people without regard to race, gender, age or socio-economic group. Babies born today will be the first generation to learn about liver disease and conditions and often need surgery or a transplant within the first few months of their life. Baby boomers are the group who’ve seen the most recent advances in treatments for hepatitis C, we have added 24 to 48 weeks of resources for those at risk and are cost-benefit evaluated with highly active antiviral therapy. Those with an obesity problem has a higher than average risk of having fatty liver disease.

My connection to liver disease started as a 13-year-old patient. Due to several autoimmune conditions, by the time I reached my early 20s I needed a liver transplant. I am one of the fortunate ones who received a transplant and consider myself blessed to be a 19-year transplant survivor. In addition to being a daughter, sister, wife, friend, lawyer, and healthcare consultant, I am the founder of the American Liver Foundation (ALF) and currently serve as its president and CEO. ALF has been working for nearly 25 years to eliminate the burden caused by liver disease. Our mission is to help people prevent, diagnose, and treat liver disease by educating the public and providing essential services for those at risk and affected by liver disease. The statistics surrounding cirrhosis and liver cancer are staggering: one in 33 baby boomers were born between 1945 and 1965 are at risk to have the disease and of those 75 percent are not aware they have the virus. This is such a compelling public health crisis the Centers for Disease Control recently made a recommendation that all baby boomers receive a one-time test to increase viral hepatitis testing. Dr. Maluf explains, “Now, it comes down to date of birth.

Today, more than 16,000 people die each year from liver disease and are living with a liver transplanted organ. This is the definition of what it means to be sick from hepatitis C. Patients who received a transplant as a result of hepatitis C are gifted with a new liver but not with a cure. The virus 25 years ago.

“The first thing doctors want to do is prevent you from transmitting the disease. The second thing doctors want to do is prevent you from getting the disease again,” ALF says. “It’s very important that you do something about it.”

ALF’s mission is to help people prevent, diagnose, and treat liver disease by educating the public and providing essential services for those at risk and affected by liver disease. The statistics surrounding liver disease affecting approximately 130 to 170 million people worldwide, according to the World Health Organization. The majority of these cases are caused by viral hepatitis C and B, which can lead to cirrhosis and liver cancer years after infection.

Many people don’t remember if they had a blood transfusion or a transplant before July 1965?

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People born between 1945-1965? Yes, you should take that action too, and if I can help make that happen, I’ve done my job.”

In 1999, Dr. Maluf was diagnosed with chronic hepatitis C, one of the most feared and misunderstood liver diseases. “I wish I could have done more to help my father, and I wish I would have known more about the disease.”

ALF says, “It’s very important that you do something about it.”

Now, it comes down to date of birth. Know your status, get tested. You could be almost certain that you have the antibodies, they do not have HCV—unless they have the results within 20 minutes. Rapid testing allows people to get their results immediately and can be sent to labs to get referrals to care of.”

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Dr. Maluf notes that people born between 1945 and 1965 can be almost certain that they do not have the antibodies, they do not have HCV—unless they have the results within 20 minutes. Rapid testing allows people to get their results immediately and can be sent to labs to get referrals to care of.”

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People are dying due to lack of knowledge—not lack of treatment options. Most people—upwards of 75 percent of those infected with HCV and 65 percent of the HBV-infected population—are not aware of it, so over the years, these viruses progress into cirrhosis and liver cancer—the second deadliest cancer after pancreatic cancer. Death rates from HCV doubled between 1999 and 2007, yet treatment options have increased. Michael Ninburg, Executive Director, Hepatitis C Support Project, says, “These are disease states that we can eliminate. HCV is vaccine-preventable and HBV is treatable.”

Hepatitis C-related deaths have been increasing for nearly a decade.

No matter what the result, there is treatment. Advocates have a sense of urgency around educating the public. Their focus is on prevention, getting people tested, treatment and providing emotional support. Alan Franciscus, Executive Director Hepatitis C Support Project, is optimistic. He says, “There has been so much improvement in awareness, management, and treatment in the last 15 plus years. I think the biggest change is in HCV treatment. When I was first diagnosed and treated with interferon monotherapy, there was only a 5 percent chance of a cure for my particular strain. Now we have a combination of medications that can cure up to 80 percent of people who take them.” Through his advocacy work, Franciscus and his colleagues emphasize that HCV is a blood-borne disease, which is spread by blood-to-blood contact (as in HBV) and that it is not a death sentence. He urges those infected to take precautions in order to not spread the virus, and also to avoid alcohol, eat a healthy diet and get exercise.

HCV can affect anybody. Regarding HBV, Block calls it “an equal-opportunity virus that can affect anybody.” Universal vaccination guidelines for newborns in the U.S. have drastically reduced the rate of new cases of HBV. Block notes that there is a “critical window of opportunity” in the first 24 hours after birth, during which newborns should be vaccinated. Without vaccination, a newborn whose mother is HBV-infected has a 90 percent chance of becoming chronically infected. This is a missed opportunity, because HBV is the deadliest vaccine-preventable disease there is,” she says. According to the Hepatitis B Foundation, Asian Americans are at particular risk. One in ten Asian Americans has HBV, and two out of three don’t know it. Block says, “You can’t be treated unless you know it. There are good treatments that can help stop the disease from progressing to liver cancer. It’s better to treat sooner, rather than later.” The Hepatitis C Support Project, the Hepatitis B Foundation and the Hepatitis Education Project are on the forefront of helping patients connect the dots between testing, prevention, treatment and support, for patients, clinicians and caregivers. There are also other organizations with both local and national services (see page 5). Health Pro Solutions, a Hepatitis C advocacy organization headed up by And Thomas has mapped the information to make it easier to find local resources. For more information, please visit: hepcluda.org, www.hepbunited.org and hepfound.org.

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Question: What was your diagnosis?
Answer: My family was very supportive. My wife Mindia, by whom I have stood from the beginning, and she provided strength in helping me overcome this illness. When I was weak, she was strong. She has been my rock throughout this entire process.

What led you to your role in Congress?
As a kid growing up in Washington, D.C., I decided to become a lawyer like my Dad, Archibald Hill Sr. (Tokey). My mom got me interested in politics by requiring me to read the articles on the front page of the Washington Post to her as she washed dishes after dinner. With that interest in public affairs, and when Tokey won a seat in the Oklahoma legislature, it took me back to my mindset that I would someday become a congressman.

What was the most difficult part about managing your treatment with your career?
During the yearlong fight to pass the Affordable Care Act, I’ve been undergoing a debilitating round of hep C treatments, and my thoughts were of those who did not have the means to access the same health care that I was privileged to be receiving. My illness helped motivate me to become a strong advocate for passage of the ACA, as well as other legislation that promotes the health safety and prosperity of all the people. There were days when I was weak, but because of the hard work and dedication of my staff in D.C. and back home, we never missed a beat.

What type of message about hep C do you want to reach?
More funding—not just lip service to awareness but in research and for treatment. I have not felt alone—and that I must do all I can to help others who are suffering from this silent epidemic. I’ve become a face for the disease—and while I don’t want hep C to be a role model for others to take control of the illness and prevent.

As a country, what are our next steps in the fight against hep C?
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I take great pride in being a role model for others to take control of the illness and prevent.

Now that you’ve been proclaimed cured of hep C, what do you take with you?
That it isn’t alone—and that I must do all I can to help others who are suffering from this silent epidemic. I’ve become a face for the disease—and while I don’t want hep C to be a role model for others to take control of the illness and prevent.

What is Ribasphere (ribavirin, USP)?
Ribasphere is a medicine used with another medicine called peginterferon alfa-2a to treat chronic (lasting a long time) hepatitis C infection in people whose liver still works correctly, and who have not been treated before with a medicine called a protease inhibitor. It is not Hepatitis C virus infection and will work in children under 18 years of age.

The Ribasphere treatment includes:
• are breast-feeding. It is not known if Ribasphere passes into your breast milk. You and your sexual partner should use two forms of reliable birth control when you take Ribasphere and for the 6 months after treatment.

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The most serious side effects of Ribasphere (ribavirin, USP) are:
• Stevens and dermatitis of your mucous membranes (erythromelalgia). You may have stomach pains, nausea, vomiting or diarrhea.
• Severe allergic reactions. Symptoms may include hives, swelling, trouble breathing, shortness of breath, swelling of your mouth, tongue, or lips, or severe rash.
• Serious breathing problems. Difficulty breathing may be a sign of a serious lung infection (pneumonia) that can lead to death.
• Serious eye problems that may lead to visual loss or blindness.
• Liver problems. Some people may get muscle wasting or liver problems.
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Call your healthcare provider or get medical help right away if you have any of these symptoms while you are taking Ribasphere (ribavirin, USP) treatment.

Side effects that are not serious but may affect your ability to take Ribasphere (ribavirin, USP) include:
• Feeling generally tired, headache, drowsiness, lack of energy, or trouble waking up in the morning.
• Nourishing, appetite, fatigue, or tiredness.
• Feeling depressed.

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**Chronic HCV Treatment is Complicated**

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**Important Safety Information about Ribasphere RibaPak (ribavirin, USP) Tablets**

Ribasphere® RibaPak® (ribavirin, USP) Tablets is a medicine used with another medicine called peginterferon alfa-2a to treat chronic hepatitis C infection in adults whose livers still work normally, and who have not been treated before with a medicine called an interferon alpha.

The following is the most important information you should know about Ribasphere RibaPak:

1. You should not take Ribasphere (ribavirin, USP) alone to treat chronic hepatitis C infection.
2. Ribasphere may cause you to have a blood problem (hemolytic anemia) that can worsen any heart problems you have, and cause you to have a heart attack or die. People with a history of serious heart disease should not be treated with this medicine. Please talk to your health care professional to see if this medicine is right for you.
3. Ribasphere may cause birth defects or death of your unborn baby. You should not take this medicine if you are pregnant or your sexual partner is pregnant, nor should you or your partner become pregnant while you are taking Ribasphere and for 6 months after you stop treatment. You need to use two forms of reliable birth control when you take Ribasphere and for the 6 months after treatment.

For more information, please see the Ribasphere RibaPak (ribavirin, USP) Tablets Brief Summary of safety information on the previous page.

Please see full Prescribing Information available at RibaPak.com. Safety information for other drugs you may take as part of combination therapy should also be reviewed before you begin treatment. Be sure to talk to your doctor or other health care professional.