



**Hepatitis B Foundation**  
*Cause for a Cure*

## **PARENT INFORMATION PACKET**



**Hepatitis B Foundation** • 3805 Old Easton Rd, Doylestown, PA 18902 • 215/489-4900 • [www.hepb.org](http://www.hepb.org)



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**Dear Parents,**

Discovering that your child has chronic hepatitis B can be a challenging experience, but you are not alone. Almost every family in your situation experiences feelings of confusion and anxiety as they try to learn more about this liver infection. Since parents of children with chronic hepatitis B have unique concerns, we have published this "*Parent Information Packet*" to help answer some of your frequently asked questions.

Please be reassured that the Hepatitis B Foundation is available to provide information and support to your family during this learning process. We have a sincere commitment to all those affected by hepatitis B. In 1991, a small group of individuals established the Foundation and dedicated themselves to funding research, raising awareness, and providing education.

Although many people think of hepatitis B as an adult infection, there are millions of children affected worldwide; and in fact, most adults were infected as children. *The good news is that the prospect of your child enjoying a full and healthy life is excellent.* Unlike many other chronic medical conditions, most children with chronic hepatitis B experience normal growth and development, and do not usually have any physical disabilities or limitations.

We highly recommend that one of the first things you do is to find a good pediatric liver specialist ("hepatologist"), or a family doctor who is very knowledgeable about hepatitis B, so that your child receives expert attention and benefits from the latest medical knowledge.

Thank you very much for requesting our *Parent Packet*. We encourage you to contact us again with any questions or concerns you may have after reading the enclosed materials. We are here to help provide support to you and your family.

Sincerely,

Outreach Staff

*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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## **PARENT INFORMATION PACKET**

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# **I. About the Hepatitis B Foundation & Available Resources**



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## **About the Hepatitis B Foundation**

*"Never doubt that a small group of committed citizens can change the world.  
Indeed, that is the only thing that ever has." Margaret Meade*

### **Mission**

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.

### **Our Story**

In 1991, Paul and Janine Witte and Dr. Timothy Block, a research scientist, and his wife Joan Block, were deeply moved by the plight of a young family affected by hepatitis B. To their dismay, they discovered there were no resources to turn to for support, nor was there any organization devoted to finding a cure for hepatitis B.

With the personal support of Dr. Baruch Blumberg, who won the Nobel Prize for his discovery of the hepatitis B virus, the Wittes and the Blocks responded to this unmet need by working tirelessly to establish the Hepatitis B Foundation.

We have since grown from a grassroots effort into a professional organization with a global reach. Our goal is to improve the lives of those affected by hepatitis B through a comprehensive program of research, education and patient advocacy.

### **Our Programs**

The Hepatitis B Foundation (HBF) offices and labs are located in a state-of-the art research center in Doylestown, PA, that is dedicated to promoting excellent science rooted in human compassion. Foundation scientists and outreach staff are working together in a unique partnership towards a common goal – finding a cure and improving the quality of life for those affected by hepatitis B.

We reach out to people across the nation and around the world through our award-winning website, free newsletter and educational materials, and our annual patient conference.

We bring hope through research by funding the HBF labs, hosting the annual Princeton Workshop, sponsoring the "Bruce Witte Fellowship", and coordinating a summer student intern program.

With 400 million people worldwide suffering from chronic hepatitis B, there are 400 million reasons why we remain so committed to our mission.



## The Hepatitis B Foundation Makes a Difference

By phone, mail, and the internet, we are touching thousands of lives through our outreach services. As the only national non-profit organization solely dedicated to the problem of hepatitis B, we are a primary source of information and support to all those infected with and affected by this liver disease.

- Comprehensive Website at [www.hepb.org](http://www.hepb.org)
- Free *B Informed* Newsletter and Brochures
- Telephone and Email Help Lines at (215) 489-4900 and [info@hepb.org](mailto:info@hepb.org)
- National Directory of Liver Specialists
- Annual Patient Conference
- Expert Legislative Testimony
- Printed and Website Information in Chinese, Korean, Vietnamese, Turkish, and Spanish

## Research for a Cure

Our research program is bringing hope through the work of Foundation scientists and the innovative activities that keep the scientific community focused on hepatitis B. Our ultimate goal is to find a cure for the 400 million living with chronic hepatitis B worldwide.

- [Institute for Hepatitis and Virus Research](#) - a promising new compound that was discovered for hepatitis B is now being developed by IHVR, the research arm of HBF.
- [Annual Princeton Workshop](#) - for the past 10 years, the nation's thought leaders have been invited by the HBF to a roundtable discussion of innovative hepatitis B treatments.
- [Bruce Witte Fellowship](#) – a competitive research award, established by co-founders Paul and Janine Witte, to encourage a beginning scientist to study hepatitis B in the HBF labs.
- [Summer Internship Program](#) - college students learn about hepatitis B and new research skills in the IHVR labs.

<b>Give a Gift Today. . . Your Donation Will Give Hope To Millions!</b>
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The Hepatitis B Foundation is a 501(c)(3) tax-exempt charitable organization.  
We need your help to continue our important work.

**Make a Secure On-Line Donation at [www.hepb.org](http://www.hepb.org)** or mail your check to our office.  
Thank you for your donation!





## **PKIDs Pediatric Hepatitis Report**

### **A Valuable Resource About Children and Hepatitis**

There is a comprehensive resource for all those concerned about children living with viral hepatitis A through E. The Pediatric Hepatitis Report is a 530-page compendium of information that was first published in December 2001 by the national nonprofit agency PKIDs (Parents of Kids with Infectious Diseases). The report is updated periodically on the PKIDs website.

PKIDs created this report, funded in part by the Centers for Disease Control and Prevention, for parents, social workers, teachers and health care providers to better understand what it means for children and their families to live with viral hepatitis.

Each chapter includes basic disease facts; information about prevention, management, and treatment, as well as personal stories written by parents.

Important non-medical issues are also addressed such as how and when to disclose a diagnosis to a young child; what civil rights protections are available to children with infectious diseases in schools, daycare centers and sports programs; how to practice standard precautions in every day life to prevent disease transmission; and how to ease children's anxieties about doctor visits.

"This report is the culmination of years of work and research," said Trish Parnell, Executive Director of PKIDs. "It is a wonderful resource that will help parents and others to understand these complex diseases."

**Visit [www.pkids.org](http://www.pkids.org) to read the entire report or to download the free PDF version. The report is available for download in English, Spanish, Russian, and Simplified Chinese.**

The mission of PKIDs is to educate the public about infectious diseases and to assist families whose children live with chronic, infectious diseases.

### **PKIDs**

**P.O. Box 5666**

**Vancouver, WA 98668**

**Toll free (parents only)**

**Voicemail**

**Fax**

**877-55-PKIDS**

**360-695-0293**

**360-695-6941**





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## **II. Parents' Frequently Asked Questions**



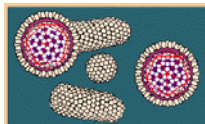
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## **Parents of Children with Chronic Hepatitis B Frequently Asked Questions**

**What is hepatitis B?** Hepatitis B is the world's most common serious liver infection. It is caused by the hepatitis B virus, which specifically attacks the liver. Worldwide, 2 billion people have been infected and 400 million people are chronically infected with the virus.



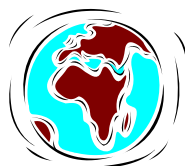
**How is it transmitted?** The hepatitis B virus (HBV) is transmitted through blood, which can occur with direct blood contact, unprotected sex, illegal drug use, and from an infected woman to her newborn baby during delivery. Hepatitis B is not transmitted casually. You cannot “catch it” through hugging, casual kissing, coughing or sneezing.

**What are the effects of a hepatitis B infection?** Hepatitis B can be acquired as an infant, child or an adult – the virus does not discriminate. Most people who are infected do not have any symptoms or they may experience mild “flu-like” symptoms. After becoming infected, 90% of healthy adults successfully get rid of the virus and recover. Approximately 10% of these adults will not be able to get rid of the virus and will develop chronic infections; therefore, they will be able to pass the virus on to others.



Children who are infected early in life have a 40-60% chance of developing a chronic infection, meaning the hepatitis B virus stays in their blood and liver for a long time (these children may be referred to as “chronic carriers” of the virus). Those infected as newborns are at the highest risk of becoming chronically infected – 90% of newborns infected at birth or during the first year of their life will not be able to get rid of the virus. All chronically infected individuals can pass the virus on to others and live with an increased risk of developing serious liver disease later on.

**Is chronic hepatitis B life-threatening?** Hepatitis B is not usually a life-threatening illness. Most people should expect to live long and healthy lives. The risk, however, is that the hepatitis B virus can cause liver damage that could lead to problems later in life. The most serious consequences of chronic hepatitis B are cirrhosis and in some cases, even liver cancer. This is why it is very important that your child be monitored regularly by a liver specialist, or a doctor who is knowledgeable about hepatitis B.



**Why is hepatitis B a concern with adopted children?** Hepatitis B is more common in certain parts of the world than in others. Asia, Central and South America, Eastern Europe, and parts of Africa and the Middle East have higher than average rates of hepatitis B infection. Many children adopted from overseas come from these regions. There are estimates that 30–35% of children adopted from outside the U.S. are chronically infected with hepatitis B.

## IMPORTANT ADVICE

- 1) All children adopted from outside the U.S. should be tested for hepatitis B as soon as they arrive (not in their country of origin).
- 2) All close household family members should receive the hepatitis B vaccine before the arrival of the adopted child.

**What tests should our adopted (or biological) child have done?** Families who adopt children from overseas should have them tested for hepatitis B (and as part of their overall physical examination) as soon as they arrive. Testing is very important, but should be done in the U.S. because many developing countries re-use needles (which can actually cause an infection), or may not properly interpret the blood test results. It is important to remember that children who look healthy can be chronically infected with hepatitis B.



**Most Common Blood Tests: Hepatitis B Panel** - please read "Understanding Hepatitis B Blood Tests" for a more comprehensive explanation of these hepatitis B markers:

- Hepatitis B surface antigen (HBsAg)
- Hepatitis B surface antibody (HBsAb or anti-HBs)
- Hepatitis B core antibody (HBcAb)
- Hepatitis B e-antigen (HBeAg)

## What medical care does my child require?

Children under 15 years who have chronic hepatitis B should schedule annual visits (or more frequently, depending on your child's situation) with a pediatric liver specialist ("hepatologist") or family doctor skilled in hepatitis B. A physical exam and blood tests are usually included in these visits. Common blood tests include liver enzymes, the hepatitis B panel, and alpha fetoprotein (AFP). Ultrasound imaging of the liver in children is not usual, but parents can discuss this with their physician.



Children over 15 years should schedule an annual visit (or every 6-months, which is the recommended schedule for adults with chronic hepatitis B) with either a pediatric or adult liver specialist. A physical exam and the blood tests listed above are used to monitor the health of the liver and to screen for early detection of possible liver cancer. Ultrasound imaging of the liver may be started at this age.

**Is there a cure for hepatitis B?** Although there is really no "cure" for hepatitis B, there are several approved treatments that reduce the risk of progressive liver damage. Two drugs are approved for children – Intron A (interferon alpha) and Epivir-HBV (lamivudine). There is a third drug approved for adults, Hepsera (adefovir dipivoxil), but testing in children is not yet complete.



**How can family members be protected from hepatitis B?** All parents, siblings, household members, and others in close daily contact with a child who has chronic hepatitis B should be vaccinated. Others with frequent contact, such as day care providers and extended family members, may also consider vaccination.



The hepatitis B vaccine has been used since 1982 and is safe, effective and readily available. In the U.S., the CDC recommends the hepatitis B vaccine for all infants and children up to 18 years of age, as well adults at high risk, which include adoptive parents.

**How will people respond when they find out my child has chronic hepatitis B?** If people are unfamiliar with hepatitis B, there is a possibility they will become alarmed when told your child has hepatitis B. The key to minimizing other people's reactions is to KNOW THE FACTS. It is essential to know that hepatitis B is transmitted through contact with blood – it is not transmitted casually.

Let friends, family and co-workers know that there is a safe vaccine against hepatitis B, and that the American Academy of Pediatrics recommends that all children up to 18 years of age be vaccinated. Universal vaccination of newborns in the United States began in 1991 and almost every child born since then has received the hepatitis B vaccine. In addition, almost all of the states have legislation requiring hepatitis B vaccination prior to school entry, and over half of the states require hepatitis B vaccination for daycare entry (read "School and Daycare" section).



**Whom should I tell?** For most parents, it is normal to want to tell everyone about your child's situation. It is a topic that is of great concern to you, and most of us want to share our burden with others. Yet, the advice from other parents who look back on their own experiences is that it is best to initially use caution and consider telling people on a "need to know basis" to give yourself time to collect the facts and prepare responses to other people's questions or concerns. As parents, you have to understand the facts and feel comfortable about your child's situation in order to respond positively to other people's possible negative reactions. *Once you tell, you can't take it back.*

Your decision could be based on evaluating the potential risk your child poses to others in terms of potential blood exposure. Consideration of your child's age, frequency of accidents, nosebleeds, biting, etc., the degree of risk a caretaker has for exposure (frequent vs. occasional contact), and of course the possible negative impact such a disclosure could have on your child and family. With the availability of a safe vaccine, however, the risk to others should be greatly reduced since all children in the U.S. should be vaccinated, and all adults should consider being vaccinated.



**Note:** Although there are no specific laws that address disclosure of a hepatitis B diagnosis, neither is there necessarily a "duty" for parents to inform others of a child's hepatitis B status. This is not to say one never has a responsibility to tell others, but it is important to use discretion and sound judgment in making any decision. The "American with Disabilities Act" (1992) is a federal law that may protect against discrimination related to chronic hepatitis B. Many states have clauses written into their AIDS disclosure laws that also protect persons with hepatitis B.

**What should I say to others?** Know your facts, use simple explanations, and remain calm. Emphasize that your child is healthy and poses no risk unless there is a blood spill. Let people



know that all infants and children up to age 18 years should already be vaccinated against hepatitis B. It is important to emphasize that hepatitis B is not the only infection spread through blood - in this era of AIDS and hepatitis C, everyone should be very cautious in handling any blood.

Consider saying this: *"Treat my child as you should treat every child – with care. You know the risk my child poses, but you don't know the risk that other children might present (not only for hepatitis B, but for other blood-borne diseases as well)."*

If possible, arrange to have your doctor or nurse serve as a medical authority for those people who need further reassurance. You can certainly refer people to the Hepatitis B Foundation as a national resource for accurate, credible information.



### **Will hepatitis B affect my child's social life and participation in extramural sports?**

Telling other parents can be the toughest situation. They will understandably make the protection of their own child paramount. But remember, all infants and children born after 1991 should already be vaccinated against hepatitis B. Most childhood group activities such as Scout meetings and sleepovers pose minimal risk of exposure (be sure to remind your child to not share toothbrushes, earrings or razors). There may be situations, however, where it could be necessary to inform another parent or sports coach when the risk of blood exposure is high (such as boxing or football).

Again, the decision of who to tell is based upon knowing the risk of your child's characteristic behavior and the possible impact that information could have on others. Telling people there is a safe vaccine against hepatitis B can help to decrease their potential anxiety. Involving your doctor is always useful since he or she is an objective voice of medical authority and reassurance.

### **Should I worry about my child possibly infecting others?**

Often in the initial phase, parents are very concerned about their child infecting someone else, but you should know that hepatitis B is not the only infectious blood-borne disease. There is AIDS and hepatitis C, both for which there is no vaccine to protect others. The good news for all parents of children with chronic hepatitis B is that hepatitis B is a vaccine-preventable disease. Other children and people have the option of being protected.

*Remember, blood is a two way street – your child can as easily acquire a blood-borne disease from others as well as potentially transmit hepatitis B. ALL blood should be handled carefully, not just your child's.*

**What should I tell my child?** Any discussion must be tailored for your child's developmental stage with additional information provided as he or she matures. Education can begin early on by including "not touching blood" as part of a child's good hygiene habits. Just as we teach toddlers to wash their hands after using the toilet, brushing their teeth every night, we can tell them not to touch one another's blood.

For school children, protection of their blood as part of their safety habits can be discussed. Blood is special and needs to be handled carefully by either a parent or an adult. The concept



of germs and infection can be introduced in that people can spread germs through their blood or open wounds can be infected by dirty hands; therefore, children should not touch each other's bloody cuts, etc.

As your child gets older, specific information about hepatitis B can be discussed. Older children understand about disease and transmission risks. They also understand the difference between "public" and "private" information, which is important to emphasize since they will want to choose carefully whom they tell.

Teens will also probably benefit from having another adult (possibly their doctor or a close family friend) to talk to since they may have questions they are too embarrassed or afraid to ask their parents.

Hepatitis B is a chronic medical condition that can be managed, just like asthma or high blood pressure. There is nothing shameful about having chronic hepatitis B.

*The primary message to give your child at all times is that he or she is a healthy person and should enjoy life to the fullest!*



### **Are there any parent support groups?**

Although there is no national listing of parent support groups, motivated parents can consider starting one through their adoption groups or with the help of their pediatric liver specialist. The adoption social worker or pediatric liver specialist can serve as the clearinghouse to reach out to other parents of children with chronic hepatitis B. This helps maintain the confidentiality of all parents during the formation of such a support group.

Parents can feel a lot less alone and benefit tremendously from talking with other parents. For those with access to the Internet, there are several useful On-Line support groups:

#### **Hepatitis B Information and Support Listserv**

**[www.geocities.com/Heartland/Estates/9350/hblist.html](http://www.geocities.com/Heartland/Estates/9350/hblist.html)** (case sensitive). A well-supervised list for adults and parents that is both informative and supportive.

#### **HBV Adoption Support Listserv**

**[www.onelist.com/community/hbv-adoption](http://www.onelist.com/community/hbv-adoption)** A well-supervised list for adoptive or biological parents of children with hepatitis B. Requires pre-approval by list owners.

#### **PKIDs Support Listserve**

**[www.pkids.org](http://www.pkids.org)**

An unsupervised list for both adoptive or biological parents of children with chronic viral diseases, including HBV, HCV, and HIV.

***The online support groups listed above can also be accessed by clicking on "Support Groups" in the Patients and Families section of our website, [www.hepb.org](http://www.hepb.org).***





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### **III. Adoption and Hepatitis B**



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## **Hepatitis B and the Adopted Child Looking on the Bright Side**

*[Excerpted from "Hepatitis B and the Adopted Child", by Jerry A. Jenista, M.D. Reprinted with permission]*

Although no one chooses to have chronic hepatitis B infection, adopted kids might actually be a little better off than others with the disease. I do not intend to belittle the parents of a non-adopted child who has acquired hepatitis B by whatever means. I only hope to make the point that children who are both adopted and have hepatitis B may have some subtle advantages over other children with hepatitis B *[who have not been adopted]*.



**When the hepatitis B infection is diagnosed before the adoptive placement, the parents have already made the decision to deal with a chronic disease.** Thus, one would expect that they might be more likely to view their child as normal but with a medical condition. In contrast, the parent who discovers hepatitis B in a previously healthy child will surely have some grief over the loss of their "normal" child.

Even when hepatitis B is not diagnosed until after the adoptive placement, the parents have already made a strong commitment to a child. Because of the protracted, intrusive and often expensive process of adoption, the parents are often far more committed to parenting a child and may be more accepting of chronic medical problems.

**When the child comes from another country or is of a heritage different from that of the adoptive family, the parents have also accepted the fact that their family will be "different" by both adoption and physical appearance.** Accepting one more difference, hepatitis B, is not so much of a leap.



Whether or not the child has been identified as infected before the adoption, one would hope that the agency or social worker has informed the prospective parents of the risk of hepatitis B and has given them access to additional information.

Although obstetricians supposedly do this during prenatal counseling, I suspect that the risk is considered much less seriously than in adoption. Thus, adoptive parents may be starting off more informed than other parents who usually have to become educated after the diagnosis.



**Because of the informing process, the adoptive family has the opportunity to protect its members by immunization in advance of or at the time of placement.** Birth families are not usually so lucky; sometimes the infection in a child is diagnosed only when another family member becomes ill.



Since hepatitis B is almost invariably acquired before the placement, the adoptive parents have less guilt concerning the infection. They cannot reasonably hold themselves responsible for the child's infection, as they had no control over the child's previous life.

**Adoptive parents are used to having to advocate for themselves.** They often have become good researchers in the process of sorting out adoption options. Thus, they tend to be aggressive and persistent in their efforts to find the latest information. I have had patients whose parents have personally called nationally known liver specialists and the Commissioner of the FDA to make sure they had the most appropriate advice!

Because adoptive families are so easily identified, they also tend to belong to support groups and/or subscribe to periodicals put out by these groups. Thus, they often have excellent access to continuing medical education about hepatitis B from other parents and through reports written specifically about infected adopted children.



**Adoption of some children with hepatitis B is probably a good thing for all children with hepatitis B.**

Because adoptive families tend to have social, economic and educational levels better than that of the general population, they are in the position to be much more influential. Adoptive parents often find themselves educating their local school district and childcare community about this infection. They are vocal in efforts to immunize other children (so they don't have to worry about transmission from their own child).

Frequently, adoptive parents are quite open about their child's infection status since they perceive there is less social stigma when the child acquired infection in some way not under the parent's control. They are also eager to try new therapies and enroll their children in research studies, thus advancing the knowledge about hepatitis B infection in all children.

Adoption of children with medical conditions seems to go along with an increasing acceptance of affected persons in mainstream U.S. society; we have seen this with many conditions such as physical handicaps, mental retardation and HIV infection.

**Perhaps the adoption of children with hepatitis B has also helped in increasing the awareness and acceptance of this infection in our society.**

Of course we hope that the final result will be increased support for research so that hepatitis B will have disappeared in the lifetime of our children.



*[Dr. Jerri Jenista, M.D., is a specialist in pediatric infectious disease and also the adoptive parent of a child with chronic hepatitis B infection, information that she publicly shares to help other parents understand her passion for writing about hepatitis B and adoption]*







## Hepatitis B: To Screen or Not To Screen?

*[Excerpted from "Hepatitis B: No Guarantee" by Jerri Ann Jenista, MD, Adoption/Medical News, Ann Arbor, MI; Dana E. Johnson, MD, University of Minnesota International Adoption Clinic, Minneapolis, MN; Laurie C. Miller, MD, New England Medical Center International Adoption Clinic, Boston, MA; Dennis L. Murray, MD, Michigan State University, East Lansing, MI. Reprinted with permission]*



Hepatitis B is the most prevalent chronic virus infection worldwide, chronically infecting 400 million people. The disease is found globally, with the highest rates in Asia and Africa and lower rates in the Americas. Local conditions, however, may lead to a high rate of infection in a particular region or institution. Although most people with hepatitis B will never show any ill effects of the disease, a significant proportion will go on to develop serious complications including cirrhosis, liver failure, cancer or death. Treatment, but not cure is available for some affected persons. Prevention by immunization is a major public initiative in many countries around the world.

Chronic hepatitis B infection is the most common serious infectious disease affecting children adopted internationally. Approximately 5% of all such adoptees to the United States have active infection at the time of arrival. A somewhat higher percentage of children show immunity from past infection or from immunization. Exposure to hepatitis B is found in children of all ages and from all countries.

Since the blood tests for hepatitis B are simple to perform, relatively inexpensive, and available in most areas of the world, adoptive parents may, quite reasonably, ask that their prospective child be screened for this infection. Many parents are dismayed to discover, however, that such pre-adoptive screening may not answer their concerns.



**Drawing blood for the test may actually expose the child to hepatitis B or other blood-borne infections.** Re-use of needles is very common in other countries, especially when there are limited resources. Sterilization of needles can be particularly difficult when hepatitis B is involved. *[In China, UNICEF estimates 1 out of 4 chronic hepatitis B infections are due to unsterile needles used for blood tests, vaccines, and medications]*



**Hepatitis B screening tests (usually hepatitis B surface antigen or "HBsAg") done in the countries from which most adopted children arrive are frequently unreliable.** Often there is a lack of appropriate chemicals, clean equipment or adequate training in the laboratory. Even if the test is run under good conditions, there may be difficulties with the actual blood sample itself. Common problems include mislabeled specimens, blood contaminated by unclean collection tubes, and cross-contamination in the laboratory from other positive specimens. Occasionally, no blood or an inadequate amount was drawn from the child to run the tests supposedly done.

**Reported results are frequently uninterpretable.** Sometimes the wrong test has been done. The result may be interpreted incorrectly, indicating that the child is immune when he is infected and vice versa. The result may be translated or reported in such a way that it is unintelligible. Occasionally, reported results are entirely fraudulent.





**The test may be run too soon to indicate the child's infection status.** Since the incubation period (the time from exposure until disease is detectable) can be as long as 6 months for hepatitis B, it is possible that a child tests negative when he actually has incubating infection. This is particularly a problem for infants less than 3 months of age with infection acquired from mother-to-baby near birth. Older children may have been exposed through a medical procedure, transfusion or other blood contact.

**Some children will accurately test negative before adoption, but will show positive results after arrival in the adoptive home.** As long as the child lives under orphanage, institutional or other non-optimal conditions, he remains at risk for hepatitis B. So, until that child is at least six months from the last possible exposure to hepatitis B, a parent cannot be absolutely assured that the child does not have an infection. Although most hepatitis B infections are detected in the U.S. after arrival, there are a few children in whom infection is not found until several months after adoptive placement.

**Testing for hepatitis B raises the cost of and may delay adoption.** Although the screening test may not be expensive, there are many hidden costs including personnel time to get the child, draw the blood, transport the specimen, and collect, translate and relay the results. All of these steps cost money and take time. If the result is uninterpretable or unexpected, more time is lost in repeating the testing or counseling all the parties involved.

**Test results may label some children as “unadoptable”.** Although many families are willing to adopt children with unknown hepatitis B status or even known chronic infection, adoption agencies and authorities in other countries may feel that such children should not be placed for adoption. Some children who are incorrectly labeled as infected, based on inaccurate laboratory tests, will be denied the opportunity for adoption, even though hepatitis B is a manageable condition in the U.S.



**There are no guarantees in adoption.** Even though hepatitis B is a well-defined and apparently easily resolved issue, it is not the only, or even the most common condition affecting internationally adopted children. Focusing resources on screening for hepatitis B may decrease the efforts put into more important assessments such as the developmental and emotional health of the prospective adopted child.



**Pre-adoption education [and vaccination] of adoptive families is the most efficient way to deal with hepatitis B.** When families thoroughly understand the issues, they can make an informed choice about whether to proceed with an international adoption. Hepatitis B must always be viewed within the context of all the medical, social, and emotional conditions affecting adopted children.

Adoption agencies, orphanage authorities, physicians and parents must consider all of the above factors in determining whether or not routine hepatitis B screening should be obtained in children prior to adoption. Although there will always be circumstances in which such screening is essential for a particular placement, in many circumstances, parents may find themselves falsely reassured by an unreliable pre-adoption assessment.

The Hepatitis B Foundation recommends that in general, adopted children should be tested for hepatitis B in the U.S., rather than their country of origin, to ensure both the health of the child and the accuracy of the test results.



# Hepatitis B Vaccine Is Imperative for Families Adopting from Abroad

By Dr. Jane Aronson

Vaccination for hepatitis B infection should be considered essential for families contemplating intercountry adoption. While the risk of an adopted child from abroad being a hepatitis B carrier varies from country to country, concerns over the possibility of transmission to others can be alleviated if family members seek the readily available hepatitis B vaccination series before the child arrives.

Recently, I was the consulting pediatrician for two families whose adopted children from abroad had been diagnosed with chronic hepatitis B infection after arrival in the U.S. Their stories were typical of families contacting adoption medicine specialists across the country. One child was a 14-month-old boy from China, and the other was a one-year-old girl from Russia. The boy had actually been in the U.S. for seven months before he was tested for hepatitis B infection. His mother told me that the pediatrician felt that the child did not need to be tested because he looked healthy. The mother and father had not been vaccinated against hepatitis B.

The mother of the little girl from Russia contacted me because she had just been told by the pediatrician that the child was a hepatitis B carrier. She was anxious about her child's health, but she was also quite disturbed about her risk and her family's risk for contracting hepatitis B infection. No one in the family had been vaccinated.

I discussed the issue of in-household transmission and reassured both families. They have all begun the process of completing the hepatitis B vaccine series.

## Visual diagnosis is impossible

The story of the Chinese boy illustrates a myth about hepatitis B. The facts are that most children who are carriers of hepatitis B are healthy in their appearance and no one can tell if a person is a carrier by just looking at him. All children adopted from abroad should be tested for hepatitis B soon after arrival in the U.S. The standard list of labo-

ratory studies that should be performed on all internationally adopted children within a few weeks of their arrival in the U.S. is found on many adoption websites including my own ([www.orphandoctor.com](http://www.orphandoctor.com)).

Among my patients, the vast majority of parents had either not completed or even begun the hepatitis B vaccine series by the time their adoption was completed. Most of the families who contact me from around the U.S. whose children are hepatitis B carriers have not completed their hepatitis B vaccine series when they find out the diagnosis for their children.

## In-household transmission

When a family calls me to discuss hepatitis B carriage, I find my time on email or the phone to be divided equally between the

Most schools have requirements for gloves and bleach for handling blood exposure.

Handwashing is also essential to the prevention of infection. People with hepatitis B carriage should not be sharing toothbrushes or razor blades.

## A chance for control

What concerns me is that the majority of families do not complete their hepatitis B vaccine series before the adoption is complete. We have so little control during the adoption process and here is an opportunity for control. For other children at home, there is usually no issue, because hepatitis B vaccine has been a universal vaccine in the U.S. since 1991. Pediatricians are actively working to catch up kids who missed the series in the first year of life. In New York State and many other locales, all children entering kindergarten must be vaccinated.

The time needed for an international adoption allows for easy completion of the three vaccine series over a six-month period. It can be administered by a family physician, internist, nurse practitioner, physician assistant, or even the prospective pediatrician for the adoptee.

The pain and guilt that families feel could be completely replaced with a feeling of control if they knew they were protected against in-household transmission with effective vaccination. We simply need to make hepatitis B vaccine universal for families considering an international adoption.

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The Joint Council on International  
Children's Services, Ph: (202) 429-0400  
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## Adopting a child from abroad?

- **Family members should get vaccinated before the child arrives.**
- **All children from abroad should be tested for hepatitis B soon after U.S. arrival.**

prognosis or treatment of chronic hepatitis B infection and the in-household transmission risks. People are very anxious about the possible infection of family members, friends, and schoolmates. I would rather see the family in a position of comfort and control knowing that with a completed hepatitis B vaccine series, they are essentially safe.

In addition to vaccination, it is, of course, essential that everyone understand the concept of "standard precautions" for prevention of infection at home or at work. Usually people do not know the infection status of children or adults in any environment since this is confidential information.

When someone is bleeding, gloves should be available so that a family member, teacher, or friend can safely assist the bleeding patient. Blood on surfaces should be cleaned up with a simple bleach solution.

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## International Adoption Medical Clinics

Directory of clinics and doctors in the US and Canada specializing in international adoption medicine.

International adoption medical clinics are great resources for international medical and health, especially if your adopted child has an ailment that is uncommon, not easily diagnosed or difficult to treat. International adoption medical clinics also provide advice on pre-adoption evaluations, immunizations and post adoption medical examinations.

### Alabama

**The University of Alabama at Birmingham**  
Jennifer Nobles Chambers, MD, MPH&TM  
[UAB International Adoption Clinic](#), Director  
MTC 201  
1600 7th Avenue South  
Birmingham, AL 35233-1711  
Phone: (205) 939-6964  
email: jchambers@peds.uab.edu ,  
adoption@peds.uab.edu

### California

**International Adoption Clinic**  
[Children's Hospital & Research Center at Oakland](#)  
<http://www.internationaladoptionclinic.org>  
Nancy Curtis MD  
Carina Grandison Ph.D.  
747 Fifty Second Street  
Oakland, California 94609  
Email: ncurtis@mail.cho.org  
Ph: 510-428-3010  
Fax 510-450-5878

### Nebraska

**Edward M. Kolb, M.D.**  
International Adoption Medical Consultants  
13110 Birch Drive  
Suite 148, Box 366  
Omaha, NE 68164  
Phone:(402) 680-3269  
Fax: (402) 496-7126  
email: adoptmedconsultants@cox.net

### New York

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### [Schneider Children's Hospital](#)

Andrew Adesman, MD  
Division of Developmental and Behavioral  
Pediatrics 1983 Marcus Ave, Suite 130  
Lake Success NY 11042  
Telephone: 516-802-6150

## **Connecticut**

### **Yale University International Adoption Clinic**

Carol Weitzman, M.D.  
464 Congress Avenue  
New Haven, CT 06520  
(203)737 1623

## **District of Columbia**

### **Georgetown University**

#### **Child Development Center, Department of Pediatrics, Georgetown University School of Medicine**

International Adoptions Health Resource Center  
Dr. Nina Scribanu, MD  
3307 M St NW,  
Washington, DC 2007  
Tel: (202) 687-8635 Fax: (202) 687-8899

## **Georgia**

#### **Emory University School of Medicine - Pediatrics Department International Adoption Research**

Dr. Pakula, Director of the International Adoption Center  
Marcus Institute  
1920 Briarcliff Rd.  
Atlanta, GA. 30329  
Email: pmason@emory.edu

## **Illinois**

### **University of Chicago Comer Children's Hospital International Adoption Clinic International Adoption Clinic**

5841 S. Maryland Avenue  
Chicago, IL 60637  
phone: (773) 702-6169  
email: adoption@uchospitals.edu

## **Indiana**

### **International Adoption Clinic**

#### **Riley Hospital**

Dr. John Christenson, Dr. Julie Keck, Dr. Maria Finnell  
ROC RI 4380 702, Barnhill Dr.  
Indianapolis, IN 46202

Fax: 516-616-5801

email: adoption@LIJ.edu

## **Ohio**

### **The International Adoption Center**

#### **Cincinnati Children's Hospital Medical Center**

3333 Burnet Avenue, MLC 7036  
Cincinnati, OH 45229-3039  
Barbee Sjödahl  
Email: Barbee.Sjodahl@CCHMC.org  
Phone: (513) 636-2877, option 2  
(800) 344-CHMC (2462), ask for ext. 62877, option 2  
Fax: (513) 636-6936

#### **Columbus Children's Hospital** (Ohio State University)

Dwight A. Powell, MD  
Director, International Adoption Clinic  
700 Children's Drive, Columbus, OH 43205  
Columbus, Ohio  
Phone: (614) 722-4459  
Fax (614) 722-4458  
Email: internationaladoption@chi.osu.edu

### **Rainbow Babies and Children's Hospital**

#### **University Hospitals of Cleveland**

#### **Rainbow Center for International Child Health**

Adoption Health Service  
Director: Dr. Karen Olness  
11100 Euclid Avenue, Mail Stop 6038  
Cleveland, Ohio 44106-6038  
(216) 844-3224  
E-Mail [RCIC@po.cwru.edu](mailto:RCIC@po.cwru.edu)

## **Oregon**

### **OHSU Adoption Health Services**

Medical Director/Adoption Medicine Specialist: Meg Hayes, MD  
Program Manager: Mary Masterson, MPH, MPA  
3181 SW Sam Jackson Park Road  
Mailcode: FM  
**Portland, Oregon** 97239-3098  
Phone: 503-494-5445  
Fax: 503-494-3396

phone: 317-274-7260  
email: washinge@iupui.edu

**Pediatric International Adoption Clinic**

St. Vincent Pediatric Rehabilitation Center  
Christopher Belcher, M.D., F.A.A.P., Fernando  
Escobar, M.D.  
1707 West 86th Street  
Indianapolis, IN 46240  
Phone: 317-338-5288 Fax: 317-415-5580  
email: jestone@stvincent.org

**Maine**

**Maine Medical Center**

Nataniel James  
22 Bramhal Street  
**Portland, Maine 04101**  
Tel: 207-871-0111

**Maryland**

**International Adoption Clinic of Kennedy  
Krieger Institute & Johns Hopkins Children's  
Center**

Kennedy Krieger Institute  
707 North Broadway  
Baltimore, Maryland 21205  
Tel: 443-923-9402

**Massachusetts**

**New England Medical Center  
International Adoption Clinic**

The Floating Hospital  
Dr. Laurie Miller  
750 Washington Street, Box 286  
Boston, Massachusetts 02111  
Tel: 617-636-8121

**Children's Hospital and Harvard Medical  
School**

Adoption Program, Children's Hospital  
Lisa Albers, MD, MPH and Kay Seligsohn, PhD  
300 Longwood Avenue,  
Boston, Massachusetts 02115  
Tel: (617) 355-5209; Fax: (617) 730-5529  
Email: albers\_l@hub.tch.harvard.edu

Email: adoption@ohsu.edu

**Ontario, Canada**

**Canadian Clinic for Adopted Children**

Dr. Angelo Simone  
2338 Hurontario Street, Suite 200  
Mississauga, Ontario, Canada  
Tel: 905-848-8303  
FAX: (905) 848-5727  
Email: asimone@attcanada.net  
Dr. Simone is also Chief of Pediatrics for the Trillium  
Health Center in Mississauga.

**St. Michael's Hospital**

Dr. Anna Banerji, MD, MPH, FRCC, DTM&H  
Pediatric Infectious & Tropical Disease  
St. Michael's Hospital  
Pediatric Ambulatory Clinic  
61 Queen Street East, 2nd floor  
Toronto, ON M5C 2T2  
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FAX: 416-867-3736

**Pennsylvania**

**The Children's Hospital of Philadelphia  
International Adoption Health Program**

34th St. and Civic Center Blvd.  
Philadelphia, PA 19104  
Dr. Alyssa Harrison  
Dr. Gail Farber  
Phone 267-426-5005  
Fax 215-590-3198  
email: chopadopt@email.chop.edu

**Rhode Island**

**Hasbro Children's Hospital**

Division of Pediatric ID  
**International Adoption Clinic**  
593 Eddy Street  
Providence, Rhode Island 02903  
(401) 444-8360  
(401) 444-5650 - fax  
Dr. Boris Skurkovich  
webpage: <http://adoptionsinternational.com/>  
email: bskurkovich@netscape.net

## **Michigan**

**St. Joseph Mercy Hospital**

**Dr. Jerry Jenista**

551 Second St  
Ann Arbor, Michigan  
Tel: 734-668-0419; Fax: 734-668-9492

## **Minnesota**

**University of Minnesota**

**International Adoption Clinic**

**Dr. Dana Johnson**

420 Delaware Street NE, Box 211  
Minneapolis, Minnesota 55455  
Tel: 612-626-2928 FAX: 612/624-8176

## **Missouri**

**St. Louis University School of Medicine**

Cardinal Glennon Children's Hospital  
F.A.C.E.S. (Foreign Adoption Clinic and  
Educational Services)  
Jennifer S. Ladage, MD  
1465 S. Grand Avenue  
St. Louis, Missouri 63104  
(314) 577-5643; (314) 268-4028 (fax)

## **Texas**

**Texas Children's Hospital**

6621 Fannin  
(5th Floor, Suite 550, Feigin Center)  
Houston, Texas 77030  
Tel: 832-824-1038 or 1-866-824-5437 (TCH KIDS)  
Fax: 832-825-1281  
Email:  
[internationaladoptions@texaschildrenshospital.org](mailto:internationaladoptions@texaschildrenshospital.org)

## **Virginia**

**Inova Fairfax Hospital**

Dr. Patrick Mason  
International Adoption Center  
8505 Arlington Blvd. Suite 100  
Fairfax, VA 22031  
Tel: 703-970-2651  
Fax: 703-970-2620

**University of Virginia**

**Children's Medical Center**

International Adoption Clinic  
Dr. Mark Mendelsohn  
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Department of Pediatrics  
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Charlottesville, VA 22908-0386  
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## **Washington**

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## **IV. Hepatitis B Primer for Parents**



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## **A Hepatitis B Primer for Parents**

**Jerry A. Jenista, M.D.**

*[Excerpted from "Hepatitis B Revisited Or Bet You Can't Believe You're Going to Read About It Again!", by Dr. Jerri Jenista. Reprinted with permission]*



### **PART I - Medical Facts About Hepatitis B**

In my job as a pediatric infectious disease consultant, I get letters or calls every day from social workers or families distressed by hepatitis B (and no, contrary to popular belief, I do not know every adoptive family in America).

What have I learned in more than a decade of such phone calls and letters?

- More children from more countries than we ever realized are affected.
- The topic is boring until it touches your life, then it is of paramount importance.
- Doctors know very little about the disease unless they specialize in caring for drug users, dialysis patients, homosexuals, or persons requiring frequent blood transfusions (none of which are too common in the ordinary pediatric or family practice.)
- Parents are often confused by the lack of or conflicting information. Many are forced to educate themselves by reading the medical literature.
- Parents of adopted children are a lot more medically sophisticated than most parents.

You can stop reading here if you haven't adopted or never plan to adopt a child, have friends or relatives who have never adopted or never been affected by hepatitis B, or live as an isolated hermit. Everyone else should read this article since hepatitis B touches all of us in some way, if no other than to be informed supporters of affected families and individuals.

In the next few paragraphs, I will try to teach you the basics of the diagnosis and evaluation of hepatitis B. This can never substitute for a physician's care; this article is only meant to provide families with important information.

Like any other virus infection, hepatitis B has an incubation period (that is, the time from initial exposure to the virus until the disease develops). For hepatitis B, the incubation period is 60 – 180 days (2 to 6 months). Not all persons develop symptoms (i.e. become sick with the infection) and not all persons make antibodies (i.e. recover and develop life-long immunity to the virus). These two features make hepatitis B difficult to diagnose and permit the existence of a



chronic infection, which means a person is unable to get rid of the virus and is able to spread hepatitis B to others.

**How do you test for hepatitis B?** This is the area of the most common mistakes. Either the wrong tests are ordered or the answers come back but no one knows how to interpret the results.

The hepatitis B virus has several different parts called “antigens”: surface, core, and “e”. The body makes “antibodies” to each kind of antigen.

**HBsAg** – hepatitis B surface antigen

**HBcAg** – hepatitis B core antigen

**HBeAg** – hepatitis B e-antigen

**Anti-HBs** – hepatitis B surface antibody

**Anti-HBc** – hepatitis B core antibody

**Anti-HBe** – hepatitis B e-antibody

**The three most common blood tests ordered are called a “hepatitis B panel” and include: HBsAg, Anti-HBs, and anti-HBc**

Just a word or two on definitions before we run any tests – a person chronically infected with hepatitis B is defined as any person who has two positive tests for hepatitis B surface antigen (HBsAg) at least six months apart. A person is immune (or recovered) if the hepatitis B surface antibody (anti-HBs) is present and there is no surface antigen.

If the chronic state and immune state depend on the surface antigen and surface antibody tests, then what about the core antibody and “e” tests?

There is a brief time late in infection when surface antigen has disappeared, but surface antibody is not yet present. During this “window”, the core antibody is present, which is the only indication a person has been infected. Thus, a person with both surface antigen and antibody negative tests results has never been exposed to the hepatitis B virus, is very late in the incubation, or is in the window period. The core antibody helps solve that problem and distinguishes between the different possibilities.

In general, when the “e” antigen is present, a chronically infected person is considered more infectious than without it.

A first set of tests will give you a good idea of whether you are dealing with an immune or a chronic infection state, but almost never will it give you a definite answer. In most circumstances, you will need two sets of tests, 6 months apart, or 1 set of tests at least 6 months after the last possible exposure to hepatitis B (that is, 6 months after the child left the foreign country).

**Who should be tested and when?** The Centers for Disease Control and Prevention (CDC) recommend that all internationally adopted children should be screened for hepatitis B (when they arrive in the U.S., not in their country of origin). Although children from Asia and Eastern Europe are at highest risk, almost all of the areas of the world have higher rates of hepatitis B infections than in the U.S.

**What happens if your child tests positive for hepatitis B?** There are both immediate and long-term consequences of chronic hepatitis B infections. The long-term problems will be



discussed in Part II. The immediate worries: Is this virus doing harm to my child? Is the virus contagious to the rest of my family?

**Is the virus doing harm to my child?** Most children with chronic hepatitis B have no serious liver damage. However, a few may have problems. Any child who is chronically infected with hepatitis B should be tested for hepatitis D (or delta hepatitis). This type of hepatitis only infects those who are already infected with hepatitis B. Children with both hepatitis B and D may have more serious liver disease. Most children can be managed by their pediatrician or family doctor; however, they should be seen at least once by a pediatric liver specialist (“hepatologist”) with possible follow-up to keep track of the most current treatment information.

A few children with chronic hepatitis B and abnormal liver function tests are candidates for treatment with interferon. The children most likely to respond to treatment are those who acquired their infection later in life (usually past the first birthday) AND who have high liver enzymes (in the range above 100). About 40% of such children will show some response to interferon treatment, meaning that the state of the liver will improve even though they will not be “cured” of infection. *[In addition, there is now an oral drug called lamivudine or Epivir-HBV, that was approved in 1998 for children].*

**Is the virus contagious to the rest of my family?** Transmission of the virus to household members in close contact with a chronically infected child can occur. We are not sure exactly how this happens, as there is almost never a known blood exposure. Studies done in the US and in Sweden before the days of the hepatitis B vaccine, however, showed that 30-60% of households with a chronically infected child had at least one other case of hepatitis B in the first year after the child's arrival. Many of these cases were totally unsuspected as no one ever thought to test and the family members had no illness.

However, no family should be at risk for hepatitis B today. There are two safe and effective vaccines available. It only takes three shots to protect you for a lifetime. All household members should be immunized. In all circumstances, the vaccine is far preferable to getting the disease.



## PART II - Social Considerations With Hepatitis B

Now you've gotten over the initial shock, confusion and disbelief. That happy healthy baby or child is a chronically infected with hepatitis B. You've settled the immediate questions: How could this happen? Is my child sick? What should I do for my family and myself?

Now the specter of the future looms in your mind. Will hepatitis B or its complications harm my child? Will hepatitis B cause my child social isolation or rejection? Should I tell anyone about my child? If so, whom? Where can I turn for advice?

Basically, these questions can be categorized into three major areas of concern: worries for the child with chronic hepatitis B, problems for the child's social circle (friends, relatives, classmates, sexual partners), and issues for the child's world at large (career choices, etc.).



## THE CHILD

First, what are the concerns for your child's long-term health? By now, you should know if your child has any liver problems or infection with another virus, such as hepatitis D. If these conditions are present, you probably have already gone to see a pediatric gastroenterologist or hepatologist (liver specialist).

Knowledge about hepatitis B is dramatically changing as new research comes out, so it is important for you or your child's doctor to have regular contact with a liver specialist. Even so, your family doctor will generally be able to manage most of your child's medical needs. Your child will still need immunizations, regular check-ups, and antibiotics for those ear infections!

## THE CHILD'S SOCIAL CIRCLE

Hepatitis B is an infectious disease that is contagious. No one wants to get it. Thus, hepatitis B becomes a social problem. Because hepatitis B is spread in ways similar to the transmission of HIV (via blood or sexual contact), the two infections are often linked in the public's mind.

Much of the stigma attached to HIV is often transferred to hepatitis B. This is totally unwarranted as hepatitis B can be prevented with a safe vaccine. As I frequently point out to alarmed families, the public awareness of HIV may be actually be advantageous to those with chronic hepatitis B. Schools, dental and medical settings, work places and daycare centers that have reasonable policies to prevent the transmission of HIV do not need to fear the spread of hepatitis B – measures adequate to contain HIV are also sufficient to contain hepatitis B.

**What measures are necessary for the highest risk social contacts of a child with hepatitis B?** The hepatitis B vaccine is the safest, most assured method of protection. All members of a child's household, whether related or not, should be vaccinated.

**What other precautions should be taken in the home?** Once everyone is immunized, even a visible blood exposure should not be a risk. However, common sense dictates that you still treat blood cautiously. Thus, you should clean up blood and handle bloody objects or clothes with care. Contact with body fluids without visible blood (i.e. tears, saliva, stool, urine) is of such extraordinarily low risk of transmitting the virus that good hand washing is sufficient protection. Toothbrushes, razors, eating utensils and food should not be shared. In this day and age of HIV, however, a prudent family should be demonstrating these basic infection-control practices to their children daily, hepatitis B or not! Children who learn these habits early will be a lot safer as teenagers and adults.

**When should I tell my child that he or she has hepatitis B?** Remember that some day your child will have to take on the responsibility of his or her hepatitis B. Like being adopted or having leukemia (or any other chronic condition), you cannot "spring" hepatitis B on your child at adolescence and expect him to deal with it easily and cheerfully. Children should be introduced to the concepts surrounding hepatitis B at very young ages. Thus, even a two-year old should understand that blood is not to be touched and should be "shown to Mommy", that "we do not share forks", and "we always wash our hands".

As the child grows older, the issues of "checking your liver to be sure it's working right", "avoiding giving (or getting) infections", can be brought up casually but repeatedly. The child who has ingrained these concepts by adolescence is not going to be crushed with anxiety about his sexual behavior or fears of being "contaminated". When at-risk situations arise, the child will



automatically know what he should do. Habits are hard to break and these are habits you want to establish firmly before your child even thinks about rebelling.

### Hepatitis B and the School

Federal laws prohibit programs that receive federal monies from discrimination because of any “handicap” (*Rehabilitation Act of 1973*) and they also provide education for handicapped persons “in the least restrictive environment” (*Education for All Handicapped Children Act, PL94-142*). In many states, such as Michigan, chronic virus infections (i.e. HIV and HBV) have been declared as chronic handicaps, therefore, they fall under state anti-discrimination laws.

Both state and federal courts have successfully invoked these laws in school cases attempting to exclude chronically infected children. Thus, it is highly likely that any public school that excludes an otherwise healthy child with a chronic infection or in any way discriminates against his (such as segregating him in a classroom or invoking precautions not applicable to all children) will lose the case in court. Although these laws also apply to any federally funded program, including early intervention or preschool classes, they may not apply to certain private schools. They also may not apply to the child who consistently shows high-risk transmission behaviors such as aggressively biting.

If at all possible, I suggest that your physician discuss the possibility of a “hepatitis B policy” and a notification letter (see our sample “Doctor Letter”) well in advance of your child starting school. The physician should not use your child’s name initially in case the school is unreasonable or unwilling to help.

### Hepatitis B and Daycare

Babies and toddlers are clearly at much higher risk than older children of transmitting hepatitis B. We suspect this happens through repeated daily exposure to minute amounts of blood and saliva from teething, minor accidents, and mouthing of toys, etc. Daycare centers practicing good infection control measures for all children should not have a problem with hepatitis B.

Since 1991, the CDC and the American Academy of Pediatrics have recommended that ALL babies born in the U.S. be immunized against hepatitis B. Thus, your child going into daycare today is very likely to be playing with a group of children who are already protected against hepatitis B. Some daycare centers even require hepatitis B immunization before allowing a child to start!

To find out about these policies in a daycare center, ask to see their “infectious disease policy”. If HIV or hepatitis B are not mentioned in the policy, ask why not. All licensed centers should have a policy in place.

**Summary:** Close household contacts, social contacts (i.e. family daycare provider or nanny), and sexual partners should be immunized. Everyone else, including your next-door neighbor, relatives you see once in awhile, the Boy or Girl Scout troop, or casual friends do not need to be immunized nor do they need to know about your child’s condition.

School may be a temporary but emotionally challenging issue, but you have the support of many court decisions on your side. Daycare should be manageable with the support of your physician.





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## **V. Working with the School and Daycare**



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## **Hepatitis B and School Medical Forms** **Jerri Ann Jenista, M.D.**

*[Excerpted from "Hepatitis B and the School", by Dr. Jerri A. Jenista. Reprinted with permission]*



Fifteen years ago, I spent much of my professional time arbitrating among schools, parents and the public health department about what should be done with children with chronic hepatitis B infection.

Fortunately, many events have transpired since then:

- Since 1991, the Centers for Disease Control and Prevention and the American Academy of Pediatrics have recommended that all newborns [*and children up to age 18 years*] be immunized against hepatitis B.
- OSHA requirements have mandated that school districts explain the risk of occupational exposure to hepatitis B and offer the vaccine to employees with increased risk. Many school districts have extended the offer to any employee who requests the vaccine.
- Almost all of the states have included hepatitis B in the list of required vaccines for school entry. Some states require the hepatitis B vaccine for entrance into licensed daycare, too.
- Universal precaution policies [*also known as "standard precautions"*] have been instituted in most school districts in response to the threat of HIV infection.
- Public understanding of how blood-borne diseases are transmitted has increased dramatically.

Although all of these events have combined to decrease the public hysteria about all blood-borne diseases, not just hepatitis B, there are still cases of overt discrimination against children known to be chronically infected with hepatitis B.

**Parents of infected children are now faced with a new dilemma. What should they write on the school immunization form in the box for hepatitis B vaccine?**

I have heard various solutions to this problem:



- An outright lie will not work since you must provide the actual dates of vaccination. Most people would hesitate to go as far as to make up a series of dates. In addition, if discovered, the child may be excluded from school for having an invalid immunization certificate.
- Some parents have proposed actually vaccinating the child so there will be true dates to write down. Not only is this false reassurance to the school, it also exposes the child unnecessarily to more pain.
- One can simply indicate that the child has a chronic hepatitis B infection. This, however, invites the school to ask more questions and leaves open the possibility of the information “leaking” from the child’s record into the school community. Even if the child is ill with hepatitis B, there is no legal mandate to report infection to the school.

**A compromise, the only one I can see for the near future, is to write that the “vaccine is not needed because of prior infection.”**

This statement tells the truth in that the child truly does not need immunization, it also does not lie in stating whether or not the prior infection has resolved. Of course, if the school nurse asks for more information, parents must gauge carefully what they wish to reveal.

**For most of my patients, I use a generic ambivalent statement, “Child had infection confirmed as of (date) and therefore does not need hepatitis B immunization. He is being seen (or has been followed) by (doctor name) and it has been determined that he needs no treatment.”**

Of course, there are some children who are on treatment protocols or who have progressive disease for whom the letter must be worded differently. In those circumstances, I typically include a phrase that the child “is receiving evaluation and treatment and does not pose a transmission risk to other children under normal school conditions.”

Most parents, of course, do not want to reveal any hint of their child’s status to the school. However, I feel that we all must comply with the immunization laws even if it does mean some risk of exposure. The greater benefit is definitely to those of us who have infected children.

If all families comply with the immunization law, then we have far less to worry that our infected child may transmit infection at school. If a child at school remains susceptible to hepatitis B, it is not our fault, but the choice of that child’s parent.

**Before writing anything on your child’s record, you should find out what the anti-HIV discrimination laws are in your state.**

The majority of these laws prohibit persons with privileged knowledge (such as doctors’ offices and schools) from making a person’s HIV status public. Many states include other conditions such as hepatitis B in the same law. Thus, if the school calls to inquire further about your child’s status, you can remind them of their responsibility under the law to keep the information confidential.







## **Hepatitis B and the School or Daycare Center**

### **Hepatitis B and the School**

*[Excerpted from "Hepatitis B Revisited!", by Jerri Jenista, M.D.]*

Federal laws prohibit programs that receive federal monies from discrimination because of any "handicap" (Rehabilitation Act of 1973) and they also provide education for handicapped persons "in the least restrictive environment" (education for All Handicapped Children Act, PL94-142). In many states, such as Michigan, chronic virus infections (i.e. HIV and hepatitis B) have been declared as chronic handicaps, therefore, they fall under state anti-discrimination laws.

Both state and federal courts have successfully invoked these laws in school cases attempting to exclude carrier children. Thus, it is highly likely that any public school that excludes an otherwise healthy carrier child or in any way discriminates against him (such as segregating him in a classroom or invoking precautions not applicable to all children) will lose the case in court.

Although these laws also apply to any federally funded program, including early intervention or preschool classes, they may not apply to certain private schools. They also may not apply to the child who consistently shows high-risk transmission behaviors such as aggressively biting.

If at all possible, I suggest that your physician discuss the possibility of a "hepatitis B policy" and a notification letter (see sample "Doctor Letter") well in advance of your child starting school. The physician should not use your child's name initially in case the school is unreasonable or unwilling to help.

### **Hepatitis B and Daycare**

*[Excerpted from "Hepatitis B Revisited!", by Jerri Jenista, M.D.]*

Babies and toddlers are clearly at much higher risk than older children of transmitting hepatitis B. We suspect this happens through repeated daily exposure to minute amounts of blood and saliva from teething, minor accidents, and mouthing of toys, etc. Daycare centers practicing good infection control measures for all children should not have a problem with hepatitis B.

Since 1991, the CDC and the American Academy of Pediatrics have recommended that ALL babies born in the U.S. be immunized against hepatitis B. Thus, your child going into daycare today is very likely to be playing with a group of children who are already protected against hepatitis B.

*[Note: Many states now require hepatitis B immunization before allowing a child to start daycare. Check with your doctor or the State Health Dept.'s Hepatitis B Coordinator]*



## Important Questions to Ask Your Child's School or Daycare

### ***Prior to Enrollment:***

1. Ask about the school's infection control policies and procedures. How do they handle bloodborne pathogens (i.e. incidents involving blood), do they provide gloves for teachers, etc.
2. Discuss the risk of HIV/AIDS and hepatitis B in general and the need for "standard precautions" (also known as "universal precautions") with all children.
3. Call the school about accepting a child with chronic hepatitis B to determine their possible response and educational needs. You may consider initially calling anonymously to protect your child's identity.
4. Check with your State Board of Education to determine whether your state requires disclosure of HIV/AIDS or hepatitis B to school officials.
5. Many states now require proof of hepatitis B vaccine or immunity to enter school. Check with the school or your local health department.

### ***Once Enrolled:***

1. You need to decide whether to inform the principal and/or school nurse of your child's diagnosis. If you choose to tell, be prepared with literature and provide a written letter from your doctor, reassuring them that your child is healthy. Remind school officials that there are other bloodborne pathogens that need to be avoided as well, not just hepatitis B.
2. Discuss the importance of universal precautions with all children and, if necessary, offer to help institute such a policy with the assistance of your local health department or physician/nurse. Ask your medical resources to provide a staff in-service on hepatitis B and the proper handling of blood spills.
3. Educate the principal and school nurse about the available hepatitis B vaccine that can prevent infection. Inform them that the American Academy of Pediatrics recommends that children up to 18 years of age be universally vaccinated. Reinforce the fact that hepatitis B is entirely preventable!
4. Stress the importance of confidentiality to protect your child from potential social discrimination. Let school officials know that there are a number of laws and statutes that protect the confidentiality of private information, including both health and educational records.

For example, the **Americans with Disability Act of 1992 (ADA)** provides protection for privacy of a student's medical records, as well as the **Family Educational Rights and Privacy Act of 1974** (the "Buckley Amendment").





## **SAMPLE DOCTOR'S LETTER FOR SCHOOL OR DAYCARE**

**(Any letter should be customized for your child's medical situation and school setting)**

To Whom It May Concern,

I am writing this letter to let you know that a child with chronic hepatitis B has [*or will be*] enrolled in your school. I expect this child will continue to remain in good health and that [*his or her*] growth and development will proceed normally.

Under usual school conditions, this child should pose no transmission risk to classmates or staff. The hepatitis B virus is transmitted through blood. Urine, feces and saliva do not transmit the virus unless blood is visible. Most importantly, hepatitis B is not spread casually; therefore, no special precautions need to be taken.

If this child should bleed due to an accident, cut or nosebleed, the teacher should, if possible, take the child out of the classroom and have the school nurse deal with the wound or nosebleed. Staff members should practice "universal or standard precautions", which includes keeping a box of gloves on hand so that they do not directly touch any blood. Areas or materials exposed to blood should be soaked with a 10% solution of bleach (Clorox) and cleaned up with paper towels. All blood-contaminated materials, paper towels and gloves should be disposed of in a well-tied plastic bag, followed by thorough handwashing.

In addition, the American Pediatrics Association recommends that all children up to the age of 18 years be universally vaccinated against hepatitis B. Most states require the hepatitis B vaccination before school entry and many states also have daycare requirements.

*Hepatitis B is a vaccine-preventable disease.* All staff in schools and daycare centers should be vaccinated against hepatitis B. Exposure to potentially infectious blood cannot be completely avoided, but hepatitis B infections can be prevented with vaccination

If you have any questions, please contact [*Dr's name and telephone number*]. For additional information, please contact the Hepatitis B Foundation, a national nonprofit organization dedicated to this liver infection, at [www.hepb.org](http://www.hepb.org) or call (215) 489-4900.

Sincerely,

Dr. John Doe



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## State Information

## Hepatitis B Prevention Mandates for Daycare and K-12

An empty box in this table indicates a "NO" answer

State	Hep B childhood vaccination mandate?	Hep B daycare mandate, year in effect	Hep B elementary school mandate, year in effect	Hep B middle school mandate, year in effect
Alabama				
Alaska	yes	2001	2001	2001
Arizona	yes	1997	1997	2000
Arkansas	yes	2000	2000	2000
California	yes	1997	1997	1999
Colorado	yes	1997	1997	1997
Connecticut	yes	1995	1996	2000
Delaware	yes	1999	1999	1999
Dist of Columbia	yes	1997	1997 prog <sup>†</sup>	1997 prog <sup>†</sup>
Florida	yes		1998 prog <sup>†</sup>	1997 prog <sup>†</sup>
Georgia	yes	1997	1997	
Hawaii	yes	1998	1998	7/02
Idaho	yes	1995	1995	children born after 11/22/91
Illinois	yes	1997	1997 prog <sup>†</sup>	1997 prog <sup>†</sup>
Indiana	yes		1999	6/05
Iowa	yes		1999	
Kansas	yes	9/09	9/04	SY 2009-10
Kentucky	yes	1998	1998	2001
Louisiana	yes	1998	1998	SY 2009-10
Maine	yes	11/02		
Maryland	yes	2000	2001 prog <sup>†</sup>	2007 prog <sup>†</sup>
Massachusetts	yes	1993	1996	1999 prog <sup>†</sup>
Michigan	yes	1997	2001	9/02
Minnesota	yes		2000	2001
Mississippi	yes		1999	
Missouri	yes	1995	1997	1999
Montana				
Nebraska	yes	2/04	1999 prog <sup>†</sup>	2000 prog <sup>†</sup>
Nevada	yes	10/07	7/02	
New Hampshire	yes	1996	children born after 1/1/93	children born after 1/1/93
New Jersey	yes		2001	2001
New Mexico	yes	2000	9/02	1999
New York	yes	1995	1998	2000
North Carolina	yes	1994	1999	9/05
North Dakota	yes		2000 prog <sup>†</sup>	
Ohio	yes	1999	1999 <sup>†</sup>	2006 <sup>†</sup>
Oklahoma	yes	1999	1998 prog <sup>†</sup>	1997 prog <sup>†</sup>
Oregon	yes	1998	1998	2000
Pennsylvania	yes	1994	1997	2002
Rhode Island	yes	1998	1999	2000
South Carolina	yes	1994	1998	1998
South Dakota				
Tennessee	yes	7/10	1999	7/02
Texas	yes	2004	1998	2000
Utah	yes	7/08	1999 prog <sup>†</sup>	
Vermont	yes	3/11	8/08	1999 <sup>†</sup>
Virginia	yes	1994	1994	2001
Washington	yes	1997 prog <sup>†</sup>	1997 prog <sup>†</sup>	7/08 <sup>†</sup>

West Virginia	yes	2000	2008	
Wisconsin	yes	1997	1997	1997 <sup>†</sup>
Wyoming	yes	1999	1999	1998

<sup>†</sup> Signifies a "progressive" law in which each new school year another successive grade becomes covered by the law (e.g., 7th grade in 2000, 7th and 8th grade in 2001).

If you have any updated information concerning this table, please call (651) 647-9009 or email [admin@immunize.org](mailto:admin@immunize.org). This table was compiled by the Immunization Action Coalition using information provided by state health departments.

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## State Information

### Hepatitis B prevention mandates for colleges and universities

An empty box in this table indicates a "NO" answer

State	Mandate for education or vaccination?	What types of institutions?	Who is covered?	Education mandate?	Proof of vaccination or waiver required?	Implementation date
Alabama						
Alaska						
Arizona						
Arkansas						
California	yes	state univ & UC system	all students <19 yrs		yes	2000
Colorado						
Connecticut	yes	all	all	yes		2005-06 school year
Delaware						
Dist. of Columbia	yes	all	all		yes	2003-04 school year
Florida	yes	all	all students in on-campus housing		yes	1/2003
Georgia	yes	UG system	all students <18 yrs at college entrance		yes	2005
Hawaii						
Idaho						
Illinois						
Indiana						
Iowa						
Kansas						
Kentucky	yes	all	all incoming students	yes		7/04
Louisiana						
Maine						
Maryland						
Massachusetts	yes	all	health science students; freshmen-juniors in 2003-04		yes	1999
Michigan						
Minnesota	yes	all	all	yes		1999
Mississippi	yes	all	all incoming students	yes		7/2003
Missouri						
Montana						
Nebraska						
Nevada						
New Hampshire						
New Jersey	yes	all	all incoming students		yes	2008-09 school year
New Mexico						
New York						
North Carolina						
North Dakota						
Ohio	yes	all public institutions	all students in on-campus housing		students must provide documentation of whether or not they've been vaccinated	7/05
Oklahoma	yes	all	all incoming students		yes	2004-05 school year
Oregon						
Pennsylvania						
Rhode Island	yes	all	health science students		yes	2001

			all students		yes	8/06
South Carolina	yes	all	all incoming students residing on campus	yes		6/05/02
South Dakota	yes	state univ & USD system	health science students		yes	2002
Tennessee	yes	all	all incoming students	yes		7/2003
		all with >200 students	health science students expected to have patient contact		yes	7/2011
Texas	yes	all	health science students		yes	1992
Utah						
Vermont	yes	all	all incoming students		yes	8/08
Virginia	yes	all 4-yr public institutions	All incoming full time students	yes	yes	7/05
Washington						
West Virginia						
Wisconsin	yes	all	all students	yes		1/01/04
Wyoming						

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## **Finding Out Your Child has Hepatitis B** ***Interviews with Leading Liver Specialists***

### **What do you say to parents when they discover their child has hepatitis B?**

**Dr. Margaret Hostetter** (Co-Director, International Adoption Clinic at the Univ. of Minnesota): I am very specific about what is “acute hepatitis B”, a “simple carrier”, and “chronic hepatitis B”. The three categories are very different in terms of prognosis. In “acute hepatitis B”, many young children less than 5 years of age do not have any symptoms when they are first infected. The infection may last 6 –18 weeks. Adults have a 90% chance of recovering without complications. Infants and young children, however have a much greater chance of developing a chronic infection. Infants have a 90% risk of developing a chronic infection if they are exposed to the hepatitis B virus. Children have a 40-60% risk. There is the “simple carrier” (asymptomatic) who has the virus in the liver, but it is not actively replicating very much. The liver is not being significantly damaged, and infection continues without symptoms for one’s entire life. “Chronic hepatitis B” is most commonly seen in children who acquired it at birth or during their first year of life. The virus is continually replicating and damaging the liver, albeit at a low level that might not cause symptoms.

**Dr. Maureen Jonas** (Director of Hepatology, Children’s Hospital of Boston): It somewhat depends on the state of the child and how it comes to the parents’ attention. If a child was adopted, all international adoptees are screened and it may come as a surprise. Or it may come to their attention if the child has a liver problem. Sometimes abnormal liver tests are found for some other reason, and further evaluation reveals a hepatitis B infection. I explain that if a person tests positive for hepatitis for more than six months, then it is considered a chronic infection. They can be either an asymptomatic carrier with a normal liver, or they could have chronic hepatitis B that might lead to serious liver disease and complication over several decades. I teach parents about precautions and modes of transmission, and if appropriate, discuss treatment options.

**Dr. Eric Maller** (Pediatric Hepatologist at Children’s Hospital of Philadelphia): Hundreds of millions of people around the world are chronically infected with hepatitis B, and many of them are not only healthy, but they have no idea they are chronically infected. So it is important for parents to understand that their child can live a long and healthy life. I try to educate parents about the differences between patients with chronic hepatitis B who are e-antigen negative (“healthy or simple carrier”) with normal liver enzymes and the patient who is e-antigen positive (“chronic hepatitis B infection”) and more likely to have ongoing inflammation of the liver and potentially more liver disease later on in life. It is important to find out how active the virus is and how much inflammation is occurring in the child’s liver. Statistically, there is an increased risk of liver cancer for those with chronic hepatitis B, and the risk seems to correlate to the degree of inflammation and cirrhosis, both of which are more likely to occur in those who are e-antigen positive.





## **PKIDs Hepatitis Report** **“Treatment Options for Children with Hepatitis B”**

*Excerpted from PKIDs Hepatitis Report (updated summer 2010), available at [www.pkids.org](http://www.pkids.org)  
PKIDs (Parents of Kids with Infectious Diseases) is a national nonprofit organization  
dedicated to families touched by HIV, HBV, and HCV.*

When given the news that their child has chronic hepatitis B, the first question many parents ask is: What treatment is available to eradicate the virus and prevent or slow liver disease?

Normally, chronic hepatitis B is a mild disease in children and teens. Often, young people experience an immune tolerant stage during the first two to three decades of infection, during which there is little damage to their livers. As a result, the incidence of liver inflammation, scarring, cirrhosis and liver cancer is low in children and adolescents.

However, in some children, the virus rapidly replicates and causes extensive liver damage when the child's immune system attacks infected liver cells. It is these children who may need immediate medical intervention from the small arsenal of drugs currently available to halt this liver disease.

The primary treatment goals for children (and adults) are to:

- strengthen the immune system so that it can effectively attack the infection
- prevent the virus from replicating, showing an undetectable HBV viral load
- halt any liver damage
- spur the immune system to create the hepatitis B e antibody (HBeAb)
- produce the surface antibody (HBsAb), which signifies recovery from the infection

In addition to slowing liver disease in children, medical researchers have another goal in mind: to eradicate the disease in the pediatric population today in order to prevent cirrhosis and liver cancer in the adults of tomorrow.

Unfortunately, the treatments available for hepatitis B infection in children have had limited success. There are only a handful of pediatric clinical trials taking place to test drugs on children that so far have been used only in adults. Few studies have followed large numbers of children with chronic hepatitis B infections and fewer yet have tracked children a decade or more after treatment.

When to treat hepatitis B in children is an area of debate within the medical research and treatment communities.

### **Treatments Available for Children Today**

As of June 2007, there were only two drugs approved by the U.S. Food and Drug Administration (FDA) to treat hepatitis B in children: standard interferon and lamivudine. More recently, three other drugs have been added to the treatment options for older children. These drugs include



adefovir (labeled for use in children over the age of twelve), entecavir (labeled for use in children over the age of 16), and telbivudine (labeled for use in children over the age of 16).

### **Standard Interferon**

Interferons are naturally occurring proteins that spur the immune system to fight viral infections and tumors. Synthetic or “conventional” interferon has been the most studied drug for treatment of chronic hepatitis B infection in children and adults.

According to the 2009 Pediatric Report, pediatric liver specialists prefer to get baseline testing and wait six months to ensure the patient is chronic and to see if seroconversion occurs before considering treatment. Treatment is not typically considered until a child’s ALT levels are greater than twice the normal limit for longer than 6 months before trying treatment. Elevated ALT levels indicate that the immune system has noticed the virus and gone on the attack. The interferon is effective only if the immune system is already engaged in war against the virus.

But interferon doesn’t work in everyone, and it can cause uncomfortable side effects, including fever, flu-like symptoms, growth impairment during the treatment phase, and anxiety and depression. However, in general, children are typically much more resilient than adults on interferon and less symptomatic, and experience adverse effects for shorter periods of time.

### **Lamivudine (Epivir)**

This drug is a nucleoside analog (artificial genetic material that prevents viral replication). Newer research indicates that lamivudine should be avoided if possible because it has a high resistance profile. This means that most users of lamivudine will develop a resistance to the antiviral, and more importantly, a cross resistance to more effective antivirals. Should another option exist, it is important to consider the alternative rather than risk mutant strains associated with lamivudine.

Three factors have been identified as predictors for successful HBeAg clearance with lamivudine treatment:

- higher ALT levels
- low serum HBV DNA load prior to initiation of therapy
- older age at the initiation of therapy

Besides the convenience of a once-a-day tablet or a liquid oral solution, lamivudine has fewer and less severe side effects than interferon. The most common side effects are fatigue, headache, nausea and abdominal pain.

### **Adefovir (Hepsera)**

In 2002, the FDA approved the first nucleotide analog drug, adefovir dipivoxil, marketed as Hepsera, for treatment of hepatitis B in adults. As of May 2010, adefovir has been approved for use in children over the age of twelve.

For patients 12-17 years of age, treatment with adefovir is recommended for HBeAg positive patients who have compensated liver function. Adefovir [also] has an important advantage: it appears to be quite effective against all hepatitis B viruses, even the lamivudine-resistant YMDD mutation.

[Studies have] determined that adefovir was effective in children between the ages of 12-17 who also had HBeAg positive chronic hepatitis B, though knowledge related to duration of effect in children is currently lacking.



The only potential problem researchers are aware of at this time is that adefovir can cause kidney problems when administered at high doses. This potential renal toxicity makes the process of establishing safe dose levels in children critically important.

### **Entecavir**

In April 2005, the FDA approved entecavir, a carbocyclic analog, for adult treatment. As of April 2007, several centers in the United States were in the early stages of recruitment for initial pediatric trials for entecavir; currently, the drug has been FDA-approved for use for children age 16 and older based on the success of studies in adults.

Entecavir can be used in patients who are negative or positive for HBeAg who have compensated liver disease. Entecavir is associated with a low rate of drug resistance and studies show that entecavir is able to suppress both the lamivudine-resistant and the adefovir-resistant viruses. Entecavir was well tolerated by adults and most adverse events were mild to moderate and temporary.

In 2010, Dr. Philip Rosenthal reported that a “phase IIb clinical trial for entecavir use in patients as young as 2 years old is currently underway and a phase III study is about to begin.” This suggests that expanding use of entecavir to younger children might become possible in the future.

### **Telbivudine (LdT)**

Based on studies that have been done in adults, telbivudine has also been approved by the FDA for children 16 years of age and older. Telbivudine is another antiviral compound that inhibits HBV replication by interfering with its DNA polymerase.

Most of the drug’s reported side effects were mild to moderate, with the most common side effects being fatigue, abdominal pain, cough and an elevated creatinine phosphokinase (CPK), which is an enzyme in muscle tissue that enters the blood stream when muscle tissue is broken down.

## **Drugs That Have Been Approved for Adults May Have a Future with Children**

In the U.S., any new drug must first gain approval for use in adults before drug makers can plan pediatric clinical trials.

### **Pegylated Interferon**

Pegylated interferon was approved for treatment for adults in 2005. What is interesting from a pediatric perspective is that this interferon formula has proven effective in adults who have the HBeAg, high HBV DNA levels and normal ALT levels. These three characteristics are common in children who are in the immune tolerant stage of the infection.

Another factor that raises hopes for successful treatment for children is that pegylated interferon appears to have greater effectiveness in patients younger than 25 year of age when compared to patients who are older. More studies of pegylated interferon use in children are needed; consequently it has not yet been approved for use in children.

### **Tenofovir**

In 2008, tenofovir (Viread), a nucleotide analog, was approved for treatment of hepatitis B in adults. This drug, along with entecavir and pegylated interferon, is considered to be among the first-line treatments for hepatitis B in adults.



As of summer 2010, Dr. Philip Rosenthal reports that “tenofovir is currently being tested in an adolescent HBV cohort.” This suggests that tenofovir might at least be approved for use in treating older children, similar to the way entecavir has already been approved for children aged 16 and older. Studies for younger children are currently in planning stages.

### **Treatments on the Horizon**

Better treatment is needed to combat hepatitis B at any age and during any stage of infection.

There is no treatment available that is consistently effective in curing this infection, and currently no medication produces durable results in lowering HBV DNA and ALT levels in the majority of those treated. For children, therapy with only interferon or lamivudine is effective in only a minority of patients.

Bottom line: current therapies are inadequate for 60 to 90 percent of patients with chronic hepatitis B.

#### *Non-Nucleoside Antivirals (sometimes called HAPs)*

A new class of compounds, non-nucleoside antivirals, which are sometimes called HAPs (for heteroaryldihydropyrimidines), has been found to inhibit HBV replication in a way that is distinctly different from existing antiviral medications. Unlike lamivudine or adefovir, non-nucleoside antivirals do not inhibit the HBV polymerase.

In 2006, five drugs of this class were in early stages of study. One of these, BAM-205, has been approved for use in Russia since 2001. This drug is in phase II/III clinical trials in the US.

Another nucleoside antiviral, (Bay 41-4109), has shown particular promise as a potent therapeutic agent in mice.

#### *Therapeutic Vaccination*

For several years, researchers have been investigating whether it is possible to use a vaccine with surface antibodies to spur a patient’s immune system into action against the hepatitis B virus.

Three types of vaccines have been studied: peptide vaccine, DNA vaccine, and antigen-based (current vaccines are surface antigen-based) vaccine.

One promising next-generation vaccine that has been trialed in humans is HBsAg-pulsed DCs. Here, HBsAg is injected, and dendritic cells (DCs) present at the injection site recognize and internalize the HBsAg. Then, the DCs communicate with T and B lymphocytes present in the immune system. As a result, B lymphocytes learn to recognize HBsAg and secrete HBsAb. When the HBsAg is pulsed, the HBsAg is paired with DCs in the laboratory and then injected back into the body to concentrate the effect of the vaccine.

In 2004, human studies demonstrated an increase of HBsAb in all participants with no adverse side effects. Future research will consider differences among races and individuals.

### **When Should a Child Be Treated?**

In November 2008, a panel of North American pediatric liver specialists developed a series of recommendations to assist practitioners in determining the best strategies for diagnosing, monitoring, and referring children for treatment who have chronic hepatitis B. The resulting



recommendations were published in the November 2009 issue of Pediatrics.

The recommendations suggest that a liver specialist should be consulted if or when two or more of the following occur: elevation of ALT, AFP greater than 10ng/ml, HBV DNA greater than 2000 IU/mL, or family history of liver disease. The liver specialist will be able to give guidance for further monitoring and treatment if needed, and can also offer evaluation for liver cancer.

The development of drug resistance in a child is an important problem. First, a drug resistant strain becomes more difficult to treat. Because of the limited arsenal of drugs available for pediatric use, treatment options at that point are extremely limited and the problem becomes a lifelong challenge.

As pediatric trials for entecavir and tenofovir progress, pediatric specialists are hopeful that these treatments will prove to be superior for use with children as well.

In spite of the drawbacks associated with using lamivudine and adefovir in children, children with high levels of ALT and HBV DNA are most likely to respond to treatment with any of the currently approved treatments.

**For a complete copy of the PKIDs Hepatitis Report, please visit their website at [www.pkids.org](http://www.pkids.org) (or go directly to [www.pkids.org/pedheprep.htm](http://www.pkids.org/pedheprep.htm)).**

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# What the Physician Can Do to Help the Child with Chronic Hepatitis B Virus Infection

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Although children with chronic hepatitis B virus (HBV) infection may follow many different clinical courses, these recommendations will help all of them maintain good health.

## 1. A yearly physical

Every child with hepatitis B needs a yearly check-up with his/her primary physician to make sure the child is healthy and growing normally.

## 2. Laboratory studies to monitor liver health

At the first clinical visit, liver enzymes (ALT and AST), INR, a complete blood count, alpha-fetoprotein (AFP) and ultrasound are usually obtained. Thereafter, liver enzymes should be checked yearly in the healthy child with HBV.

## 3. Screening for hepatocellular carcinoma

There are no definitive guidelines for screening children with HBV for hepatocellular carcinoma. AFP is a tumor marker and is increased in 85% of individuals with hepatocellular carcinoma, often before clinical evidence of cancer is present. It may be elevated at a time when the tumor can be resected completely. We recommend yearly AFP in the child with HBV, and twice yearly testing with hepatic ultrasound in the child with cirrhosis and HBV. It should be noted that even close monitoring of these tests does not guarantee early diagnosis of hepatocellular carcinoma.

## 4. Hepatitis B testing every 3-5 years

Few children convert from HBsAg to anti-HBs (HBsAb), especially if they acquired the disease in the perinatal period. It is important to occasionally check to see if the patient is still infected.

## 5. Referral to a pediatric gastroenterologist

Any child with an AST >2 times the upper limit of normal, evidence of hepatic dysfunction, failure to thrive, an elevated AFP, a need for family counseling, or abnormalities on hepatic ultrasound should be referred to a pediatric gastroenterologist for evaluation.

## 6. Treatment

Although medications are available to treat hepatitis B, they are generally useful only in patients with on-going hepatic injury (active hepatitis). Consultation with a pediatric gastroenterologist will help identify those patients who would benefit from medical therapy.

## 7. Vaccination of household members

All members of the child's household and caregivers who have close contact with the child should be vaccinated against hepatitis B, even if pregnant.

## 8. Hepatitis B education

Each child with hepatitis B and his/her parents should receive age-appropriate hepatitis B education. This should include methods for prevention of transmission of the virus and assistance for the child in dealing with his/her positivity throughout the school years and as a teenager. Older children should receive counseling on the use of condoms to prevent viral transmission to their sexual partners.

## 9. Maintaining personal health

Immunization against hepatitis A is recommended to prevent a second injury to the liver. Ethanol should be avoided. When prescribing other medications, care must be taken to avoid or monitor those with known hepatotoxicity.

For more information regarding the child with hepatitis B, please contact Dr. Sarah Jane Schwarzenberg in the division of Pediatric Gastroenterology, Hepatology and Nutrition, University of Minnesota, Department of Pediatrics, 420 Delaware Street SE, Minneapolis, Minnesota 55455; Telephone (612) 624-1133.