

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

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Patient resources
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**MEDIA
PLANET**

September 2012

HEPATITIS & LIVER HEALTH

**GET
TESTED
TODAY!**

LISTEN UP!

Musicians advocating for
hepatitis awareness:



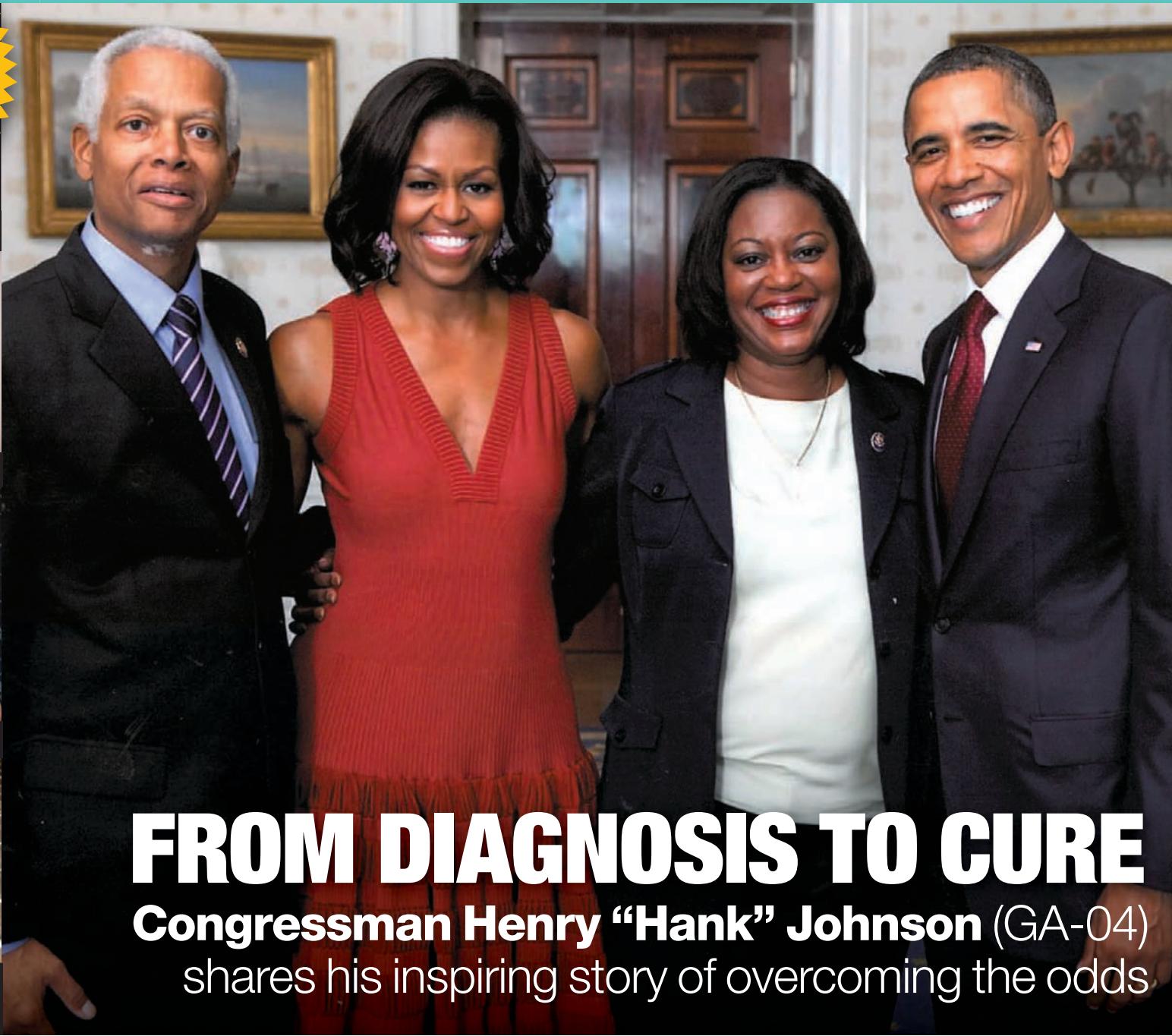
NATALIE COLE



JON SECADA



GREGG ALLMAN
PHOTOS ABOVE: TUNE IN TO HEP C
PHOTO RIGHT: SPECIAL FROM CONGRESSMAN
JOHNSON'S OFFICE



FROM DIAGNOSIS TO CURE

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

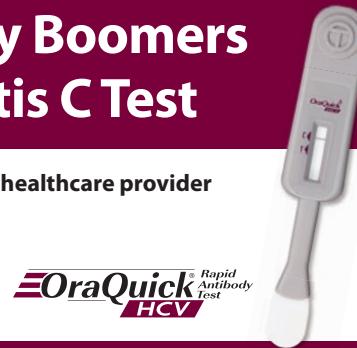
20

minutes to know
if you may have
Hep C

CDC recommends **all Baby Boomers**
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CHALLENGES



WE RECOMMEND



Q&A with Jon
McCone Jr.
MD, FACG,
AGAF

PAGE 10

“...get a HCV
antibody test.
IT CAN
BE CURED.”

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PLANET

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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

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



hronic hepatitis B virus (HBV) and chronic hepatitis C virus (HCV), referred to together as viral hepatitis, are called “silent killers” because they can be asymptomatic for years while slowly causing severe liver damage. Silent too, because viral hepatitis remains virtually unknown to the general public, at-risk populations, and even healthcare providers lack critical knowledge about these infections. Complacency and inaction by policy makers contributes to the silence.

High risk communities

Asian Americans and Pacific Islanders account for over half of chronic HBV cases. Baby boomers account for nearly three quarters of chronic HCV cases. African Americans, Latinos, and American Indians/Native Alaskans have disproportionately high rates of both viruses. Yet most of the estimated 5 million people living with chronic viral hepatitis in the United States do not know it because no wide reaching system is in place to test high prevalence and at risk populations. Opportunities for life-saving prevention and care are missed. HBV is vaccine-prevent-

able, yet, tragically there are still 800 to 1,000 new cases of perinatally acquired HBV in the U.S. each year, due to missed vaccination of newborns. Moreover, HCV is largely curable, but rates of diagnosis and treatment remain low. The CDC recently recommended that all baby boomers be tested for the virus. This recommendation is significant and long awaited, but the recommendation will go nowhere without infrastructure to support the identification and care for people with HCV.

The societal impact is far-reaching. Chronic viral hepatitis is the primary cause of liver cancer, resulting in the loss of lives and the destruction of families. More than 150,000 Americans will die from liver cancer or end-stage liver disease in the next decade. Viral hepatitis remains the leading cause of liver transplantations in the U.S. The cost of medical care and hospitalization for end stage liver disease, liver transplant, and liver cancer far outweighs the cost of identifying those who are at risk.

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

“Without knowledge of status, an individual cannot receive timely treatment or make life changes.”



Martha Saly,
DIRECTOR, NVHR

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

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.

MARTHA SALY

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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.

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>

★ DON'T MISS

Social status: online tools seek increased liver donations

Obesity rates challenge supplies

Today, more than 16,000 patients wait for liver transplants, most suffering from hepatitis C and fatty liver disease, a build-up of triglyceride fat in liver cells. With half of nation's donation centers now capping donors' body mass index at 35, improving donor health seems daunting. Instead, groups are focusing on broadening the donation call, with many efforts going online.

A friend in the cause

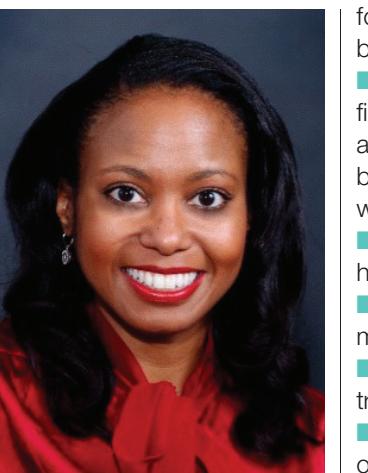
Earlier this year, organ donation found an ally in Facebook when the site offered users the ability to display their organ donor status as part of timeline's Health and Wellness section. The tool also links users to their state's official organ-donation site, so users can complete legal registries if they haven't already done so. Less than four months into the program, 260,000 users signaled their commitment.

Facebook Director of Policy Communications Sarah Feinberg points out that beyond the number of listed donors, word spreads exponentially as endorsements and confirmations of a donor's desires. "The average Facebook user has 120 friends. So every time they are sharing that information with a huge group of that 120," said Feinberg.

"We're so excited to see things like the Facebook campaign reaching out and creating opportunities," Donna Cryer, President and CEO of the American Liver Foundation, said. "I think the most important step of that is making sure friends and family who'd be actually making the real decision to donate on their behalf know about the desire to donate."

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MITIGATING THE RISK



Donna Cryer
President and CEO,
American Liver Foundation

The American Liver Foundation is often asked, "Who gets liver disease?" and the answer surprises people. Liver disease strikes people of every age, gender, race and socio-economic group. Babies are born with life-threatening liver conditions and often need surgery or a transplant within the first few months of their lives. Baby boomers are the group most likely to have contracted the hepatitis C virus. Anyone 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 auto-immune conditions, by the time I reached by early 20s I needed a liver transplant. I am one of the fortunate ones who received a transplant and consider myself blessed to be an 18 year transplant survivor, in addition to being a daughter, sister, wife, friend, lawyer, and

healthcare consultant.

I now have the privilege of transforming my personal patient experience into professional patient advocacy as the President and CEO of the American Liver Foundation. The Foundation serves patients and families facing all types of liver disease and with the most recent advances in treatments for hepatitis C, we have added extra support and resources for those at risk and those already diagnosed with hepatitis C.

The statistics surrounding hepatitis C in the United States are staggering: one in 33 baby boomers (those 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 looming public health crisis the Centers for Disease Control recently made a recommendation that all baby boomers receive a one-time test for hepatitis C.

And if you are not a baby

boomer, what are the other risk factors? The list is short but important:

- Worked in a place where you came in contact with infected blood or needles, for example, health care workers
- Received a blood transfusion or organ transplant before July 1992
- Received a blood product

DONNA CRYER
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A CONCERT FOR A CAUSE:

Fighting back against hepatitis C with education, advocacy, and music.

Chronic hepatitis C is a blood-borne disease affecting approximately 130 to 170 million people worldwide, according to the Centers for Disease Control and Prevention, including 3.2 million Americans.

Tune In to Hep C, a public health campaign between Merck and the American Liver Foundation is designed to help raise awareness of chronic hepatitis C virus infection.

Living with hepatitis C

According to the National Institutes of Health (NIH), symptoms of chronic hepatitis C virus (HCV) infection include fatigue, jaundice and dark urine. However, approximately 70 to 80 percent of infected individuals don't show any symptoms. HCV leads to liver



NATALIE COLE

"One thing is for sure — there's a stigma surrounding hepatitis C because it's associated with IV drug use. But it really doesn't matter how you got the virus. What's important is that you do something about it."



JON SECADA

"I wish I could have done more to help my father, and I wish I had known more about the disease. That's why I'm sharing my family's personal story with others."



GREGG ALLMAN

"Doing nothing is not an option; they need to talk with their doctor."

In August 16, 2012, the CDC issued new hepatitis C (HCV) testing guidelines that could help identify more than 800,000 cases of undiagnosed cases of HCV in people born between 1945 and 1965. More than 2 million people in this target birth cohort—"the baby boomers"—are HCV infected, and 75 percent don't know it.

People in this target birth cohort are five times more likely to be infected than other adults. And because HCV is asymptomatic until the liver starts to show signs of damage, more than 15,000 people in this group die each year of cirrhosis or liver cancer simply because they were not tested.

Had they been tested, they could have been treated or made lifestyle changes to greatly improve their long-term outcomes.

There is a big push underway to increase viral hepatitis testing. An important boon to this effort has been more widespread use of the OraQuick HCV Rapid Anti-

body Test, an FDA-approved, point-of-care test. According to Colleen Flanigan, RN, Viral Hepatitis Coordinator, New York State Department of Health, "This is a good test. We are using it as part of a statewide program. It only requires a finger prick and you don't need an onsite lab to get results. For patients, it's less invasive. You can get tested and have the results within 20 minutes. Rapid testing allows people to get screened, and if necessary, get referred to linkage of care."

It is important to note that the OraQuick test is antibody based. That means that it is designed to detect HCV antibodies. If antibodies are present, then further medical attention and diagnostics are required. If a patient does not have the antibodies, they can get treated if they have symptoms—and if not, they can get a simple ultrasound each year to check the health of their liver. Being aware of HCV status can not only help people live longer, but put their minds at ease.

Both Dr. Maluf and Ms. Flanigan agree that the new testing guidelines decrease the stigma around testing. Dr. Maluf explains, "Now, it comes down to date of birth. Many people don't remember whether they had a blood transfu-

"Now it comes down to date of birth."

sion as a child, or they don't want to discuss topics they consider taboo, such as injectable drug use or sexual history." The advantages of testing outweigh the inconvenience of taking 20 minutes to get tested. Dr. Maluf notes that if a person is HCV-positive, they can get treated if they have symptoms—and if not, they can get a simple ultrasound each year to check the health of their liver. Being aware of HCV status can not only help people live longer, but put their minds at ease.

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BABY BOOMERS: Know your status, get tested

FIND OUT IF YOU HAVE HEPATITIS C IT COULD SAVE YOUR LIFE

BORN FROM 1945-1965?

Up to 75% of people living with Hepatitis C DO NOT KNOW THEY ARE INFECTED

CDC recommends anyone born from 1945-1965 GET TESTED

TESTED

KNOWING YOU HAVE HEPATITIS C can help you make important decisions about your health

RX Many people can get LIVESAVING CARE AND TREATMENT

Successful treatments can ELIMINATE THE VIRUS from the body

NOT TESTED

LEFT UNTREATED, HEPATITIS C can cause liver damage and LIVER FAILURE

HEPATITIS C is the #1 CAUSE OF LIVER TRANSPLANTS

HEPATITIS C is a leading cause of LIVER CANCER

PETRA CANAN
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Don't go down the wrong path, talk to your doctor about getting tested. It could save your life.

CDC

U.S. Department of Health and Human Services Centers for Disease Control and Prevention

KNOW MORE HEPATITES

NEWS

GETTING SMART ABOUT VIRAL HEPATITIS

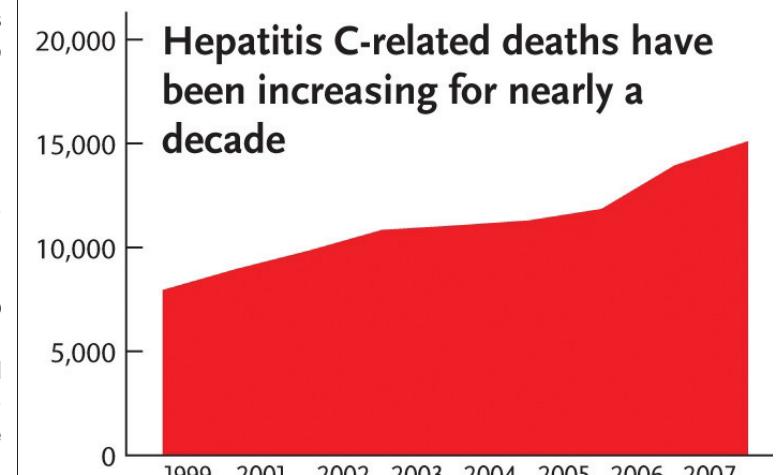
Recently, there has been a lot of positive news about viral hepatitis. In April 2012, investigators were excited about the results of a large clinical trial in which hepatitis C (HCV) was cured in 82 percent of patients treated with a new combination of antiviral drugs. Most exciting was the fact that the drugs could be taken orally and had few side effects, compared with earlier treatment options. It was big news for the advocacy community.

Educators and advocates who focus on the needs of the viral hepatitis community—including HCV and hepatitis B (HBV)—viewed this medical breakthrough as another important step forward; however a lot remains to be done when it comes to disease-state awareness.

What you don't know can kill you

Consider this: Each year, approximately 15,000 HCV-infected individuals die of related causes, as do roughly 5,000 people who are HBV infected. Joan Block, RN, BSN, Executive Director and Co-Founder, Hepatitis B Foundation, explains, "Viral hepatitis is the leading cause of liver cancer in the United States (U.S.) and liver cancer is the only cancer that is increasing in prevalence."

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



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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 9 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,

"People are dying due to lack of knowledge—not lack of treatment options."

Franciscus and his colleagues emphasize that HCV is a blood-borne disease, which is spread by blood-to-blood contact (as is 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.

HBV can affect anybody

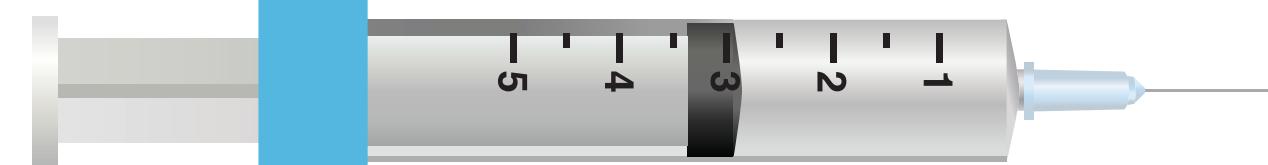
Regarding HBV, Block calls it "an equal-opportunity virus that can affect anybody." Universal vaccination guidelines for newborns in the U.S. have drastically reduced the rate of new cases of HBV. Block notes that there is a "critical window of opportunity" in the first 12 to 24 hours after birth, during 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 Andi Thomas has mapped the information to make it easier to find local resources. For more information, please visit: healthpro.us/maps. The Hepatitis B Foundation has done the same for HBV-related resources and information: hepbunited.org.

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ONE NEEDLE, ONE SYRINGE, ONLY ONE TIME.



Safe Injection Practices Coalition

www.ONEandONLYcampaign.org

The One & Only Campaign is a public health campaign, led by the Centers for Disease Control and Prevention and the Safe Injection Practices Coalition, to raise awareness among patients and healthcare providers about safe injection practices. The campaign aims to eradicate outbreaks resulting from unsafe injection practices. The CDC Foundation is a founding partner and serves as the coordinating organization of the coalition.



CDC FOUNDATION

Helping CDC Do More, Faster

INSPIRATION

QUESTION
& ANSWERJonathan
McCone, Jr.,
MD, FACG, AGAF

CONGRESSIONAL COURAGE

Mediaplanet sits with Congressman Henry "Hank" Johnson

What are the most common symptoms of hepatitis C?

Symptoms are late—often after decades. A small scarred liver cannot make proteins and clear poisons—confusion, forgetfulness, swelling of legs and abdomen, yellow eyes, dark urine and itching, enlarged esophageal veins under pressure may rupture and bleed and skin bruising from low platelets may occur. Goal: be cured of virus before these signs and symptoms occur.

If diagnosed, how should people alter their lifestyle?

AVOID ALCOHOL—it accelerates the disease and makes a cure less likely. Avoid anything that might transfer blood: sharing toothbrushes, needles, razors, manicure or pedicure instruments. Basically it's not a sexually transmitted disease—but transmission can occur if rough sex results in bleeding, during anal receptive intercourse without condoms, or if a partner is HIV positive.

What's the biggest misconception surrounding HCV?

That it is like HIV/AIDS, that it cannot be cured, that transmission is easy by touching, kissing, breathing, or sharing eating utensils, that if you're not sick and have normal standard blood tests you are ok.

What steps can be taken to protect myself and my loved ones?

Avoid the risky blood sharing behavior mentioned in #2—avoid alcohol, get a HCV antibody test. IT CAN BE CURED.

JONATHAN MCCONE JR.
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"I take great pride in being a role model for others to take control of the illness and prevail."

Congressman Johnson, Mereda Johnson, and President Obama

Question: What was your reaction when you were first diagnosed with Hepatitis C?

A: My family was very supportive. My wife Mereda has stood by my side 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.

Q: What led you to your role in Congress?

A: As a kid growing up in Washington, D.C., I decided to become a lawyer like my cousin Archibald Hill, Sr. (Tokey). My mother 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 became a part of my mindset that I would someday become a congressman.

Q: How did your family and friends respond to the news?

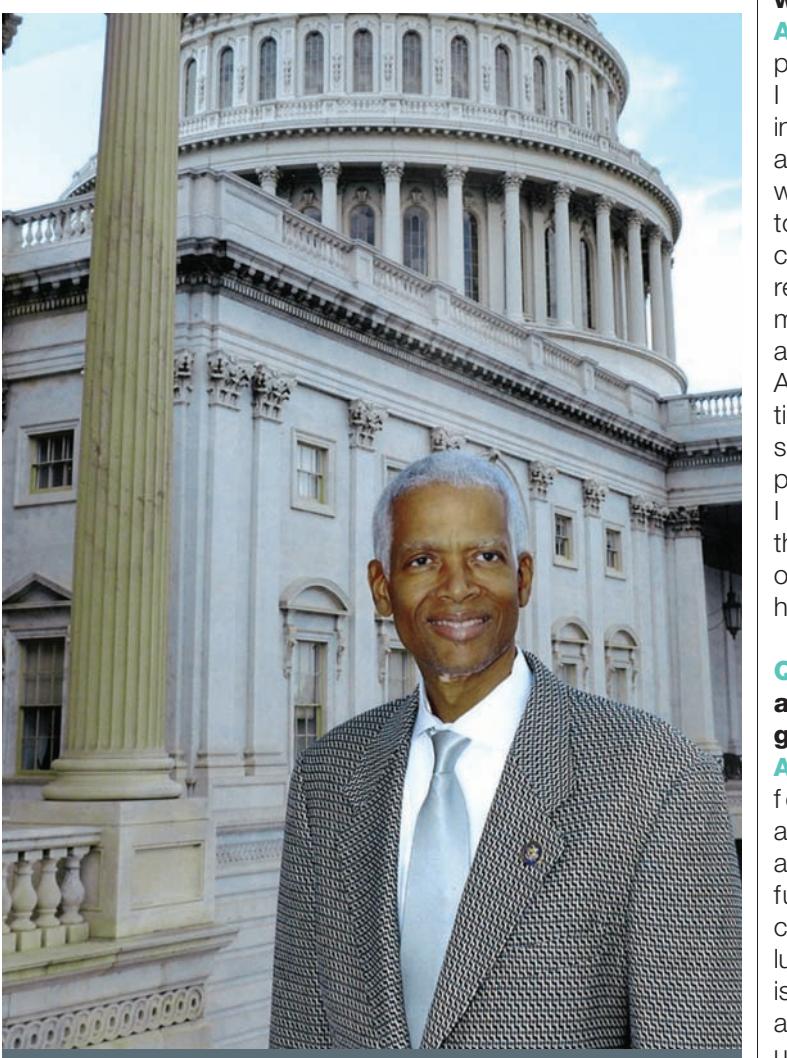
A: During the yearlong fight to pass the Affordable Care Act, I was undergoing a debilitating round of hep C treatments, and my thoughts were of those who did not have the means to access the same health care that I was privileged to be receiving. My illness helped motivate me to become a strong advocate 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.

Q: As a country, what are our next steps in the fight against hep C?

A: More funding—not just simply to raise awareness but in research and testing. Specifically, I'm asking for my colleagues to support H.R. 3381, the Viral Hepatitis Testing Act of 2011. We can save lives and help others avoid the needless suffering and debilitating medical costs associated with treating this disease.

Q: What type of message about hep C do you want to get across to Capitol Hill?

A: The critical need for access to quality, affordable health care for all Americans. Thankfully, I had access to great care, but not everyone is so lucky. The Affordable Care Act is a step in the right direction, and now that the ACA has been upheld, we must rededicate ourselves to ensuring that all Americans have the care



A TRUE ADVOCATE
Congressman Johnson challenges D.C. to take hepatitis seriously
PHOTOS: SPECIAL FROM CONGRESSMAN JOHNSON'S OFFICE

HENRY "HANK" JOHNSON
editorial@mediaplanet.com

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Ribasphere® RibaPak®
(ribavirin, USP) Tablets

The most serious side effects of Ribasphere (ribavirin, USP) are:

- Swelling and irritation of your pancreas (pancreatitis). You may have stomach pain, nausea, vomiting or diarrhea.
 - Severe allergic reactions. Symptoms may include hives, wheezing, trouble breathing, chest pain, 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 vision loss or blindness.
 - Liver problems. Some people may get worsening of liver function. Tell your healthcare provider right away if you have any of these symptoms: stomach bloating, confusion, brown urine, and yellow eyes.
 - Severe depression
 - Blood disorder involving low levels of red blood cells (anemia).
 - Suicidal thoughts and attempts
- Call your healthcare provider or get medical help right away if you have any of the symptoms listed above. These may be signs of a serious side effect of Ribasphere (ribavirin, USP) treatment.

Common side effects of Ribasphere (ribavirin, USP) taken with peginterferon alfa-2a includes:

- flu-like symptoms—feeling tired, headache, shaking along with high temperature (fever), and muscle or joint aches
- mood changes, feeling irritable, anxiety, and difficulty sleeping
- loss of appetite, nausea, vomiting, and diarrhea
- hair loss
- itching

Before you take Ribasphere (ribavirin, USP), tell your healthcare provider if you have or have had:

- treatment for hepatitis C that did not work for you
- serious allergic reactions to Ribasphere
- breathing problems. Ribasphere may cause or worsen your breathing problems you already have.
- vision problems. Ribasphere may cause eye problems or worsen eye problems you already have. You should have an eye exam before you start treatment with Ribasphere.
- certain blood disorders such as anemia
- high blood pressure, heart problems or have had a heart attack. Your healthcare provider should test your blood and heart before you start treatment with Ribasphere.
- thyroid problems
- diabetes. Ribasphere and peginterferon alfa-2a combination therapy may make your diabetes worse or harder to treat.
- liver problems other than hepatitis C virus infection
- human immunodeficiency virus (HIV) or other immunity problems
- mental health problems, including depression or thoughts of suicide
- kidney problems
- an organ transplant
- drug addiction or abuse
- infection with hepatitis B virus
- any other medical condition
- are breast-feeding. It is not known if Ribasphere passes into your breast milk. You and your healthcare provider should decide if you will take Ribasphere or breast-feed.

Medicine Interactions:

Tell your healthcare provider about all the medicines you take, including prescription and non-prescription medicines, vitamins and herbal supplements. Some medicines can cause serious side effects if taken while you also take Ribasphere. Some medicines may affect how Ribasphere works or Ribasphere may affect how your other medicines work. Especially tell your healthcare provider if you take any medicines to treat HIV, including didanosine (Videx®² or Videx EC³), or if you take azathioprine (Imuran³ or Azasan⁴).

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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.

Ribasphere® RibaPak®
(ribavirin, USP) Tablets