

B HEPATITIS B

INFORMED

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CAUSE FOR A CURE

"The only non-profit organization solely dedicated to the cause and cure of chronic hepatitis B"

NIH Recommendations for HBV Hoping for a Future

Almost ten years after the first drug was approved for chronic hepatitis B, the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) of the National Institutes of Health (NIH) sponsored the first ever 3-day conference on "The Management of Hepatitis B: 2000" last year in Bethesda, MD (see spring issue of *B Informed*). The NIH workshop provided a forum for caregivers from around the world to benefit from the experience of their colleagues and to share results of large, well-controlled studies.

According to **Anna Lok, M.D.**, meeting co-chair, "the workshop was held because new advances in diagnostic tests and treatment have created many controversies about their utilization, so summary recommendations were needed." A formal report including these recommendations, "*Management of Hepatitis B: 2000 - Summary of a Workshop*", was prepared by **Drs. Anna Lok, Jenny Heathcote, and Jay Hoofnagle**, and published in "Gastroenterology" June 2001.

The workshop recommendations attempt to standardize (and reform) terminologies describing HBV infected individuals and identify general criteria regarding monitoring and antiviral drug treatment (see p. 6). The degree of controversy over these matters remains to be seen, but most of the

suggestions should not be surprising to those in this field.

The workshop certainly provided a clearer picture about the state and direction of HBV care; however, it is unclear whether or not these recommen-

dations will be followed. As Dr. Lok explained, "the article is a report of a workshop and does not carry the weight of an officially endorsed guideline." So the key question is, if the recommendations are not embraced by professional medical organizations, will clinicians feel comfortable following this advice?

Just as every patient with chronic hepatitis B requires good follow-up care for future success, so do the NIH recommendations. Although Dr. Lok did not anticipate follow-up meetings any time soon, and Dr. Hoofnagle was uncertain whether there was enough data on HBV therapies to hold a formal NIH consensus conference, there is hope. The HBF has learned that the European Association for the Study of the Liver (EASL) is planning a consensus conference on hepatitis B next fall 2002. Fortunately the dialogue will continue.

"Chronic infection with the hepatitis B virus is estimated to affect 400 million persons and to be the single most common cause of cirrhosis and hepatocellular carcinoma (liver cancer) worldwide."

*Opening statement
"Management of Hepatitis B: 2000-
Summary of a Workshop"
(June 2001)*



Message from the President

Timothy M. Block, Ph.D.

Is HBV Ready For Consensus ?

In this issue of *B-Informed*, the recent report, "Management of Hepatitis B: 2000-Summary of a Workshop" was reviewed (see front page). To be sure, the scientific community is replete with meetings. This one is different, though, in several respects because it has both symbolic and practical value.

Symbolically, although this was not an official National Institutes of Health (NIH) "Consensus Conference", the meeting still had the imprimatur and credibility of the NIH. From a practical perspective, the recommendations resulting from the workshop were drafted by three highly respected authorities in the treatment of HBV and have been published in a major medical journal.

An NIH workshop has great prestige, however, it apparently does not carry the authority of an NIH "Consensus Conference". The NIH Consensus Development Conference Program, which was established in 1977, is a formal process that culminates in a "consensus statement" that is widely distributed and includes recommendations for clinical practice that are often adopted as official guidelines by appropriate professional organizations. Such guidelines are what physicians feel most comfortable using in their practices. For example, the NIH consensus conference for HCV in 1997 resulted in recommendations that have become the standard of care.

Despite a greater clinical experience with the management of HBV, compared with HCV, it is possible that HBV therapy is still too controversial. We hope that it is for this reason that a consensus conference has not been called - and not because of a lack of interest.

HBV patients need and deserve clear guidelines for the management of their disease. If the expectation by doctors is that formal guidelines must be embraced by their professional organization, and if a "consensus conference" is the most expeditious way to achieve this goal, then the hepatitis B community must speak up and voice their message - we cannot wait much longer. It should also be known that the HBF stands ready and eager to help support such a conference at any time and anywhere.

In The News



U.S. FDA Approves Lamivudine For Pediatric Use

On August 16, 2001, the U.S. FDA approved lamivudine for the treatment of children aged 2 years and above with chronic hepatitis B. Data on the pediatric indication will be presented by Glaxo for the first time in the U.S. at the North American Society for Pediatric Gastroenterology and Nutrition Conference in Orlando, FL, October 25 -28th.

Entecavir Phase III Clinical Trials Put On Hold

Bristol-Myers Squibb (BMS) has put a temporary hold on phase III clinical studies of entecavir pending analysis of the results of animal studies of the drug's potential carcinogenicity. More information may become available within the next 60 days, according to BMS. [Sept. 10, 2001, http://www.hivandhepatitis.com/hep_b/news/091001a.html]

Alert to Liverite Users: Company Fined \$60,000 for False Claims

Liverite Products, Inc. agreed to pay a \$60,000 fine and settle Federal Trade Commission (FTC) charges that they made unsubstantiated claims about the ability of their dietary supplements to treat or prevent a wide range of liver diseases, including cirrhosis and hepatitis. According to the FTC, these representations were not supported by competent and reliable scientific evidence. Products sold include Liverite; Liverite 3 in 1 for Men; Liverite 3 in 1 for Women; and Liverite. [FTC Press Release, August 21, 2001-www.ftc.gov]

Israeli Health Ministry Orders HBV Vaccine for All Survivors of Suicide Bomb Attacks

Two of the recent suicide bombers in Israel were found to be HBV carriers. A person wounded in one of the attacks had a fragment of the bomber's bone in his body. As a precautionary measure, the Israeli Health Ministry ordered HBV vaccination of all survivors of suicide bombs. Hepatitis B is endemic in the Middle East, and about 10% of the Arab population in Israel are carriers. All infants born since 1992 have been vaccinated, whereas few Israeli adults have been. [British Medical Journal, August 25, 2001 www.bmj.com]

China - Biggest Hepatitis B Epidemic in World

Chinese officials report that surveys show that two-thirds of China's 1.26 billion people have been infected with hepatitis B. The most common source of transmission is the use of dirty needles, which are often reused to save money. An estimated 60% of infected individuals were exposed to HBV in childhood, usually during routine vaccinations or at birth. Many others were infected through acupuncture procedures. HBV-related liver cancer and cirrhosis kill about 300,000 people each year in China. [CDC HIV/STD/TB "Prevention News Update", August 23, 2001]



The HBF extends our sympathy to those affected by the tragic events of September 11, 2001. The horror and grief of that day reminds all of us of the importance of life. We also acknowledge with gratitude the email messages received from friends in the Middle East, expressing their condolences and support to the U.S. during this difficult time.

8th Annual Hepatitis Coordinators Conference

State Coordinators Key to Prevention and Control of Viral Hepatitis

July 29 – August 2, 2001, Richmond, VA

The Centers for Disease Control (CDC) sponsored the 8th Annual Hepatitis Coordinators Conference to promote the exchange of information about program successes and obstacles encountered this past year. Over 350 attendees assembled in Richmond, which included **Molli Conti**, HBF Associate Director and **Chari Cohen, MPH**, HBF Program Coordinator.

The conclusion of the conference solidifies the state hepatitis coordinators' position as the key players in the continuing effort to prevent and control hepatitis B and C since they serve as the critical link between the CDC and state and local health departments. Each state has a hepatitis B coordinator, and 26 states have a hepatitis C coordinator.

The good news at the conference is that routine vaccination coverage of young children has increased to more than 80% (from only 10% in 1992), and all but seven states now have laws in place that require the HBV vaccine upon school entry. However, now the primary prevention goal is to educate and vaccinate high-risk adults and communities.

In Washington state, the health department launched a community-based campaign targeted to Asians, which included a media blitz and vaccination of adults and children. In a large Hmong community in Detroit, Michigan, health department workers found that going into churches was an effective way of reaching out to high-risk communities. The Florida and Massachusetts state health departments have created multilingual posters and brochures that are distributed in city clinics, STD treatment centers, correctional facilities, drug and alcohol treatment centers, and high-risk neighborhoods.

As awareness of viral hepatitis increases, future conferences will inevitably expand to include a wider range of disciplines encompassing viral hepatitis prevention. For more information about your state hepatitis coordinators, visit the CDC at www.cdc.gov/ncidod/diseases/hepatitis or the Immunization Action Coalition at www.immunize.org

Fast Fact



More than
500 million people have been vaccinated
against HBV worldwide.

HEPDART 2001: Frontiers in Drug Development for Viral Hepatitis

HBF Invited to Speak at International Scientific Conference

December 16-20, 2001 Maui, Hawaii

HEP DART 2001 is an international conference that brings together clinicians and scientists from academia, government, and industry to discuss the current and future challenges in therapeutics for hepatitis B and C infections. The conference is open to anyone interested in therapies for viral hepatitis. However, the content of this meeting was developed to interest primarily scientists and clinical researchers in the infectious diseases.

The HBF has been invited this year to speak at a special session on "Public Health and Outreach Efforts" by meeting co-chairs **Drs. Jean-Pierre Sommadossi, Raymond Schinazi, and Charles Rice**. In addition, the program will include presentations on pathogenesis, co-infections, and drug development.

Specific conference objectives include the need to understand the role of viral targets and assess the impact of resistance and treatment failure in the drug development and discovery process; identify the next generation of inhibitors of viral hepatitis; increase awareness of the clinical impact of antiviral agents; understand the consequences of co-infection with HIV on the management of patients; and assess the role of vaccines and therapeutic vaccines in future therapies for viral hepatitis.

For more information, visit Informed Horizons at www.informedhorizons.com or email info@informedhorizons.com.

Princeton Workshop Surfs to Hawaii This Year

December 17, 2001, Maui, Hawaii

In December, the HBF will hold the 7th Annual Princeton HBV Workshop in Hawaii to accommodate many scientists who are juggling a crowded conference schedule. Instead of inviting thought leaders to New Jersey, the HBF will travel to Hawaii to convene a special workshop session on Monday December 17 at the Hep Dart 2001 meeting. Discussions started last year about research priorities will be continued — this year the HBF has invited FDA officials from the USA, China, and France to add a regulatory perspective. So far, there have been no complaints about the change of venue!

HBV Drug Watch

Compounds in Development

For Chronic Hepatitis B

Update September 2001

Links to the pharmaceutical companies are provided for your information only and are not intended as an endorsement for the therapies or the manufacturers listed below.

FAMILY/DRUG NAME	MECHANISM	COMPANY	WEBSITE	STATUS, USA
INTERFERONS Mimic naturally occurring infection-fighting immune substances produced in the body				
Interferon alpha-2b (Intron A)	Immunomodulator	Schering-Plough, Madison, NJ	www.schering.com	FDA Approved 1991
NUCLEOSIDE ANALOGUES Interfere with the viral DNA polymerase enzyme used for hepatitis B virus reproduction				
Lamivudine (Epivir-HBV)	Inhibits viral DNA polymerase	GlaxoSmithKline, RTP, NC	www.gsk.com	FDA Approved 1998
Adefovir Dipivoxil	Inhibits viral DNA polymerase	Gilead Sciences, Foster City, CA	www.gilead.com	Phase III
Entecavir	Inhibits viral DNA polymerase	Bristol-Myers Squibb, Princeton, NJ	www.bms.com	Phase III
FTC (Coviracil)	Inhibits viral DNA polymerase	Triangle, RTP, NC	www.tripharm.com	Phase III
DAPD (DXG)	Inhibits viral DNA polymerase	Triangle	www.tripharm.com	Phase II
L-FMAU (Clevudine)	Inhibits viral DNA polymerase	Triangle	www.tripharm.com	Phase II
AM365 NEW	Inhibits viral DNA polymerase	Amrad, Victoria, Australia	www.amrad.com.au	Phase II, Australia & Asia
LdT	Inhibits viral DNA polymerase	Novirio, Boston, MA	www.novirio.com	Phase II
LdC	Inhibits viral DNA polymerase	Novirio	www.novirio.com	Phase I
MCC478	Nucleoside analog "prodrug"	Eli Lilly, Indianapolis, IN	www.lilly.com	Phase I, Germany
Fluoro-L and D nucleosides	Inhibits viral DNA polymerase	Pharmasset, Tucker, GA	www.pharmasset.com	Preclinical
Racivir (RCV)	Inhibits viral DNA polymerase	Pharmasset	www.pharmasset.com	Preclinical
L-Fd4C (ACH-126,443)	Inhibits viral DNA polymerase	Achillion New Haven, CT	www.achillion.com	Preclinical
Robustaflavone NEW	Inhibits viral DNA polymerase	Advanced Life Sciences, Woodbridge, IL	www.advancedlifesciences.com	Preclinical
NON-NUCLEOSIDE ANTI-VIRALS				
XTL-001	Human monoclonal antibodies	XTL Biopharm, Rehovot, Israel	www.xtlbio.com	Phase II, Israel & U.S.A.
Imino-Sugars (Nonyl-DNJ) *Discovered by HBF scientists	Protein folding inhibitor	Synergy, Edison, NJ	Tel: 732-302-1111	Preclinical
HepBzyme NEW	nuclease resistant ribozyme	Ribozyme, Boulder, Co	www.rpi.com	Preclinical
NON-INTERFERON IMMUNE ENHANCERS Boost T-cell infection-fighting immune cells and the body's natural interferon production				
Theradigm	Immune Stimulator	Epimmune, San Diego, CA	www.epimmune.com	Phase II
Thymosin alpha-1 (Zadaxin)	Immune Stimulator	SciClone, San Mateo, CA	www.sciclone.com	Phase II w/ lamivudine Orphan drug approval in US Approved in 24 countries
HBV DNA Vaccine	Immune Stimulator	Jefferson Center, Doylestown, PA	www.jeffline.tju.edu/cwis.jcbr	Preclinical
PreS1/S2 Vaccine (Hepagene)	Immune Stimulator	Medeva, London, U.K.	www.medeva.com	Preclinical
EHT899	Oral Viral Protein	Enzo Biochem, NY, NY	www.enzo.com	Phase II, Israel
HBV Antigen	Oral Tolerance	OraGen, Philadelphia, PA	Tel: 215-923-5124	Preclinical
POST-EXPOSURE AND/OR POST-LIVER TRANSPLANT TREATMENT				
BayHep B	HBV immunoglobulin	Bayer U.S., Pittsburgh, PA	www.bayer.com	FDA Approved 1977
Nabi-HB	HBV immunoglobulin	Nabi, Boca Raton, FL	www.nabi.com	FDA Approved 1999
Anti-hepatitis B	HBV Immunoglobulin	Cangene, Ontario, Canada	www.cangene.com	Phase III, Canada

Sincere thanks to Brent Korba, Ph.D. (Georgetown University Medical Center, Rockville, MD) and Raymond Schinazi, Ph.D. (Emory University Medical School, Atlanta, GA) for their regular review of the HBF Drug Watch Update.

Foundation at the Forefront

Nagy Golf Tournament Raises \$6,000 for HBF!

The 2nd Annual Joseph Nagy Golf Tournament scored "an eagle on a par three" this year with twice as many golfers participating and three times as much money raised for the HBF. The tournament raised \$3,000, and **Met Life** once again agreed to a match, bringing the total to \$6,000. To all of you who played and to Met Life, thank you so much. We extend a special thank you to **Kevin Drake**, grandson-in-law, and the entire **Nagy family** for their leadership and generosity in organizing this successful benefit for the HBF! The tournament was established in honor of Joseph Nagy, "gramps", who died of complications from a chronic hepatitis B infection acquired through a blood transfusion in earlier years.



Kevin and Suzanne Nagy Drake with daughter (July 16, 2001).

HBF Website Wins Award!

American Social Health Association
WEBSITE AWARD

The HBF learned at the 8th National Hepatitis Coordinators Conference that its website (www.hepb.org) was rated the "best hepatitis B website" by the American Social Health Association, which reviewed all hepatitis materials, in all forms. The websites were judged by their content and how completely they explained key topics. The HBF is proud to have its website publicly recognized for its excellence by an independent review organization.

Fast Fact



An estimated one-third of those in the U.S. with chronic HBV acquired infections as infants or young children.

Welcome Aboard Gurney Sloan!

Welcome to our newest board member, Gurney Sloan, Esq., who brings a wealth of impressive business and law experiences to the HBF. After serving as an officer in the U.S. Air Force, Mr. Sloan served as VP of Marketing at William H. Rorer, the predecessor of Rhone-Poulenc Rorer. He left to attend law school, subsequently specializing in corporate and securities law. Currently, Mr. Sloan is retired from private practice, however, he continues to be an active participant in new business ventures, serves as a consultant, and is a trustee and director of several trusts.

An Old Friend Assumes New HBF Position

Chari Cohen, MPH ... does the name sound familiar? It should. We had the opportunity to work with Chari this past year while she conducted the "Internet Survey of HBV Carriers" as her senior project for a Masters in Public Health at Temple University. As a result of this successful partnership, we are proud to announce that Chari recently joined the HBF as our new Program Coordinator. She will focus her efforts on improving and expanding our outreach services. We are happy to have her join the HBF team!



HBF Summer Internship Program Makes An Impact

The HBF offered research internships to ten college juniors and seniors this past summer. Students signed up to learn research skills and the HBF hoped to raise their awareness about the importance of hepatitis B. Faculty scientists supervised all projects at the Jefferson Center for Biomedical Research. A student said at the end of the ten weeks, "My experience was actually career changing for me." So, the internship program worked! The HBF has helped make an impact on at least one student's life. For information about the summer internship 2002 program, contact the HBF at info@hepb.org or call 215-489-4900.



Highlights of NIH Workshop 2000 Report: Summary Recommendations for the Management of Hepatitis B

Last year, the NIDDK of the National Institutes of Health sponsored the first ever 3-day workshop September 8 - 10, 2000, in Bethesda, MD, to discuss the management and care of chronic HBV patients. A written summary of this meeting, "Management of Hepatitis B: 2000- Summary of a Workshop", was prepared by three of the nation's leading authorities in the field, Drs. Anna Lok, Jenny Heathcote, and Jay Hoofnagle; and published as a special report in *Gastroenterology* (June 2001: 120:1828-1853).

This much anticipated report concludes with "Summary Recommendations" for the management of hepatitis B. The HBF has chosen highlights from the concluding recommendations, which are written as a narrative summary, and organized them in an outline format for easier reading. We are providing this information as a review of an important NIH workshop on hepatitis B; it is not intended to serve as personal medical advice. Individual questions and concerns raised by this review should be discussed with a qualified health care provider.

I. Standardization of Nomenclature & Terminology

A. The Disease

1. Should refer to the disease as "chronic hepatitis B" with the following attributes:
 - a. Virologic – HBeAg + or -; with or without detectable HBV DNA
 - b. Biochemical – with or without ALT elevations
 - c. Histologic status – activity and degree of fibrosis
2. Avoid terms such as "asymptomatic" or "healthy carrier state".
3. "Inactive carrier state" refers to a patient who is HBsAg+, HBeAg-, normal ALT and HBV DNA <100,000 copies/mL.
4. Resolved HBV should include normal ALT, absence of HBsAg, presence of anti-HBc (with or without anti-HBs) in serum.

B. Responses to Therapy

1. Responses can be classified using the following criteria:
 - a. Virologic – decrease in HBV DNA to <100,000 copies/mL; loss of HBeAg in those who were initially positive
 - b. Biochemical – normal ALT levels
 - c. Histologic – decrease in inflammation and necrosis
2. Responses should also be designated either as:

- a. Initial – occurring within first 6 months
- b. End-of-Treatment – at the time of stopping therapy
- c. Maintained – at the time of last evaluation during long-term therapy
- d. Sustained – within 6 to 12 months after stopping therapy
- e. Combined – meets virologic, biochemical, and histologic criteria
- f. Complete – sustained loss of HBsAg

C. The Virus and Variants

1. Mutants and variants should be defined based on protein region, nucleotide changes or amino acid changes.

II. Evaluation and Monitoring

A. Baseline Evaluation

1. An initial evaluation should include routine liver tests, virologic assays for anti-HDV, HBeAg, anti-HBe and HBV DNA levels, as well as abdominal ultrasound.
2. Baseline information affects eventual recommendations for management:
 - a. Patients with elevated ALT should be considered for therapy, therefore, a liver biopsy is warranted.
 - b. Patients with normal ALT do not require a liver biopsy unless there is evidence of other significant or underlying liver disease.

B. Monitoring Chronic HBV

1. All patients with chronic HBV should be monitored regularly. Frequency will be determined by the progression of liver disease and/or the decision to start therapy.
2. Minimal level of monitoring recommended for chronic HBV includes:
 - a. Visits at 6-month intervals with repeat aminotransferase levels
 - b. Serial HBV DNA testing is not necessary, and repeat liver biopsy is not needed unless therapy is being considered.
3. At present, routine surveillance for HCC (liver cancer) at defined intervals should be reserved for those at moderately-high risk, which include:
 - a. Patients with cirrhosis or family history of liver cancer
 - b. Patients older than 40 years from endemic areas of the world
 - c. Those infected as infants or children

4. AFP testing and liver ultrasound exams every 6 months is an acceptable approach to HCC surveillance.

III. Therapy

A. Making the Treatment Decision

1. The decision should be based on a combination of:
 - a. Serum liver tests (ALT elevations)
 - b. Virologic assays (HBeAg+ and HBV DNA >100,000 copies/mL)
 - c. Liver histology (moderate disease activity and fibrosis)
 - d. Tests that exclude concurrent HCV, HDV, and HIV infections
2. In patients with "inactive" or mild disease, it is appropriate to monitor ALT levels and defer therapy until advances have been made that allow for sustained benefit.
3. However, the key question is what criteria should be used to define "moderate-to-severe" disease and subsequent treatment recommendations?

B. ALT Levels and Response Rates

1. Retrospective analyses suggest that ALT levels can be used as a basis for recommending therapy, at least in those with HBeAg+ chronic HBV.
2. Response rates to lamivudine and interferon strongly correlate to ALT levels:
 - a. More than 50 % of patients with ALT levels greater than 5 times the upper limits of normal responded to therapy. Therefore, therapy can be readily recommended for these patients if there is no evidence of spontaneous loss of HBeAg after a 2-3 month observation.
 - b. Only 20 –35% of patients with ALT levels in the range of 2-5 times the upper limit of normal responded to therapy. Factors such as liver histology, age, and other health issues should be considered in the treatment decision.
 - c. Response rates are low in patients with normal or minimally elevated ALT levels (<2 times the upper limit of normal). In these patients, therapy is best deferred.

C. Monotherapy or Combination Therapy?

1. Interferon alpha
 - a. Advantages – given for a limited time, no antiviral resistance develops, and

quality and durability of long-term response are excellent.

- b. Disadvantages – expensive, significant side effects
 - c. Not recommended for patients with decompensated cirrhosis
2. Lamivudine
 - a. Advantages – easy to administer and monitor; few, if any, side effects
 - b. Disadvantages – long-term durability of responses appears to be less than with interferon, and prolonged therapy is often needed, which is associated with a high rate of viral resistance.
 - c. Lamivudine monotherapy should be reserved presently for patients with moderate-to-severe disease.
 - d. Long-term therapy is recommended for patients with advanced or decompensated chronic HBV, regardless of HBeAg status. However, therapy should be coordinated with a liver transplant team because timing of lamivudine may be critical.
 3. Combination of Interferon and Lamivudine has not been proven to be significantly more effective than either drug alone and therefore, cannot be recommended outside of clinical trials.

IV. Future Research

- A. Development of Safe and More Effective Treatments
 1. Major contribution of new agents in the pipeline is likely to be in combination with each other or with lamivudine.
- B. Key "Surrogate" Endpoints for Combination Trials:
 1. Maintain suppression of HBV DNA
 2. Prevention of viral resistance
- C. Reliable and Standardized HBV DNA Tests
- D. Clinical Studies in "Problem Populations" with HBV
 1. Studies of new therapies are needed in patients with renal failure, organ transplantation, HIV coinfection, substance or alcohol abuse, hemophilia, and advanced liver disease.

Editor's Note: If there are any editorial errors or omissions in our highlights of the NIH workshop summary recommendations, please contact the HBF so that we can make the necessary corrections.

First Book on "HepBers" "Living with Hepatitis B: A Survivor's Guide"

"Living with Hepatitis B", by Gregory T. Everson, M.D., and Hedy Weinberg, is the first guidebook devoted entirely to hepatitis B. The length of the book, almost 300 pages, takes readers step-by-step through the process of diagnosis and ongoing care with detailed chapters on HBV infection, the liver, tests and liver biopsies, treatments (the longest chapter in the book), transplants, cancer, co-infection, children, research trends, plus 130 resources for patients. Chapters on emotional, financial, and nutritional issues address frequently asked questions.

The authors wrote this book with three hopes: (1) that it focuses public attention and research dollars on HBV — not only with statistics, but also through the voices of people with hepatitis B; (2) that it helps lessen the feelings of isolation, fear, and even shame, that patients and families endure; and (3) that it helps patients become more informed and thus better able to work with their physicians.

Co-author **Hedy Weinberg**, an award-winning writer and essayist, spoke at the HBF's June patient conference (see spring issue of *B Informed*). Her description of the six common problems of HBV struck a responsive chord and is included in the chapter titled "Taking Care of Yourself Emotionally":

1. Feeling Low, Physically and Emotionally: Fatigue narrows your world as you find yourself less able to work or play. Grieving these losses allows you to move on.

2. Feeling Contaminated: You may feel dirty and ashamed. The public's ignorance about the ways in which people contract HBV adds to your burden. *"I didn't keep anything back. No secrets. I told everyone I had hepatitis B. I was so naïve. Once, my friends were gathering names to help make food for a funeral. I volunteered to bake a pie, and the woman in charge said, 'Maybe you could buy the pie.' I knew right away what she was implying. So I bought a pie."*

3. How You Got Infected: No matter how you got HBV, you have issues to resolve — coming to peace with the behavior of others or forgiving yourself. *"I've tried for years to find out how I got the virus. Could it have been from my mother who died of liver cancer? Did I get it from dental work or surgeries or in one of the hospitals where I worked? ... I've arrived at a place of peace in my life. I accept the fact that I'll never know — and I no longer search for that answer. Now I focus on how the virus can be stopped from spreading."*



4. Being Sick but Looking Good: Many people, including yourself, may not believe you are ill, and you may not get the support you need.

5. Up and Down Nature of Hepatitis B Treatment: Life becomes a roller coaster. *"After three years on treatment, the virus started mutating. My DNA viral load went up drastically in three months. 'Hey', I said, 'I'm a mutant!'"*

6. Lack of Information: *"When I adopted my baby and then found out he had hepatitis B, I stayed up most of the night looking for information on the Internet. Our pediatrician didn't know much either. But the public health department called right away. A week later they sent me a letter wanting to know who my son's sexual partners were. He's five months old."*

"Living With Hepatitis B" is a book that truly reflects the hepatitis B experience. As Hedy observed, "living with hepatitis is an intense physical and spiritual struggle, but people should know that they are not alone." Now there is finally a book about "hepBers" to help bridge the information gap.

The collaboration between Dr. Everson and Hedy has produced three editions of "Living with Hepatitis C: A Survivors Guide" and "My Mom Has Hepatitis C", a children's book. Dr. Everson, Director of Hepatology at the University of Colorado Medical School, presents accurate, reliable medical information. As a person living with hepatitis C, Hedy addresses the concerns of people struggling with the challenges of chronic illness, and translates medical jargon into language that patients can understand.

Order Your Book Today From the HBF!

"Living with Hepatitis B: A Survivor's Guide"

Gregory T. Everson, M.D., F.A.C.P.
and Hedy Weinberg
Available November 2001 (\$15.95)

For those who order a book from the HBF, almost half of the purchase price will be a donation to support our cause. For more information, visit www.hepb.org or call 215-489-4900.

The book will be available in stores and online this November.

Readers can also call Hatherleigh Press at 1-800-528-2550 and mention you saw it in our newsletter *B Informed* for free shipping.

Speaking Personally

Steve Bingham

Co-Owner of the Internet Hepatitis B Information and Support List (HB-L)

Zippers, Tigers and Gophers

If you find hepatitis B confusing, you're not alone. Trying to figure out hepatitis terminology can bring on a spell of "brain fog". Even our best hepatitis scientists have trouble with the terminology. A well-known scientist predicted that the lack of uniform terminology would be a major obstacle to HBV research. Who would have thought that the big guys would be having the same difficulty with semantics that we little guys have?

My frustration with hepatitis terms grows when I try to explain HBV basics to the 500 subscribers of our internet group. We "oldies" in the group are continually trying to come up with new and creative ways to explain hepatitis B to the "newbies". Explaining things becomes even trickier when you realize that our subscribers live in 30 different countries!

Our lab reports are probably the most confusing, which can be complicated and difficult to interpret. A typical oldie-to-newbie explanation goes something like this: "Your SGOT is the same as your AST; your SGPT is your ALT, and these are all called enzyme tests, or possibly LFTs, which stands for liver function tests, but strictly speaking, ALT/AST's aren't really LFT's because they measure inflammation and not function."

Another question that inevitably comes up is, "How can I be cured?" The word "cure," it turns out, is very contro-

versial when it comes to chronic HBV and is only whispered in private. Instead, we use the terms "seroconversion" or "sustained response", which provide leeway in case there are a couple of viruses hiding somewhere deep in the liver.

Last month, to make it a bit easier for all of the support group newcomers, list members tried using analogies to explain some of the difficult concepts. In a discussion on how HBV mutations occur, Maureen compared the double helix of DNA to a zipper. Sharat explained that having only the surface antigen, without any other HBV markers, was like having a tiger skin without the tiger. I compared the hep B virus to a gopher: "You have to wait until the gopher becomes active and sticks his head out of his hole before you whack him with a shovel" (the shovel being Interferon or Eпивir-HBV).

Perhaps in the near future, standardized terminology will be created so that we can communicate more effectively with each other in order to live more successfully with HBV. Until then, I

offer my best wishes — *"That your zippers don't lose any of their teeth, that your tiger doesn't come back for his skin, and that your gophers won't know what hit 'em."*

**Thanks to all of you,
Steve**

I compared the hep B virus to a gopher: "You have to wait until the gopher becomes active and sticks his head out of his hole before you whack him with a shovel."

New Resources

Toll-Free HBV Information & Assistance Line for the Asian Community

Call **1-888-888-0981** anywhere in the United States for HBV information, physician referrals and screening sites. Available languages include Mandarin, Cantonese, Korean, Vietnamese and English. GSK launched this free nationwide telephone help-line to increase awareness and education.

The Asian Liver Center at Stanford University Expands Its Programs

The Asian Liver Center is a nonprofit organization founded in 1996 by Samuel So, M.D., Associate Professor of Surgery at Stanford University School of Medicine. It was formed to address the high prevalence of liver disease in

the Asian population. The major goals are to serve as a clinical resource center; formulate public health care policies; conduct public education specifically for the Asian community; and run clinical trials and basic research programs focused on liver disease. Patients and families are encouraged to call the Center for information at 650-498-5687, or visit their website <http://liver.stanford.edu>

"Hepatitis B: The Global Challenge" Video Now Available In Four Languages

This moving 24-minute documentary chronicles the impact of chronic hepatitis B in the U.S.A. and around the world. Good, easy-to-understand information about hepatitis B is provided in a seamless mix of narration and interviews. The video is produced by GlaxoSmithKline and is *suitable for lay audiences*. Languages available include English, Chinese, Korean and Vietnamese. Contact the HBF at info@hepb.org or call 215-489-4900 to order a copy.

Calendar of Events



October 15 – 21, 2001

International Hepatitis B Awareness Campaign

Sponsors: GlaxoSmithKline
Contact: 215-489-4900 or info@hepb.org

November 9 – 13

52nd Annual AASLD Meeting and Postgraduate Course

American Association of the Study of Liver Diseases
Wyndham Anatole Hotel, Dallas, TX
Contact: 703-299-9766
www.aasld.org

November 17 - 18

The National Seminar for Hepatic Infections

Romanian Liver Organization, *SANO-HEP*
Brasov, Romania
Contact: sanohep@hotmail.com
www.emilelsan.home.ro

December 2 – 6 CANCELLED

4th International Conference on Therapies for Viral Hepatitis

Isla Verde, Puerto Rico
www.intmedpress.com

December 16 - 29, 2001 NEW DATE

41st ICAAC Meeting

American Society for Microbiologists
Chicago, IL
Contact 202-942-9248
www.icaac.org

December 16 – 20

HEP DART 2001

Frontiers in Drug Development for Viral Hepatitis

Ritz-Carlton, Maui, Hawaii
Co-Chairs: Drs. Jean-Pierre Sommadossi and Raymond Schinazi and Charles Rice
Contact: 678-395-0029 or info@informedhorizons.com
<http://informedhorizons.com/HEP-dart2001>

April 27, 2002

Crystal Ball

HBF Gala Celebration, Doylestown, PA
Contact: 215-489-4900 or info@hepb.org

May 3, 2002

3rd Annual Bruce Witte Distinguished Lecturer

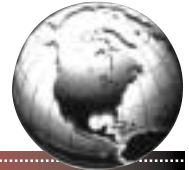
Frank Chisari, M.D., Scripps Research Institute
Hepatitis B Foundation, Doylestown, PA
Contact: 215-489-4900 or info@hepb.org

May 19 – 22, 2002

Digestive Disease Week

DDW Administration
San Francisco, CA
Chair: Dr. Emmett B. Keefe
Contact: 301-272-0022
www.ddw.org

Internet Support Groups



Hep B Information and Support List

<http://www.geocities.com/Heartland/Estates/9350/hblist.html> (case sensitive)

To subscribe, send a blank email to:
hepatitis-b-on@mail-list.com

Well-supervised list with useful information and lively exchanges between supportive members. For those with HBV, their caregivers, and anyone interested in or affected by HBV are invited to participate.

HBV Adoption Support List

<http://www.onelist.com/community/hbv-adoption>

For adoptive or biological parents of children with HBV. This is a restricted list to protect the privacy of parents and children, and requires pre-approval by the list owner to join.

PKIDS Support List

<http://www.pkids.org/>

For adoptive and biological parents of children with chronic viral infectious diseases, including HBV, HCV, and HIV.

Hepatitis Clinical Trial Websites

Gilead Announces HBV Clinical Trials Open for Enrollment. For more information about the studies, visit Gilead:

http://www.gilead.com/webpage_templates/frame_home.php3

Centerwatch Clinical Trials Listing Service

<http://www.centerwatch.com/studies/cat79.htm>

National Institutes of Health Clinical Trials

<http://clinicaltrials.gov>

Resource Roundup



Hepatitis B Foundation
215-489-4900 www.hepb.org
info@hepb.org

Comprehensive website dedicated solely to hepatitis B with facts, useful advice, Drug Watch, liver specialist directory, and a responsive email service. Includes a new *Chinese Chapter* with translated HBV information.

American Liver Foundation
1-800-GO-LIVER www.liverfoundation.org
webmail@liverfoundation.org

Information about all liver diseases, including viral hepatitis. Fact sheets, legislative advocacy, research funding.

Centers for Disease Control, Hepatitis Branch
1-888-443-7232
www.cdc.gov/ncidod/diseases/hepatitis

The National authority for viral hepatitis information: epidemiology, disease facts, prevention, scientific studies, national recommendations, and more.

CDC Hepatitis Immunization Hotline
1-800-232-2522 (English) www.cdc.gov/nip
1-800-232-0233 (Spanish)
nipinfo@nip1.em.cdc.gov

Hepatitis B Research List
To subscribe, send a blank email to:
HBV_Research-on@mail-list.com

A free electronic research list maintained by Sheree Martin that provides abstracts, reports and notices.

Hepatitis B Research Archive Website
http://dispatch.mail-list.com/archives/hbv_research
Archived research bulletins posted on the Hepatitis B Research List, from 1998 until current year.

Hepatitis B Virus Page
<http://www.globalserve.net/~harlequin/HBV/index.html>

Maintained by Robert Garces, Ph.D. Candidate in Virology, at the University of Toronto.

Hep C Connection
1-800-522-4372 www.hepc-connection.org
info@hepc-connection.org
Comprehensive information to assist Hep C-challenged individuals and their families.

Hepatitis Control Report.
www.hepatitiscontrolreport.com
A quarterly print and online newsletter devoted to hepatitis epidemiology, control programs, and public policy.

Hepatitis Foundation International
1-800-891-0707 www.hepfi.org
mail@hepfi.org

Information about viral hepatitis, support groups, research articles, and education programs.

Hepatitis Magazine
1-800-310-7047 www.hepatitismag.com
editor@hepatitismag.com

The only print magazine published bi-monthly for those affected by viral hepatitis.

Hepatitis Neighborhood
www.hepatitisneighborhood.com
info@HepatitisNeighborhood.com

Features a Town Hall with a Live Speakers Forum. Sponsored by Priority Healthcare Corporation.

HIV and Hepatitis Treatment Advocates
www.hivandhepatitis.com

Professional online publication with updates, conference reviews, free teleconferences, and an e-mail service.

Immunization Action Coalition
651-647-9009 www.immunize.org
medinfo@immunize.org

Comprehensive resource of practical immunization and information health care providers can use. "IAC Express" is a free email announcement service.

National Center for Complementary and Alternative Medicine
1-888-644-6226 www.nccam.nih.gov

Sponsored by the National Institutes of Health, this site contains databases galore and research articles.

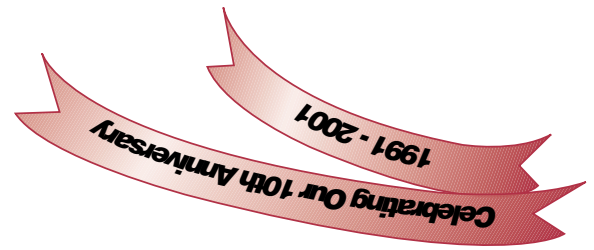
Parents of Kids with Infectious Diseases
1-877-55-PKIDS (toll-free) www.pkids.org
pkids@pkids.org

An excellent resource for parents who need information and support. Pediatric clinical trials, "Ask Dr. Jane", Legislative Action Center, support listserv, and useful articles.

PKIDS Legislative Action Center Website
<http://capwiz.com/pkids/>

This website makes it easy to contact your legislators and keep current about the latest legislation online! Just enter your zipcode and you're on the way to the Capitol.

PKIDS Research List and Archive
<http://fleet.mail-list.com/archives/pkids>
Free electronic research list and archive maintained by Sheree Martin that highlights research articles on pediatric infectious diseases.



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The growing number of people seeking information and support each year continues to affirm the importance of the HBF's *Cause for A Cure* since we rely on the generosity of individual donations, we need your help to continue our work. Thank you!

Yes! I wish to join the *Cause for A Cure*. Enclosed is my tax deductible gift.

Name _____ \$40 Donor
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 Address _____ \$100 Supporter
 \$250 Fellow
 City _____ \$500 Patron
 \$1,000 Leader
 State _____ Zip _____ Other

Check MasterCard Visa Card # _____

Name on card _____ Exp. Date _____

Signature _____

Please make checks payable to: Hepatitis B Foundation
 700 East Butler Avenue, Doylestown, PA 18901

Contributions will be acknowledged in our Winter newsletter unless otherwise requested.

A copy of the official registration and financial information may be obtained by calling the Pennsylvania Department of State toll-free within PA at 800-732-0999 or out-of-state at 717-783-1720. Registration does not imply endorsement.



HB FOUNDATION
 700 East Butler Avenue
 Doylestown, PA 18901-2697

We are a voluntary, 501(c)(3) nonprofit organization dedicated to the cause and cure of hepatitis B through research, education and patient support.

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