



ABOUT THE HEPATITIS B FOUNDATION

The Hepatitis B Foundation, founded in 1991, is the only national nonprofit organization dedicated solely to those affected by hepatitis B. With its offices and state-of-the-art research facilities in Bucks County, Pennsylvania, the foundation accomplishes its work with a dedicated staff of researchers, educators, and outreach experts. We work with leading physicians, scientists, academic institutions, corporations, government agencies, and other nonprofit organizations in our search for a cure and in raising public awareness.

With one in 20 Americans having already been infected with hepatitis (and one out of three people worldwide), it is a serious problem that reaches people of all ages and crosses all cultures around the world. Through its efforts the Hepatitis B Foundation brings new hope through discovery research and compassionate outreach to meet its clearly stated mission.

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LIVING WITH HEPATITIS B

Hepatitis B Foundation

Cause for a Cure



Our Mission Statement

The Hepatitis B Foundation is a national nonprofit organization dedicated to finding a cure and improving the quality of life for those affected by hepatitis B worldwide. Our commitment includes funding focused research, promoting disease awareness, supporting immunization and treatment initiatives, and serving as the primary source of information for patients and their families, the medical and scientific community, and the general public.



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Special Note to Families and Children With Hepatitis B

Hepatitis B does not usually affect a child's normal growth and development. Most children with chronic hepatitis B infections will enjoy long and healthy lives. Unlike other chronic medical conditions, there are generally no physical disabilities associated with hepatitis B, nor are there usually any physical restrictions for these children.

As a parent, you can take comfort from the fact that every child presents unique challenges. Therefore, your child with hepatitis B is just like any other child. The challenges of raising a child with hepatitis B are manageable if you are well informed and use common sense.

The Hepatitis B Foundation has compiled a list of useful guidelines that may be helpful. Please visit our website @ hepb.org/patients/advice_for_parents for more detailed information or call 215-489-4900 to speak to one of our trained counselors about your personal situation.



One / Hepatitis B is...

Hepatitis B is the most common liver infection in the world. It is caused by the hepatitis B virus (HBV), which can attack and injure the liver. HBV is transmitted through blood and infected bodily fluids. This can occur through direct blood-to-blood contact, unprotected sex, unsterile needles, and from an infected woman to her newborn during pregnancy or delivery.

- ▶ Two billion people around the world (almost one out of three persons) have been infected with hepatitis B. Of these, 400 million are chronically infected.
- ▶ Each year, there are 10-30 million new infections worldwide.
- ▶ Each year, there are one million deaths worldwide due to hepatitis B.
- ▶ In the U.S., there are approximately 1.25 million people who are chronically infected with hepatitis B, and there are almost 100,000 new infections each year.
- ▶ Hepatitis B is a silent disease, which means that someone can be infected for years, even decades, without having any symptoms.



Did You Know

Most healthy adults who are infected with hepatitis B will recover without problems. Unfortunately, this is not true for infants and children. The younger a person is when they are first infected with the virus, the greater their risk of developing a chronic infection.

- ▶ If an adult is infected – 10% will develop chronic infections
- ▶ If a child is infected – up to 50% will develop chronic infections
- ▶ If an infant is infected – 90% will develop chronic infections

Two / Understanding Your Blood Tests



Through a blood test, perhaps because you have been having symptoms, or perhaps after you have donated blood, you have tested positive for hepatitis B. The first thing to remember is *Don't Panic*. The Hepatitis B Foundation is here to help. We describe in this booklet what you need to learn and do next in small, simple steps.

Remember to ask the doctor to explain each test result to you, and get a copy of your blood test results for your own files. The following section will explain the three tests that make up the hepatitis B blood panel.

Three Hepatitis B Blood Panel

The hepatitis B blood panel is made up of three tests, but you only need to give one blood sample. This test can be done easily in your doctor's office or local health clinic.

- ▶ **Hepatitis B Surface Antigen (HBsAg):**
 If this test is positive, then the hepatitis B virus is present in the blood. This means that you have a hepatitis B infection.
- ▶ **Hepatitis B Surface Antibody (HBsAb or anti-HBs):**
 If this test is positive, then you are immune to (or protected against) hepatitis B.
- ▶ **Hepatitis B Core Antibody (HBcAb or anti-HBc):**
 If this test is positive, then you may have been exposed to the hepatitis B virus, but it does not confirm a current infection.



Four Common Hepatitis B Test Results

Sometimes the hepatitis B blood panel can be difficult to interpret. Your blood test results may look different than these, so please make sure your doctor fully explains the results to you. Please refer to the Blood Tests page of our website for more detailed information at www.hepb.org/patients/your_blood_tests.

NOT INFECTED

Tests	Results	Interpretation	Recommendation
HBsAg	Negative (-)	NOT IMMUNE – has not been	Get the vaccine
HBsAb	Negative (-)	infected but is still at risk for possible	
HBcAb	Negative (-)	future infection – needs vaccine	

IMMUNE

Tests	Results	Interpretation	Recommendation
HBsAg	Negative (-)	IMMUNE – has been vaccinated	Vaccine is not needed
HBsAb	Positive (+)	or recovered from previous	
HBcAb	Negative or Positive	infection – cannot infect others	

Five Testing Positive for Hepatitis B

POSSIBLE INFECTION

Tests	Results	Interpretation	Recommendation
HBsAg	Negative (-)	UNCLEAR – several interpretations are possible – all 3 tests should be repeated	Find a knowledgeable doctor for further evaluation
HBsAb	Negative (-)		
HBcAb	Positive (+)		

Acute hepatitis B infection

A new hepatitis B infection with or without symptoms.

Chronic hepatitis B infection

A patient who tests positive for the hepatitis B virus for more than six months is considered to have a chronic hepatitis B infection.

POSITIVE INFECTION

Tests	Results	Interpretation	Recommendation
HBsAg	Positive (+)	ACUTE or CHRONIC infection – hepatitis B virus is present – can spread the virus to others	Find a knowledgeable doctor for further evaluation
HBsAb	Negative (-)		
HBcAb	Negative or Positive		

If your test results are positive for hepatitis B, then your doctor will want to retest you in six months to see if you are rid of the virus and recovered. You may or may not have symptoms during this time, but most people do not.

Six Chronic Hepatitis B

Six months after you test positive for hepatitis B, you should be tested again. If you are still positive for hepatitis B, then you have a chronic infection. This means that your body was not able to get rid of the virus and it still remains in your liver and blood. Chronic hepatitis B can increase your risk for developing more serious liver disease later in life, such as cirrhosis or even liver cancer. Therefore, it is important to seek a knowledgeable doctor who can help manage your disease now, before it is too late.

It is also important to learn how to avoid spreading the virus to your loved ones, and to take good care of yourself so you can enjoy a long and healthy life. Please know that you are not alone. The Hepatitis B Foundation is here to help. We have free literature and trained counselors who can answer your questions by phone, mail or online.

The remainder of this booklet has been designed to help walk you through the process of learning how to live successfully with chronic hepatitis B. Just like those who have high blood pressure or diabetes, you can take control of your chronic condition by becoming informed, finding a good doctor, and seeking the support you need to ensure your continued best health.

Seven **F**irst Steps

Here are some things you can do right now to help keep yourself and your liver healthy.

- ▶ Make sure you follow-up with your doctor and keep all appointments. Ask for copies of all test results.
- ▶ Get plenty of rest and talk to your doctor about treating any symptoms that you are having.
- ▶ Have household family members and sexual partners tested and vaccinated.
- ▶ Until you know that your family members are protected: avoid unprotected sex, sharing razors, needles, nail clippers, tooth brushes or earrings.
- ▶ Avoid alcohol, smoking and illegal drug use.
- ▶ Talk to your doctor before taking any medication, including over the counter medicines, vitamins, and herbal supplements because some of these can be harmful to your liver.



Eight **F**inding a Liver Specialist

If you are diagnosed as having chronic hepatitis B, here are some tips on managing your diagnosis.

- ▶ Find a liver specialist (also known as a hepatologist), who will work closely with your doctor. Make sure they are experienced in treating hepatitis B, you are comfortable with them, and they take time to answer your questions.
- ▶ The Hepatitis B Foundation can help you find a specialist in your area. Visit our Liver Specialist Directory at www.hepb.org/resources/liver_specialist_directory.

Hepatologist

A doctor who specializes in the study and treatment of liver disease.

Gastroenterologist

A doctor who focuses on the function and disorders of the gastrointestinal system, which includes the esophagus, stomach, pancreas, intestines, and liver.

Nine **V**isiting Your Doctor

When you first visit your doctor, he/she will take your medical history and give you a physical exam. They will also take some blood for tests and perhaps order an ultrasound of the liver.

To prepare for your doctor's visit:

- ▶ Take a list of questions with you
- ▶ Bring copies of your previous blood test results
- ▶ Invite a friend or family member along for support
- ▶ Take notes while you talk to the doctor so that you have important information written down



Visit hepb.org for more information.

Ten **Q**uestions to Ask Your Doctor

1. What kind of hepatitis B infection do I have: a new "acute" infection, or a "chronic" infection?
2. Could you please explain each hepatitis B blood test result, and any additional test results? Please make copies of my test results for my own personal files.
3. Where can I get my family, spouse or sexual partner tested and vaccinated for hepatitis B?
4. How will having hepatitis B affect my job or ability to work?
5. Here are the names of the medications that I currently take. Are they safe for my liver?
6. What over the counter medications or herbal supplements can I safely take for pain, cold symptoms, etc.?
7. Am I a good candidate for treatment? Why not?
8. If yes, please explain why and tell me about the treatment options?
9. Could you tell me about clinical trials? Do you offer any clinical trials for hepatitis B? If so, could you please explain them to me?
10. If I need to start treatment now, at what point can I consider having children?

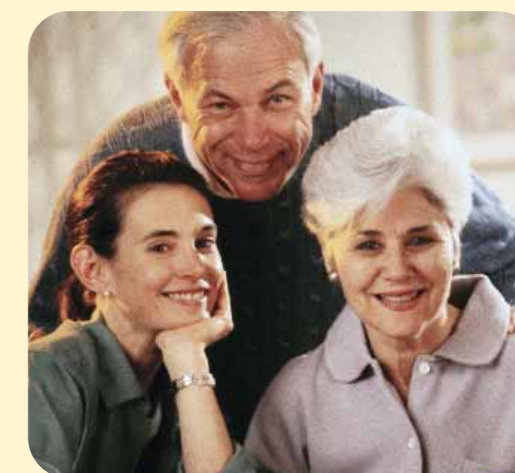


Eleven **A**dditional Tests

Here are some additional tests that your doctor might order.

- ▶ ALT (alanine aminotransferase) blood test used to evaluate the health of your liver
- ▶ HBV-DNA measures the amount of hepatitis B virus in your blood
- ▶ AFP (alpha-fetoprotein) used as an early liver cancer marker
- ▶ e-antigen and e-antibody measure how active the virus is in your body. (These results can change over time or during treatment.)
- ▶ Ultrasound of the liver allows the doctor to see if there are any abnormalities on the surface of your liver
- ▶ A liver biopsy, uses a special needle to remove a small piece of tissue from the liver that is examined under a microscope to look for inflammation or liver damage.

The results of these tests will tell you and your doctor how active the virus is in your body, whether you have any liver damage and if you are a candidate for treatment.



Visit hepb.org for more information.

Twelve

Monitoring Your Hepatitis B



Depending on your test results, you and your doctor might decide to wait and monitor your condition. If your test results indicate that you would be a good candidate for treatment, then your doctor will discuss the current treatment options with you. Whether you start treatment or not, your doctor will want to see you at least every six months, or more frequently.

Before you start any treatment, make sure you ask your doctor to thoroughly explain each option so you are well informed. It also might be a good idea to get a second opinion from another liver specialist before starting any treatment.

Thirteen

Approved Hepatitis B Treatments

Although there is currently no cure for chronic hepatitis B, there are several FDA approved medications that can slow down the virus and help prevent liver damage. Please be sure to discuss each treatment option with your doctor to find out which one is right for you.

The Hepatitis B Foundation offers additional treatment resources that can be useful for you and your doctor. Visit our website to learn more.

- ▶ Approved HBV Drugs at www.hepb.org/patients/hepatitis_b_treatment.
- ▶ HBV Drug Watch at www.hepb.org/professionals/hbf_drug_watch.

Fourteen

Treatment Issues to Consider

There are several issues you should consider before making the decision to start any hepatitis B treatment:

- ▶ Make sure your doctor clearly explains why he/she is recommending treatment for you.
- ▶ Ask your doctor to discuss the pros and cons of the treatment option that is being recommended.
- ▶ If possible, get a second opinion to make sure you are getting the best advice.
- ▶ If you are a woman who wants to have children now, or in the near future, talk to your doctor about treatment and pregnancy. Some questions to consider are: should you postpone treatment to become pregnant now, or do you need to start treatment and postpone pregnancy? Also, speak to your doctor about acceptable forms of birth control while you are on treatment.

Fifteen

Clinical Trials

There are several other promising new drugs that are being tested for hepatitis B treatment.

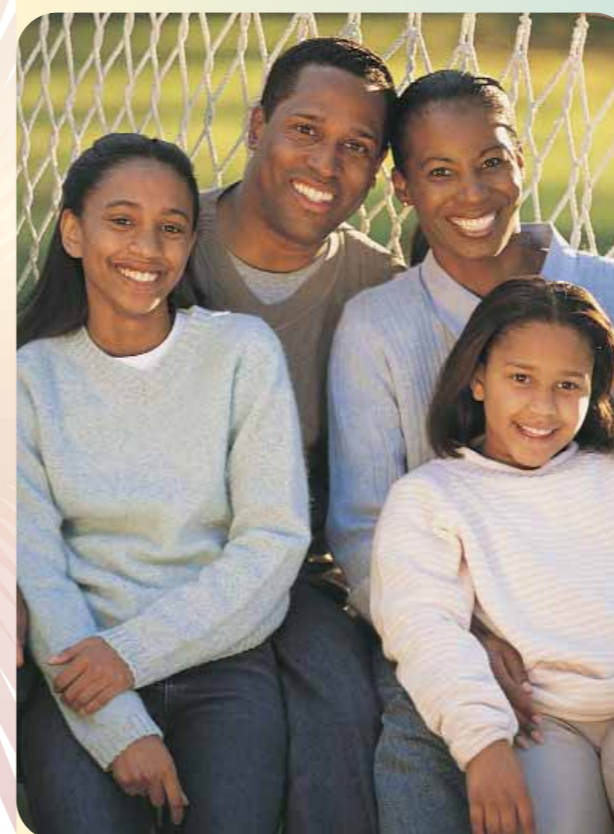
- ▶ Before any drug is approved for general use, it must go through three phases of testing called "clinical trials".
- ▶ People volunteer to participate in these clinical trials and must meet strict criteria before being accepted.
- ▶ Clinical trials can provide free medical visits, blood tests and treatment medicines to those who participate in the study.

Sixteen

Protect Your Loved ones

It is important to make sure you protect your loved ones from hepatitis B infection:

- ▶ The first step is to have household family members and sexual partners tested, and vaccinated if they are not infected.
- ▶ Hepatitis B can be spread through direct blood contact, unprotected sex, and contact with infected bodily fluids, so until you know that your family members are protected:
 - avoid unprotected sex
 - don't share razors, needles, nail clippers, tooth brushes or earrings
 - make sure you keep all cuts and open sores covered
 - clean all blood spills with a fresh solution of bleach and water (1 part bleach to 9 parts water).
- ▶ Hepatitis B is NOT spread through casual contact such as hugging, coughing, sneezing, or eating food prepared by someone who is infected. So, even while your family members or sexual partners are completing the vaccine series, enjoy your loved ones. This is a time when you need them the most.



Seventeen

See Your Doctor Regularly

Make sure you see your doctor regularly:

- ▶ Follow up with your physician twice a year (or more frequently as needed), even if you are not on treatment, so he/she can closely monitor your health and the health of your liver.
- ▶ Inform your doctor of any symptoms or changes that you are concerned about.
- ▶ Speak to your doctor about getting the hepatitis A vaccine to prevent you from getting another dangerous liver infection.
- ▶ Talk to your doctor before taking other medications, vitamins, or herbal supplements to make sure they are not harmful to your liver or will not interfere with any hepatitis B treatment.

Eighteen **M**ake Healthy Life Choices

Maintaining a healthy lifestyle can help keep you and your liver healthy!

- ▶ Avoid alcohol since chronic hepatitis B and alcohol are a dangerous mixture. Studies have shown that even small amounts of alcohol can damage an already weakened liver.
- ▶ Avoid smoking and illegal drug use.
- ▶ Eat a balanced diet. Although there is no diet specific for chronic hepatitis B, studies show that eating green and yellow vegetables (cabbage, broccoli, cauliflower) is good for the liver. The American Cancer Society's diet, which includes low fat, low cholesterol, and high fiber food is beneficial as well.
- ▶ Shellfish is generally not recommended for anyone with hepatitis B because of the risk of eating contaminated shellfish that can harm your liver.
- ▶ Get regular exercise, but make sure you speak to your doctor before starting any exercise program.
- ▶ Reduce your stress as much as possible.
- ▶ Make sure you get enough rest. Listen to your body when you are tired. Lie down, take a nap, read quietly, or try meditation to help you relax and refresh yourself.
- ▶ Avoid inhaling fumes from paint, paint thinners, glue and household cleaning products that may contain chemicals that could damage the liver.



Nineteen **P**regnancy and Chronic Hepatitis B

If you are chronically infected with hepatitis B and pregnant, or thinking about becoming pregnant, there are some things you need to know. The virus CAN be transmitted to your baby during pregnancy or delivery.

Fact: 90% of babies born to hepatitis B infected moms will become infected with hepatitis B unless properly vaccinated at birth.

Fact: The good news is that you CAN prevent the hepatitis B virus from infecting your baby.

Visit hepb.org for more information.

Twenty **P**rotect Your Newborn

Protecting your newborn:

- ▶ Your baby must be given two shots in the delivery room. Within the first 12 hours of life the first dose of hepatitis B vaccine and one dose of hepatitis B immune globulin (HBIG) should be given.
- ▶ Make sure you tell your obstetrician and your baby's future pediatrician that you have hepatitis B before you give birth so the doctors will have these two shots available in the delivery room.
- ▶ Your baby will need additional doses of hepatitis B vaccine at one and six months of age to provide complete protection.
- ▶ The baby can be tested any time after 12 months of age to make sure they have developed immunity to the hepatitis B virus.
- ▶ Make sure you regularly follow-up with your liver specialist throughout your pregnancy.

If the hepatitis B vaccine and HBIG are given correctly within the first 12 hours of life, a newborn has a 95% chance of being protected against a lifelong hepatitis B infection. It is very important to make sure you protect your child as soon as he/she is born!



Twenty One **H**epatitis B and Breastfeeding

Women with hepatitis B are encouraged to breastfeed their babies since the benefits of breastfeeding outweigh the very small potential risk of transmitting the virus through breast milk. Since all newborns should receive the hepatitis B vaccine at birth, this further reduces any small risk of transmission.

According to the leading hepatitis B experts at the Centers for Disease Control and Prevention (CDC) and the World Health Organization (WHO), it is safe for an infected mother to breastfeed her infant.

Twenty Two **H**Health Insurance and Employment

Many people with chronic hepatitis B have health insurance and employment questions. Hepatitis B should not be a barrier to your employment. If you are having difficulties at work, check your employer's infection control policies through employee health or human resources.

The Americans with Disabilities Act (ADA) is a broad law that protects those with a disability, which can include hepatitis B. For more information, visit the ADA website at www.ada.gov. You can also check the U.S. Equal Employment Opportunity Commission at www.eeoc.gov to help answer questions regarding employment and hepatitis B.

To receive a free money management educational booklet, "*Managing Your Money While Living with Viral Hepatitis*" please contact the Hepatitis B Foundation by calling 215-489-4900 or send an email request to info@hepb.org.

Visit hepb.org for more information.

Twenty Three **Support Groups**

It is important to get the support that you need as you manage your hepatitis B. Support groups, both in-person and online, are a great way to find the emotional support you need from people who are going through similar experiences. Often you can find many answers through support groups from people who have lived with chronic hepatitis B for many years and are happy to share their knowledge and experiences with you.

It might be difficult to find an in-person support group near you that focuses on hepatitis B. However, there is an international online support group, the **Hepatitis B Information and Support List** at www.hblist.org. This group, run by volunteers who live with chronic hepatitis B, is a great resource for patients, families, and others affected by hepatitis B.

The Hepatitis B Foundation sponsors the annual *B Informed Patient Conference*, the only patient-focused hepatitis B conference. Patients, family members, and health care providers get the chance to share stories and experiences, learn about the latest updates in treatment and research, and form a strong hepatitis B community of friends.



Twenty Four **Get Educated**

Get educated about hepatitis B! The Hepatitis B Foundation has free newsletters, information packets, printable material, and videos. You can also find great books at our online bookstore on our website at www.hepb.org/resources/hbf_bookstore. The more information you have about hepatitis B, the better you will be able to manage this chronic condition.

Twenty Five **Enjoy Your Life**

While living with hepatitis B can be difficult and scary at first, the more information and support that you have, the easier it gets. Many patients become such experts at managing their hepatitis B that they sometimes teach their health care providers about the latest research and information!

The most important thing to remember is that hepatitis B is a chronic medical condition (such as diabetes and high blood pressure) that can be successfully managed if you take good care of your health and your liver. You should expect to live and enjoy a long, full life.

Twenty Six **Spread The Word**



Don't forget to spread the word! It is important that we make everyone aware that hepatitis B is an important health issue. Help us educate the public about hepatitis B, how easily it can be prevented, and how important it is to continue research for improved treatments and hopefully a cure.

You can also financially support our efforts at the Hepatitis B Foundation to find a cure and improve the lives of those affected by hepatitis B worldwide through research, education, and patient advocacy.

Visit hepb.org for more information.

Additional Resources

Americans with Disabilities Act:
www.usdoj.gov/crt/ada/adahom1.htm

Asian Liver Center at Stanford University:
<http://liver.stanford.edu>

Centers for Disease Control and Prevention:
www.cdc.gov/hepatitis

Hepatitis B Information and Support List:
www.hblist.org

HepClinics:
www.hepclinics.org

Immunization Action Coalition:
www.immunize.org

Parents of Kids With Infectious Diseases:
www.pkids.org

Patient Rights:
www.patientrights.com/links/links7.htm

U.S. Equal Employment Opportunity Commission:
www.eeoc.org

Hepatitis B Foundation Web Pages

Annual Patient Conference:
www.hepb.org/patients/patient_conference.htm

Blood Tests:
www.hepb.org/patients/your_blood_tests.htm

Bookstore:
www.hepb.org/resources/hbf_bookstore.htm

Clinical Trials:
www.hepb.org/clinicaltrials

Donate:
www.hepb.org/about/make_a_donation.htm

Drug Watch:
www.hepb.org/drugwatch

Glossary:
www.hepb.org/glossary

HBF Newsletters:
www.hepb.org/newsletter

Journal Articles:
www.hepb.org/professional/journal_articles.htm

Resources Directory:
www.hepb.org/resources

Specialist Directory:
www.hepb.org/specialistdirectory

Vaccination:
www.hepb.org/pdf/vaccine.pdf

LIVING WITH HEPATITIS B

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