

# B HEPATITIS B

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**CAUSE FOR A CURE**

**"The only non-profit 501(c)(3) organization dedicated solely to the cause and cure of chronic Hepatitis B"**

# INFORMED

## The 10th Anniversary *Crystal Ball* Clearly the Occasion to Honor a Special Founder

Bag pipes, a jazz band, dancing and table serenades were some of the festive ingredients that kept the Hepatitis B Foundation's *Crystal Ball* rolling! The black-tie event, held April 21<sup>st</sup>, celebrated the milestone anniversary and honored **Nobel Laureate Baruch Blumberg, M.D., Ph.D.**, with the prestigious *Founders' Award*.

Reflecting on the changes of the past decade, HBF President and Co-Founder, **Timothy Block, Ph.D.**, joked with the 160 guests, "You can see how far we've come. When we started the foundation 10 years ago, George Bush was in the White House and Donald Rumsfeld was a member of the cabinet!" And thus, set the tone for an evening of science mixed with laughter.

Only ten years ago, Paul and Janine Witte, and Dr. Block were deeply moved by the plight of a young family affected by hepatitis B. After learning there was no organization dedicated to finding a cure for this disease, the Wittes and Dr. Block decided to establish the Hepatitis B Foundation (HBF).

With this ambitious goal, they reached out to the most prominent scientist in the field, Dr. Baruch Blumberg, who won the Nobel Prize in Medicine in 1976 for his discovery of the hepatitis B virus (HBV), and also invented the first HBV vaccine. He responded to the Blocks and Wittes, compassionately and enthusiastically, and joined as a charter member of the fledgling HBF. Over the years, a productive collaboration flour-

ished and in 1993, while serving as Master of Balliol College at the University of Oxford, Blumberg collaborated with Dr. Block and **Prof. Raymond Dwek, FRS**, world-renowned as the "father" of Glycobiology. Together they discovered a novel anti-HBV drug, NBDNJ, which is currently in development by an American biotech company.

After a lifetime of working on HBV, Dr. Blumberg has embarked on yet another career. In 1999, he was asked to serve as the Director of the NASA Astrobiology Institute, and recently, was appointed Senior Advisor to the Administrator for Biology of NASA. For this gala night, however, he noted with delight that he "was back on earth to be with old friends".

Several "old friends" on hand for the evening's festivities were members of the original research team, from Fox Chase Cancer Center (Phila-

delphia, PA), that discovered the hepatitis B virus: **Anna O'Connell, B.S., Veronica Coyne, M.D., W. Thomas London, M.D., and Harvey Alter, M.D.** The evening made for a joyful reunion of these scientific pioneers.

Dr. Alter, Chief, Infectious Disease Section, National Institutes of Health, was the recipient of the HBF 2000 Distinguished Scientist Award. While perhaps better known as the principal investigator in studies identifying the hepatitis C virus, attendees of last year's HBF Award's celebration remember him as somewhat of a "stand-up" scientist. "Economizing on the budget, we've



Award Presentation to Special Founder (Whitney Photography) L. to R. Dr. Tim Block, Dr. Baruch Blumberg and Dr. Tom London



## Message from the President

Timothy M. Block, Ph.D.

### Giving Hope To Millions Is As Easy As Giving. Please Make Your Donation Today!

The journey and creation of the Hepatitis B Foundation these past ten years has been incredibly exciting. Through the combined efforts of the board, volunteers, staff, friends and donors, we have been able to accomplish so much in a relatively short amount of time.

We have grown from a kitchen grassroots effort into a professional organization that has helped create and support a cutting-edge research facility in Doylestown, Pa. Our comprehensive outreach program and world-class research are making a difference in the lives of those affected by this disease. And through our many efforts, we are helping to keep the focus on hepatitis B at both the local and national level.

However, our work is not done. There are still 400 million reasons why the HBF mission continues to be so urgent – a cure must be found for the 400 million people who suffer from chronic hepatitis B.

As we celebrate our 10<sup>th</sup> Anniversary, we are very grateful to all of you who have made our success possible, through donations of time and money. Thank you!



Please make a donation in honor of our 10<sup>th</sup> Anniversary.

Please help support our Cause for a Cure!

To continue the momentum of these past 10 years, we are counting on all our newsletter readers to pledge or renew their commitment to the Hepatitis B Foundation.

To make it even easier for you to give, we have enclosed a remittance envelope in this newsletter.

## In The News



### World's Only Combination Hepatitis A & B Vaccine Approved by FDA

On May 11, 2001, the U.S. Food & Drug Administration (FDA) approved a new combination vaccine that protects individuals 18 years of age or older against hepatitis A and B. The vaccine, called Twinrix®, combines two already approved vaccines, Havrix (Hepatitis A Vaccine, Inactivated) and Engerix-B (Hepatitis B Vaccine [Recombinant]), so that people at high risk for exposure to both viruses can be immunized against both at the same time. Twinrix, manufactured by GlaxoSmithKline (GSK) is already licensed in 70 countries and is the world's first adult combination vaccine that "provides simultaneous protection against these two diseases and reduces the number of injections from five to three," said John Jabara, vice president and director, GSK's U.S. Vaccine Business Unit. Each year up to 200,000 Americans are infected with hepatitis A, and up to 320,000 are infected with hepatitis B. The most common side effects associated with the vaccine were soreness at the injection site, headache, and fatigue, which were mild and self-limiting, lasting no more than 48 hours. [FDA Announcement, May 16, 2001 and GlaxoSmithKline Press Release, May 14, 2001 [www.gsk.com](http://www.gsk.com) ]

### American Cancer Society Urges Use of First Anti-Cancer Vaccine: Hepatitis B Vaccine

Citing research that has shown hepatitis B virus infection as the most significant risk factor for development of liver cancer later in life, the American Cancer Society (ACS) endorsed promoting greater efforts to increase immunization rates against this virus for all children, from birth to 18 years. "The hepatitis B vaccine is the first effective cancer prevention vaccine and we are committed to increasing public awareness and use of this proven anti-cancer weapon," said Dr. Dileep Bal, national president of the ACS. An estimated 5,000 Americans die each year from liver failure caused by hepatitis B infections, which includes 1,500 who die of liver cancer. Dr. Moon Chen, a national board member of the ACS, added, "Let us join in a 'catch-up' hepatitis B campaign so that our children do not need to die from a vaccine-preventable disease. An ounce of prevention is worth a pound of cure... and in the case of liver cancer, the chance of cure is slim." [American Cancer Society, April 26, 2001 [www.cancer.org](http://www.cancer.org) ]

### Hepatitis B Subtype Increases Risk of Eпивir-HBV® Resistance

Hepatitis B virus has four subtypes of surface antigen: adw, ayw, adr and ayr. A study to determine the effect of HBV subtype on Eпивir-HBV (lamivudine) resistance was conducted in Hamburg, Germany and reported in The Lancet on March 24<sup>th</sup>. HBV genotyping was performed on 26 chronic HBV patients who had never received lamivudine treatment. Genotyping revealed 13 patients with "adw" subtype and 13 patients with "ayw" subtype. There were no significant differences in age, gender, HBV viral loads, and previous treatment with interferon alpha. Each patient received a 100 mg tablet of Eпивir-HBV daily for an average

(continued on pg. 3)

(In the News-continued from pg. 2)

period of 12 months, with serum HBV DNA levels checked every 3 months. Eпивir-HBV resistance occurred in 7 patients of the "adw" subtype and 1 with the "ayw" subtype in a median of 12 months of therapy. The investigators concluded that "adw" subtype of HBV is associated with a high risk of Eпивir-HBV resistance; that "ayw" subtype have a reduced risk, therefore, may need to be considered for a modified treatment regimen (e.g. combination therapy); and that the HBV subtype of chronic carriers should be included as a variable in further therapeutic studies for hepatitis B. [HIVandHepatitis.com, April 9, 2001 ] For a copy of the journal article, B. Zollner, "20-Fold Increase in the Risk of Lamivudine Resistance in Hepatitis B Virus Subtype adw", *The Lancet*, 2001; 357,9260: 934-935, visit [http://www.thelancet.com/journal/vol357iss9260/full/llan.357.9260.original\\_research.15616.1](http://www.thelancet.com/journal/vol357iss9260/full/llan.357.9260.original_research.15616.1)

### Hepatitis B Genotype Affects Response to Interferon Therapy

Investigators from the Hepatitis Research Center, National Taiwan University Hospital, reported in the *Journal of Hepatology* their findings from a study of whether differences among HBV genotypes affects the response to interferon alpha therapy. Although there are seven genotypes (A to G) that can be classified, they retrospectively analyzed the efficacy of interferon alpha-2b (IFN) in the treatment of 58 chronic hepatitis B patients with either HBV genotype B or C. Within the group, 32 patients were genotype B and 26 patients were genotype C. "The response to IFN was defined as normalization of serum aminotransferase levels, loss of hepatitis b e-antigen and HBV DNA 48 weeks post-treatment. Baseline data of both groups of patients were comparable, however, genotype C patients had a higher serum aminotransferase level and a higher frequency of core promoter mutation." Results showed "the response rate to IFN was 41% and 15% in genotype B and C patients, respectively. In those with higher serum aminotransferase levels, the response rate was 50% and 17% respectively. Additionally, younger age and genotype B infection may predict a better response to interferon alpha." Investigators concluded that, "HBV genotype C, compared to genotype B is associated with a higher frequency of core promoter mutation, and a lower response rate to interferon alpha therapy." [JH Kao, "Hepatitis B Genotype And the Response to Interferon Therapy", *J. of Hepatology*, 2000; 33:998-1002] For a PDF version of the journal article, visit [http://journals.munksgaard.dk/pdf/08pdf.nsf/all/336998/\\$FILE/0021a.pdf](http://journals.munksgaard.dk/pdf/08pdf.nsf/all/336998/$FILE/0021a.pdf)

## Fast Fact

- 1991: No organization exists to promote finding a cure for chronic hepatitis B.
- 2001: Hepatitis B Foundation, the first nonprofit dedicated to HBV, celebrates 10 years.

(10th Anniversary Crystal Ball - continued from page 1)

combined honorees with entertainment!" said Dr. Block in his introduction of the well-known scientist. Alter admitted to always being "good humored about disease" and thus, presented a funny slide show highlighting Blumberg's career that kept the audience laughing.

Dr. London, Director, Liver Cancer Prevention Center at Fox Chase Cancer Center and HBF Board Member, was the recipient of the HBF 1998 Distinguished Scientist Award for his outstanding contributions to HBV research. He officially presented the Founders' Award to his "friend, colleague and at one time boss." He reminisced about Blumberg's vision and wisdom from a time when they first met. "I clearly remember Barry telling me about genetic polymorphisms and their relationship to disease susceptibility, and I hadn't the slightest idea what he was talking about! Now, 38 years later, this is a major field of research." London went on to note that the "hepatitis B virus story" (see p. 9) was just unraveling when Blumberg received the Nobel Prize, and the nobel committee recognized him not only for his worldwide contribution, but for such vision.

Graciously accepting his award, Dr. Blumberg thanked the HBF for its award and said, "I admire your efforts to create and sustain the foundation. Many patients and their relatives owe a great debt of gratitude to you for your dedicated and effective leadership in generating local and national support". He went on to say that "science is never a singular event", and quoted Isaac Newton, "in science we stand on the shoulders of giants". He then acknowledged by name the many people who contributed to the discovery of HBV and the ongoing research of this virus.

Before returning to the dance floor, guests were left with a final message of gratitude and hope, which truly represents the experience of the Hepatitis B Foundation these past ten years: "Never doubt that a small group of committed citizens can change the world. Indeed, that is the only thing that ever has." (Margaret Meade)



L.to R. PA State Senator Joe Conti, Dr. Blumberg and former PA State Senator Joe Uliana (Whitney Photography)



Curt and Roseanne Friehs, Kronos Associates

# HBV Drug Watch

## Compounds in Development For Chronic Hepatitis B

Update June 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
<b>INTERFERONS</b> Mimic naturally occurring infection-fighting immune substances produced in the body				
Interferon alpha-2b (Intron A)	Immunomodulator	Shering-Plough, Madison, NJ	www.schering.com	<b>FDA Approved 1991</b>
<i>Other brands of Interferon are FDA approved for HCV treatment, but not for HBV: Wellferon (Glaxo), Roferon (Roche), and Infergen (Amgen)</i>				
<b>NUCLEOSIDE ANALOGUES</b> 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	<b>FDA Approved 1998</b>
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
L-dT <b>NEW</b>	Inhibits viral DNA polymerase	Novirio, Boston, MA	www.novirio.com	Phase II
L-dC <b>NEW</b>	Inhibits viral DNA polymerase	Novirio	www.novirio.com	Phase I
MCC-478 <b>NEW</b>	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) <b>NEW</b>	Inhibits viral DNA polymerase	Achillion New Haven, CT	www.achillion.com	Preclinical
<b>NON-NUCLEOSIDE ANTI-VIRALS</b>				
XTL-001 <b>NEW</b>	Human monoclonal antibodies	XTL Biopharm, Rehovot, Israel	www.xtlbio.com	Phase II, Israel
Imino-Sugars (Nonyl-DNJ) *Discovered by HBF scientists	Protein folding inhibitor	Synergy, Edison, NJ	Tel: 732-302-1111	Preclinical
<b>NON-INTERFERON IMMUNE ENHANCERS</b> 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 13 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
<b>POST-EXPOSURE AND/OR POST-LIVER TRANSPLANT TREATMENT</b>				
BayHep B	HBV immunoglobulin	Bayer U.S., Pittsburgh, PA	www.bayer.com	<b>FDA Approved 1977</b>
Nabi-HB	HBV immunoglobulin	Nabi, Boca Raton, FL	www.nabi.com	<b>FDA Approved 1999</b>
Anti-hepatitis B <b>NEW</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.

# Drug Notes

## L-dT Moving Forward Into Phase II Clinical Trials For Chronic HBV

Dr. C.L. Lai, University of Hong Kong, recently presented data on L-dT, a new L-nucleoside that is being studied as an inhibitor of HBV DNA polymerase, at the EASL and DDW 2001 Conferences this past spring. He reported preliminary study findings from a group of 6 patients treated with this oral drug for up to one month. An approximate 2.5 log decrease in HBV DNA levels was noted within 28 days in all 6 patients treated with active drug. The dose was increased from 25 to 50 to 100, 200 and eventually 400 mg/day in each without evidence of drug-related toxicity. The fact that there were no significant adverse effects is consistent with L-dT's excellent preclinical safety profile. While the data are still preliminary, the results are very encouraging. Phase IIb studies are currently underway in Hong Kong to investigate higher doses of the drug and dose-relatedness of later phase HBV clearance. [*HIV and Hepatitis.com, May 30, 2001 at [www.hivandhepatitis.com/hepb/news/053001b.html](http://www.hivandhepatitis.com/hepb/news/053001b.html)*] For more information about Novirio Pharmaceuticals (Boston, MA), visit [www.novirio.com](http://www.novirio.com)

## Phase II Combination Trials Started with XTL-001 and Lamivudine

Phase II studies combining five-dosing regimens of XTL-001 with a standard treatment regimen of lamivudine will be conducted in a multi-center, double-blind, dose ranging study with an expected enrollment of 60 patients for up to 12 months, announced XTL Biopharmaceutical on May 16<sup>th</sup>. XTL-001 is a compound that consists of "two high affinity human monoclonal antibodies that act at multiple sites on the HBV surface antigen." In Phase I studies of 27 patients, various single and multiple dosing regimens of the XTL-001 without lamivudine were well tolerated, with rapid and consistent decrease in HBV viral levels in all patients receiving multiple doses of the drug. There were no serious adverse effects observed. [*May 16/PR Newswire/XTL Biopharmaceuticals (Rehovot, Israel)*] For more information, visit [www.xtlbio.com](http://www.xtlbio.com)

## Novel Approach to HBV Treatment: Heat Shock Protein (Hsp) Fusion

Based on positive preclinical data that was presented at the Experimental Biology Meeting 2001 held in April, Stressgen Biotechnologies announced it has chosen to evaluate an Hsp fusion for its therapeutic potential to treat HBV. The technology involves a "novel fusion protein containing an Hsp fused to a highly conserved protein from HBV. This fusion has been shown to elicit cytotoxic T cells, which recognize HBV antigens, suggesting they would be capable of killing HBV-infected cells. These T cells were also shown to produce the cytokine interferon gamma, which is known to suppress HBV replication in infected cells." According to Marvin Siegel, Ph.D., Executive V.P. of Research & Development of Stressgen, "the results of these studies demonstrate the potential efficacy of this novel fusion in the immunotherapy of chronic HBV infection." [*BioSpace News, April 17, 2001*] For more information about Stressgen (Victoria, Canada), visit [www.stressgen.com](http://www.stressgen.com)

## Phase I Trials of HBV Drug Initiated Within 1<sup>st</sup> Year of New Company Launch

ACH126,443 (L-Fd4C) is an orally administered anti-viral agent with potent activity against HBV and HIV. However, "because of the extraordinary potency of this drug against HBV, Achillion will initially pursue development for treatment of chronic HBV infection," said Lisa M. Dunkle, M.D., Sr. V.P. of Drug Development. One year after launching the company, Achillion announced this past February that Phase I clinical trials of its lead antiviral drug were being initiated in Scotland. Achillion, a privately held biopharmaceutical company, began operations in February 2000 and concentrates on innovative anti-viral therapies. [*For more information about Achillion Pharmaceuticals (New Haven, CT), visit [www.achillion.com](http://www.achillion.com)*]

## Can Vaccines Be Used For More Than Prevention?

Bruce Witte  
Distinguished  
Lecturer Award  
presented by HBF  
Co-founders  
March 21, 2001.  
L. to R.: Dr. John  
Gerin, Ms. Janine  
Witte, and Mr.  
Paul Witte



## Distinguished Lecturer Focuses On New Combination Vaccine Therapy

**John Gerin, Ph.D.**, Professor and Director, Division of Molecular Virology, Georgetown University College of Medicine, the HBF's second **Bruce Witte Distinguished Lecturer** presented, "Combination Immuno and Antiviral Therapy for Hepatitis B Virus Woodchuck Model" to a packed house of scientists on March 21<sup>st</sup> at the Hepatitis B Foundation. His current research has been conducted in woodchucks chronically infected with woodchuck hepatitis virus. He reported that the HBV vaccine could serve as a therapeutic when used in combination with an effective antiviral agent, such as L-FMAU. In some of the treated woodchucks, this combination therapy resulted in the disappearance of the hepatitis B virus due to the immunological response (e.g. immune system's attack) on the virus, even after both drugs were discontinued.

Although this work has not been performed in people, the implications are profound. For example, people who are chronic carriers of HBV could some day mount an antibody response to get rid of the virus if properly treated with combinations of vaccine and antivirals. Dr. Gerin is one of the great statesmen of hepatitis research and recent recipient of the prestigious King Faisal Award for scientific achievement. He is credited with the discovery of hepatitis delta virus, a serious co-factor in hepatitis B infections, and pioneered the use interferon alpha in the treatment of chronic hepatitis B.

# Patient Conference

## B Informed 2001: First Gathering of Friends June 8-10, Doylestown, PA

From as far away as Spokane, Chicago, and Dallas, forty people living with chronic hepatitis B attended the first patient conference "**B-Informed 2001**" the weekend of June 8 - June 10. The Hepatitis B Foundation (HBF) in collaboration with the Internet Hepatitis B Information and Support List (HB-L) sponsored this groundbreaking meeting just for "hepBers".

For the first time, patients were able to freely pat each other on the shoulder or embrace, show their tears and share their laughter. The conference blended the emotional, the practical, and the intellectual. As the patients soaked up information from experts, they began to feel less alone in their daily struggle with this chronic disease.

The meeting started with introductions and welcome comments from the HBF and the HB-L. Chari Cohen, MPH, kicked off the information sessions with a presentation about results from her survey conducted this past winter using the HB-L support group (see pg.12 – survey results).

### Questions about Employment Rights and Disability

Paul Cohen, Esq. spoke about employment issues in the context of the American with Disabilities Act (ADA). "This powerful statute provides protection for people who are unable to perform work or who are *perceived* as being unable. It can protect you from unfair treatment caused by reality or perception."

Key points in ADA law are that it could protect patients, that employees have rights, and employers (with 15 or more employees) are required to make an effort to accommodate health problems or disabilities. But, patients must speak up and talk to their employees about their situation. For insurance problems, there are "appeals processes" for every health plan that may be used if coverage or reimbursement for treatment is denied. States generally have

insurance boards where patients can also appeal insurance company decisions.

### Research and Treatment

The most recent research was presented on antivirals, immuno sugars, and combination therapies. "We look for an anti-viral treatment anywhere we have a lead," stated Dr. Tim Block. He provided a highly informative talk using simple analogies to explain the disease, the research and treatments.

An update on adefovir dipivoxil, a drug in phase III clinical trials, was provided by Gilead. Participants interrogated the drug reps, demanding an explanation of the FDA approval process and why treatments are available in other countries that are not available in the U.S. Gilead explained that there are so few HBV drugs in this country because the drug development process is a complicated and tedious process that may take 10 to 15 years.

Patients expressed concern about potential kidney damage due to adefovir. Gilead explained that this was a problem identified in early trials of the drug for HIV. In those trials, HIV patients

were given 160 mg compared with only 10 mg for HBV patients. Since the clinical trials for HBV are not yet completed, the question about nephrotoxicity cannot yet be fully answered.

### Treatment and Liver Transplants

Drs. Tom London and Ken Rothstein led a lively Q&A session about treatment and liver transplants. Most participants sought information on their personal situations. While their questions were

answered, both doctors repeatedly advised them to go back and talk with their own doctors or seek a second opinion if they were unsatisfied. As Dr. Rothstein stated forcefully, "I've been a patient for non-hepatitis illnesses, and my best advice is that you have to put your docs' backs against the wall to get the answers to all of the questions that you're asking today."

(Continued on pg.7)



A gathering of friends, June 9, 2001

***"I feel like a tiny hole in my heart has been filled up by being with other people just like me, who know what it's like to live with the fatigue and fear that can be caused by hepatitis B."***

***"It has really filled in a lot of gray areas, pulled a lot of things together for me in a way that makes sense. I look forward to meeting next year!"***

The question of how much of a variable cirrhosis is for liver cancer was raised. The answer is that cirrhosis increases risk tremendously and patients should be monitored frequently. However, 25 percent of patients who develop liver cancer have normal alpha-fetoprotein (AFP). Therefore, Dr. Rothstein emphasized the importance of receiving regular ultrasounds, which will catch small tumors as soon as three months after the most recent screening.

The risks and benefits of liver biopsy were discussed extensively. Of note is that not all chronic carriers nor all liver transplant candidates require biopsies. With any biopsy, there is always a risk of bleeding and/or "seeding" additional virus through the liver as a result of the process, thus each decision is individualized.

***"So many of us are best friends, and we have never met before."***

### **E Antigen "Flip Flop"**

Most patients believe that once they seroconvert from e-antigen negative to positive, and then develop positive e-antibody, this is a permanent result. It has been discovered, however, that there are patients who will "flip-flop" between e-antigen negative and positive for awhile before finally stabilizing. Other patients will continue to bounce back and forth indefinitely. Although this "flip-flop" is known to be an immunological response, the biological mechanism is not yet understood.

Dr. London also explained that the e-antigen is only a surrogate marker that does not necessarily have any pathogenic meaning. HBV DNA levels provide more information about the liver's condition than the e-antigen or e-antibody status.

### **Same Time Next Year?**

The information sessions concluded Saturday evening outside under the stars with HB-L members sharing their expertise: Christopher spoke about nutrition, the importance of listening to your body for what it needs; Pam spoke about "activism" and encouraged "hepBers" to learn from the HIV community to effect positive change; and Maureen spoke about the concerns of parents with children who have HBV.

Finally, the participants shared personal comments about the conference and everyone unanimously agreed that there should be another meeting next year because there is still so much more to learn and share. As one participant summed up so well, "This was an excellent meeting for information and it was really fantastic meeting all those screen names in person. Cyber contact is fine but it will never replace human connections!"



## **B Informed 2001: First Gathering of Friends June 8-10, 2001**

### **Welcome and Introductions**

Joan Block, R.N., HBF Co-Founder  
Molli Conti, HBF Associate Director  
Steve Bingham and Sheree Martin, Co-owners of HB-L

### **Personal Stories**

Hedy Weinberg, Author of 2 hepatitis books

### **Report of the "OnLine Survey" Results**

Chari Cohen, MPH

### **Employment Rights and Insurance**

Paul Cohen, Esq. and Ed M.

### **HBF Lab Tour and Research Review**

Timothy Block, Ph.D., HBF President & Chief Scientist

### **Adefovir Dipivoxil Update**

Jonathan Zalk, Gilead

### **Treatment and Liver Transplantation**

Thomas London, M.D., Director, Liver Cancer Prevention Center, Fox Chase Cancer Center  
Kenneth Rothstein, M.D., Medical Director of the Liver Transplant Team, Albert Einstein Medical Center

### **Informal HB-L Discussion**

Nutritional Tips for HepBers - Christopher  
Politics & Hep B - Pam  
Children with Hep B - Maureen



**Hedy Weinberg is co-writing a book, Living with Hepatitis B: a Survivor's Guide, which will be published this fall. She is also co-author of a book about HCV. She provided suggestions on coping with the emotional aspects of having a chronic disease based on her own HCV infection. Her most powerful piece of advice was stated as, "I have a soul untouched by hepatitis. I am NOT my illness."**

### **Hepatitis B: Six Common Problems**

1. Feeling Low: Physically and Emotionally
2. Feeling Contaminated
3. Constantly Thinking about the Cause of Infection
4. Responding to People Who Say You Look Good When You Feel Bad
5. Up and Down Nature of Hepatitis B

### **Hedy's Rx For People Living with HBV**

1. Be Patient with Yourself
2. Make Changes Slowly
3. Allow Yourself to Feel Grief
4. Do Whatever Works
5. Learn to Say No
6. Be Kind to Yourself
7. Find Meaning
8. Help Someone Else

# Foundation at the Forefront

## HBF: A Decade of Accomplishments

- 1991
  - Incorporation as a 501(c)(3) nonprofit organization.
- 1992
  - Pa. state grant is received to produce HBF video, "Someone You Know Has Hepatitis B", which includes an introduction by Dr. Snyderman of Good Morning America.
  - The B Informed Newsletter is launched.
- 1993
  - Drs. Timothy Block, Baruch Blumberg, and Raymond Dwek discover a new anti-HBV drug at Oxford University.



HBF Helps Establish New Research Center (1998) The HBF's new home at Jefferson Center for Biomedical Research.

- 1997
  - HBF outreach campaign results in Pa. Governor Tom Ridge declaring June "Hepatitis Awareness Month".
  - Oliver, the HBF liver mascot, makes its debut on the Capitol in Harrisburg, Pa.
- 1998
  - HBF partners with Jefferson Medical College and Delaware Valley College to help establish a new research center in Doylestown, Pa.
- 1999
  - A major Pa. state grant is received to support HBF outreach efforts, promote hepatitis research, and to conduct statewide viral hepatitis trainings.
- 2000
  - The "Bruce Witte Research Fellowship" is established to fund a young scientist pursuing hepatitis B research.
  - 6th Annual Princeton Workshop identifies "National Research Priorities for Hepatitis B".
- 2001
  - HBF celebrates 10 years of success!



Hepatitis B Foundation Lab Opens (1994) HBF Senior Scientist Dr. Xuanyong Lu (center) demonstrates technique to research associates.

- 1994
  - The HBF research lab is established at Jefferson Medical College, Philadelphia, Pa.
- 1995
  - HBF invites 25 of the nation's leading scientists and clinicians to participate in the first Princeton Workshop, which is focused on hepatitis B therapeutic research.
- 1996
  - The first official HBF office is opened in Jenkintown, Pa.
  - HBF goes on-line, creates a website ([www.hepb.org](http://www.hepb.org)) and is flooded with e-mails from around the world.
  - HBF advocacy efforts result in Pa. legislature passing Act 15 that adds the hepatitis B vaccine to the list of immunizations covered by insurance.



HBF Co-Founders Still Working Together (2001) The past ten years have only strengthened the commitment of the HBF Founders! L. to R.: Tim Block, Jan Witte, Paul Witte, and Joan Block.

## The Hepatitis B Virus Story Looking for One Thing, Finding Another

Scientific findings are often serendipitous. Such was the case with the discovery of the hepatitis B virus. Dr. Baruch Blumberg did not set out to discover the cause of "serum hepatitis", now known as hepatitis B, but an open mind and an understanding of the scientific process led him to a profound discovery that has made an enormous global impact.

As a medical anthropologist in the early 1960's, Dr. Blumberg was interested in the biochemical differences between people and observed that people differ in their susceptibility to different diseases. Although the environment and other factors were thought to contribute most to these differences, Dr. Blumberg also believed that there were inherited differences in susceptibility to disease.

He and his team started the search for inherited differences by collecting and analyzing blood samples from native populations around the world. They were successful in identifying several new kinds of inherited variations. In the process, they developed a method for testing the blood of

people who had received many blood transfusions. They pursued this research with the hypothesis that patients who had received multiple blood transfusions would develop antibodies against "foreign" proteins that they had not inherited or acquired. These "antibodies" could then be used to identify the inherited factor or genetic difference.

Eventually they found an antibody that had never been seen before. This unknown antibody reacted with a protein called the "australia antigen", so named because the protein was found in the blood sample of an Australian Aborigine. For six months they sought an explanation for this phenomenon. A series of field and clinical observations led to the suspicion that the "australia antigen" was the cause of "serum hepatitis".

In 1967, Dr. Blumberg and his team confirmed their suspicion and identified the "australia antigen" as the hepatitis B virus. Two years later, Drs. Blumberg and Irving Millman invented the hepatitis B vaccine, which is another fascinating story!

## Meet the Scientist **Baruch Blumberg, M.D., Ph.D.**



### Human Bodies to Astro Bodies, An Illustrious Career is Still Going On

Dr. Baruch Blumberg, Nobel Laureate, has been a tremendous source of inspiration for the Hepatitis B Foundation. His discovery of the hepatitis B virus and invention of the first HBV vaccine are considered among the great medical achievements of the 20th century. When the HBF met with Dr. Blumberg ten years ago, he told us that a cure was

indeed possible and within reach. With his support and encouragement, we believe the circle of discovery that he started will be completed!

Born in New York City in 1925, Blumberg earned his B.S. in physics at Union College in Schenectady in 1946 and for a year did graduate work in mathematics at Columbia University. He received his M.D. from Columbia's College of Physicians and Surgeons in 1951.



Dr. Baruch Blumberg

As a medical student, he spent one summer at a mining company hospital in Surinam, South America, where he got his first taste of clinical research. Later, as an intern and assistant resident at New York City's Bellevue Hospital, he experienced all the demands of patient care under crowded urban conditions. After a clinical fellowship at Columbia Presbyterian Medical Center, he went to England to earn his doctoral degree at Oxford's Balliol College.

In 1957 he returned to the United States to join the National Institutes of Health and headed its Geographic Medicine and Genetics Section until 1964, when he became associate director for clinical research at Fox Chase Cancer Center in Philadelphia, PA, and a senior member of its scientific staff. Before becoming head of Balliol College in 1989, he held numerous other academic positions over the years, including Professor of Medicine and Anthropology at the University of Pennsylvania from 1977 to the present. In 1976, Blumberg won the Nobel Prize in Medicine for his discovery of the hepatitis B virus.

Currently, Dr. Blumberg has turned his attention away from the human body and is looking into the mysteries of outer space. In 1999, he became as Director of the NASA Astrobiology Institute in Moffett Field, CA, and was recently invited to serve as Senior Advisor to the Administrator for Biology at NASA in Washington, D.C. Dr. Blumberg continues to also serve as Senior Advisor to the President at Fox Chase Cancer Center.

# Conference Highlights

## Digestive Disease Week Conference May 20-23, 2001, Atlanta, GA

### "Report On Hepatitis B"

by Mack C. Mitchell, Jr., MD, HIV and Hepatitis.com  
Chairman of the Department of Internal Medicine, Carolinas Medical Center and Clinical Professor of Medicine, University of North Carolina

Overall, there were a relatively small number of presentations at *DDW 2001* related to hepatitis B virus (HBV) infection. While new treatments for chronic hepatitis B are currently being studied, few of these studies were complete enough for presentation at this meeting. The interest in hepatitis B infection is very high, due to the expanded treatment options now available.

**Long-Term Follow-Up Of Chronic HBV Infection In Children Of Different Ethnic Origin (Abstract 257)** This study from Montreal examined the natural history of chronic HBV infection in children from Asia, eastern Europe, French Canada and Latin America. All children (n=174) were HBeAg positive at the beginning of the study and were followed for a mean of 4.5 + 3.1 years. The seroconversion rate to HBeAb was lower in children from Asia (28%) than in those from other ethnic groups (50%). HBsAg loss occurred in 8% of all children during follow-up. Those children treated with lamivudine or with interferon experienced more rapid seroconversion, although the overall rates in this uncontrolled observational study appeared to be similar during the period of follow-up.

The study suggests that spontaneous seroconversion occurs in many children (40%). Whether treatment-induced seroconversion will result in fewer adverse liver-related events in children with chronic HBV remains to be determined. Unfortunately, long-term follow-up studies will be needed to evaluate this possibility. However, there may be other indirect benefits of treatment such as reduced infectivity among those with chronic hepatitis B as they become sexually mature.

### The Efficacy And Safety Of Long-Term Administration Of Alpha-Interferon And Lamivudine In Patients With Chronic Hepatitis B (Abstract 2906)

This study compared the efficacy of lamivudine monotherapy (100 mg daily for 12 months) with interferon monotherapy (6 MU 3x/week for 12 months); or the combination of lamivudine for 1 month followed by the combination of lamivudine and interferon for 12 months, followed by lamivudine alone for 6 months. 101 patients with positive HBV DNA were enrolled. 82 were HBeAg negative CHB. End of treatment responses (negative HBV DNA) were 100% for lamivudine monotherapy, 58% with interferon, and 88% with combination. 6 months after treatment was stopped, only 33% of patients in the lamivudine monotherapy group were still negative, compared with 45% for interferon monotherapy, and 50% for those on combination therapy. ALT was normal in 61% on combination, 50% on interferon and 47% on lamivudine. HBeAg seroconversion rates were 77% in the group on combination therapy. Histological improvement in necroinflammatory activity was seen in all groups, but fibrosis improved only in the lamivudine group and those on combination therapy. The results of this combination trial are encouraging and suggest that combination treatment may be better than either drug given as monotherapy.

(Continued on Pg. 11)

### The following important points were made at the DDW conference, which reviewed existing data regarding treatment of chronic hepatitis B (CHB):

- The decision as to which drug should be given as first line therapy is a decision that is complicated. Most felt that the decision should involve patient preference as well as the presence or absence of cirrhosis.
- Both interferon and lamivudine are effective treatments for patients with elevated ALT and HBeAg positive HBV infection.
- Combination therapy with interferon and lamivudine may be better than either treatment given alone in patients with HBeAg-negative chronic hepatitis B.
- Patients with HBeAg-negative CHB frequently have cirrhosis at the time of diagnosis. Antiviral therapy with either lamivudine or interferon reduces the risk of decompensation in this subset of patients with chronic hepatitis B. However, they remain at risk for the development of hepatocellular carcinoma even after successful antiviral therapy.
- A normal ALT is a good surrogate marker for successful treatment of HBeAg-negative CHB, although virological relapse may still occur in a few patients.
- Dr. Wright specifically stated that lamivudine could be safely given to patients with advanced disease even if transplantation was contemplated. Although concern has been raised that development of YMDD mutations might make transplantation more difficult, the fact that Child-Pugh scores improve in most patients and reduce the need for transplantation in many people offsets any concerns.
- Genotypic variants of HBV may be more or less likely to form pre-core mutants. Genotypes B, C, D and E are more likely to form pre-core mutants because of stable base-pairing at position 1858.

## 36<sup>TH</sup> Annual Meeting of the European Association for the Study of the Liver (EASL) April 18 – 22, 2001, Prague, Czech Republic

### Treatment Breakthrough for Children With Chronic Hepatitis B

LAVAL (Quebec), Canada, April 22 *IPRNewswire* - BioChem Pharma Inc. announced that new data on Zeffix\* (lamivudine), presented at the recent EASL Conference, show that a year's treatment with Zeffix, induces a complete virologic response, a good indicator that the virus has been effectively suppressed, in almost a quarter (23%) of children suffering from the disease. These children were therefore able to stop treatment. This was significantly better than the placebo group, where only 13% achieved the same outcome. The result is similar to that observed after one year's treatment in adults suffering from chronic hepatitis B, where Zeffix is already an established treatment. Professor Etienne Sokal, in Brussels, Belgium, who was the lead European investigator in this study, commented, "Zeffix is also a well tolerated oral treatment, and such a safety profile is of particular significance when treating young children."

This large international multi-center study involved 286 children between two and seventeen years of age with chronic hepatitis B. In addition to a significantly higher complete virologic response with Zeffix compared to placebo, the results also demonstrated that: significantly more children became HBeAg negative on Zeffix (26%) compared with placebo (15%); significantly higher numbers of children achieved sustained normalization of ALT with Zeffix (55%) compared with placebo (13%); and HBV DNA was undetectable in 61% of children taking Zeffix compared with 16% in the placebo group. Zeffix is indicated for treatment of patients 16 years of age or over with chronic hepatitis B and evidence of HBV replication. A regulatory application to extend the indication for the treatment of chronic hepatitis B in patients two years and above was submitted to the FDA in March 2000. More than 200,000 patients have been treated with Zeffix since its first launch in November 1998. GlaxoSmithKline manufactures and sells lamivudine worldwide, except in Canada where they have formed a commercial partnership with BioChem Pharma. [For more information, visit [BiochemPharma at www.biochempharma.com](http://BiochemPharma.com) or [GlaxoSmithKline at www.gsk.com](http://GlaxoSmithKline.com)]

\*Note: Zeffix is currently available in over 50 countries worldwide, including China (as Heptodin), the USA (as Eпивir-HBV), Canada and the EU (as Heptovir).

### Multinational Studies Show Positive Resistance Profile for Adefovir Dipivoxil

Prague, The Czech Republic, April 22 *BW HealthWire* - Gilead Sciences, Inc. announced data from four studies of adefovir dipivoxil, the company's anti-HBV drug, at the 36th Annual EASL meeting. Data from four studies presented at the conference characterize the emerging efficacy, safety and resistance profile of adefovir dipivoxil, including: a virologic response of -4.01 log<sub>10</sub> copies/mL reduction in HBV DNA after 48 weeks of treatment to the 10 mg dose in patients with lamivudine-resistant HBV and HIV co-infection; no significant changes in serum electrolytes or renal function in patients with lamivudine-resistant HBV and HIV

infection following 48 weeks of treatment; no resistance mutations were identified in nucleoside treatment-naive HBV patients following up to 60 weeks of treatment; a mean reduction in HBV DNA of -3.92 log<sub>10</sub> copies/mL at 24 weeks of treatment in lamivudine-resistant HBV-infected liver transplant patients; and similar virologic response in "precore mutant" (hepatitis B "e" antigen negative) HBV-infected patients and in patients with hepatitis B "e" antigen positive virus. An oral daily dose of adefovir dipivoxil 10 mg is being evaluated as a monotherapy treatment for chronic HBV infection in two multinational Phase III clinical trials. Gilead intends to file for regulatory approval of adefovir dipivoxil 10 mg in the United States and Europe in the first half of 2002. [For more information, contact Gilead Sciences Medical Information at 1-800-GILEAD-5 or 1-650-574-3000 from outside the United States. Visit [www.gilead.com](http://www.gilead.com)]

(DDW Conference Highlights - Continued from Pg. 10)

### Thymosin-a1 For The Treatment Of Chronic HBV Infection: A Meta-Analysis (Abstract 2910)

Meta analysis is a statistical method for comparing and combining results of different randomized trials. Most of the previous studies of thymosin for treatment of chronic hepatitis B have not shown significant improvement. This meta-analysis reviewed the results of 5 previously published studies including a total of 435 patients. In 4/5 trials, thymosin was given for 6 months and in the other for 12 months. Although there was no difference in the virological or biochemical response between the thymosin-treated group and the control group at the end of treatment, 6 months after treatment, the virological response was significantly greater. The biochemical response, however, remained similar between the two groups. No serious adverse events were noted. Even though this meta-analysis suggests that there might be some benefit to thymosin treatment, current treatment with lamivudine or interferon appears to be much better. Therefore, it would seem unlikely that thymosin would find a role in treatment except possibly as part of combination therapy.

The above excerpts are reprinted with permission by HIV and Hepatitis.com. For a complete web text copy of Dr. Mitchell's "Report On Hepatitis B" from the DDW 2001 Conference, please visit, [www.hivandhepatitis.com/conferences/ddw2001](http://www.hivandhepatitis.com/conferences/ddw2001)

## Fast Fact

- 1991: There are no treatments for chronic HBV.
- 2001: 2 FDA approved drugs, 11 in clinical trials and 7 in development for chronic HBV.

## The Results Are In! First Online Survey of HBV Patients Completed Chari Cohen, M.P.H

In collaboration with the Hepatitis B Foundation (HBF) and the online Hepatitis Information & Support List (HB-L), the first internet survey of adults living with chronic hepatitis B has been completed. The primary goal of the survey was to assess the need for information and support among chronic HBV carriers. The survey results highlight the importance of "electronic support groups" for those living with a chronic disease.

### Who participates in the HB-L?

The survey results indicate that the membership is split down the middle by gender: about half are men and half are women. The average age of an HB-L member is 42, but the ages range from 20 to 64. Over half of the U.S. members live in a suburban area, with another 37% residing in an urban community. In addition, the members of the HB-L are highly educated - half of the respondents have attended graduate school. More than 60% of respondents were diagnosed as HBV carriers at least 2 years ago. To manage their health, most members see a hepatologist or gastroenterologist, rather than a general practitioner. 97% of group members join the HB-L to get important hepatitis-related information and 63% consider the HB-L to be the *most useful* source of information in their lives.



Successful defense of MPH thesis, April 18, 2001. L. to R: Chari Cohen, Dr. Amy Jessop, Mollie Conti and Joan Block

### What topics are of greatest concern?

Group members are most interested in the following topics: *treatment (92%), diet (79%), doctor-patient communication (63%), diagnosis (58%), and prevention (21%)*. However, the most common topics discussed by the group include: *treatment information (42%), general hepatitis B information (29%), side effects of treatment (11%), disease progression (8%), and diagnostic/lab information (8%)*.

### Conclusions

Hepatitis B carriers want more information about treatment and diet to help them lead healthier lives. They want better communication and information from their physicians, and they need to get support. Group members consider the HB-L a convenient and accessible way to get information and support from people around the world.

The study also confirms that the Hepatitis B Foundation is providing essential disease and treatment information. Based on the survey results, the HBF plans to expand its educational literature to meet the specific needs of those living with chronic hepatitis B. In addition, the HBF hopes to develop literature to help educate physicians about hepatitis B in order to decrease the "information gap" with hepatitis B patients.

## Highlights from the Online Patient Survey Results

*HB-L participants are making important changes in their lives due to their participation in the group. The results indicate that the longer one is a member of the HB-L, the more likely s/he is to make a health behavior change. For example:*

- 53% made a change in their diet
- 40% changed the way they use non-prescription medications
- 18% changed their alcohol intake
- 18% got a second opinion from another doctor
- 16% decided to begin treatment (interferon or lamivudine)
- 11% tried an alternative therapy

In addition to information, HB-L participants utilize the group as a means of gaining social support:

- 87% are comfortable disclosing personal experiences to the group
- 74% feel that the type of support they receive from the HB-L is hard to get elsewhere
- 58% feel that the HB-L routinely plays a positive supportive role in their lives

HB-L members identify that there is a lack of information from their physicians:

- 82% replied that they get more information from the HB-L than they do from their physicians
- 68% consider their physician to be knowledgeable in the area of diagnosis, but only half of respondents think that their physician is knowledgeable about hepatitis B management, treatment, or prevention
- 50% are satisfied with the quantity and quality of information they receive from their physician

There is a high level of awareness of the Hepatitis B Foundation among group participants:

- 82% of survey respondents have visited the HBF website
- 26% have called or e-mailed the HBF to ask questions directly. The lack of questions, however, may be due to our comprehensive website and enthusiastic promotion of the HB-L support group!

# Speaking Personally

Steve Bingham  
Co-List Owner of the Internet Hepatitis B Information  
& Support List (HB-L)

## From My Computer to the Czech Republic

Friends, I want to tell you all about my recent trip to the Czech Republic. I thought that if I waited awhile and let the whole experience sink in a bit, it would be easier to write down my thoughts. But that hasn't happened, so here goes anyway ...

Computers are becoming more accessible in developing countries like the Czech R. I knew that because we had a Czech gastroenterologist, Dr. Vladimir Strakrle, on our online hep b list (HB-L), but he seldom spoke up, mostly just observed, as do many health professionals. Last September, I got an email from him inviting me to come to his country to speak about patient support groups on the internet at a medical conference. I wrote back that I didn't think I could afford to come to the Czech R., and assumed that would be the last of it. However, he wrote right back and said his meeting sponsor would pay all my expenses!

So on April 18, "team-member" Jack and I found ourselves in Brno (pronounced Brrr NO'), the second largest city in the Czech R. On April 20, the one-day conference, "Exploitation of Information Technologies in Health Service in the New Millennium", was held for Czech medical professionals to learn how to benefit from the Internet. It's not often that a patient is asked to speak at medical conferences, even though we, the patients, comprise 50% of the doctor/patient relationship. Therefore, I thought it was quite progressive that they would even invite me to speak. There were nine speakers and two "honored guests", who came from around the world to attend. The only other American other than myself was from the Centers for Disease Control in Atlanta, GA.

Just to give you an idea of some of the topics discussed, here is a list of some of the more interesting ones: "The Myths of the Internet Revealed" (Canada); "CDC Travelers' Healthy Information: From 'Mission Impossible' to the 'The Right Stuff' - How the Internet Transformed CDC Services" (USA); "The Importance of Information Technologies in the Health Service in Emerging Economies" (Ghana). Headphones were available for those who didn't understand English.

All nine speakers were allotted different amounts of time for their presentations. I was assigned 55 minutes, which made me feel like the keynote speaker of the conference! My presentation was "Patient Information and Support Groups on the Internet". I spoke about how Sheree Martin and I became the HB-L list owners, talked about the advantages and disadvantages of online support groups, emphasized ways doctors could take advantage of patient support groups, and ended with some personal thoughts of

how satisfying it is for me to be of use to my hep B brothers and sisters throughout the world. I told them about you, my vast "online community", while projecting a map of the world and pointing to where all of you live. This was done so they could see how international the HB-L is.

The audience was really quiet and attentive. Unfortunately, they were also quiet the few times that I tried to tell a joke. Overall, I think they liked my talk because it was less technical and more human and dramatic. And you all know the drama that we experience daily on our list here!

Although I've previously been asked to speak at conferences in the USA, the opportunity to speak in the Czech Republic was a totally unexpected life bonus. Just when I think I might have some control over my life, fate and circumstance happily teach me otherwise.

I want to end my report to all of you by saying that my HB-L support group is a source of constant satisfaction for me. It was fun to actually go to Europe, but I travel around the world each morning when I turn on my computer. The strangers that I meet online quickly become friends; friends become brothers and sisters; and then we all become survivors as one united family.

Thanks to all of you,  
**Steve**

P.S. If you live anywhere near Idaho, I'd like to come over and show you my photos!



Medical Conference Committee and Speakers, Czech Republic, April 20, 2001. L. to R.: A. Pokorny (Czech), **Steve Bingham** (USA), D. Gandacu (Israel), R. Dewart (USA), S. Wilkie (Australia), R. Pounder (UK), V. Strakrle (Czech), J. Pistek (Czech), J. Wu (Taiwan), S. Lanfranco (Canada), S. Surel (Czech), and M. Senkyrik (Czech)

## Fast Fact

- 1991: 300 million people worldwide suffer from chronic HBV.**
- 2001: 400 million people worldwide suffer from chronic HBV.**

# Calendar of Events, 2001



**July 29 – August 2**  
**2001 International Meeting on the Molecular Biology of Hepatitis B Viruses**  
University of Massachusetts at Amherst  
Amherst, MA  
Contact: Shelley Gibbons at  
[sgibbons@mail.aux.umass.edu](mailto:sgibbons@mail.aux.umass.edu)  
<http://public.bcm.tmc.edu/hbv2001>

**July 30 – August 2**  
**National Hepatitis Coordinators' Conference**  
Centers for Disease Control and Prevention  
Co-sponsor: Immunization Action Coalition  
Omni Richmond Hotel, Richmond, VA  
Contact: Tasneem Malik at 404-639-4213 or  
Scott Damon at 404-371-5319.

**November 9 – 13**  
**52<sup>nd</sup> 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](http://www.aasld.org)

**December 2 – 6**  
**4<sup>th</sup> International Conference on Therapies for Viral Hepatitis**  
International Medical Press  
Isla Verde, Puerto Rico  
Contact: 404-233-6446 or  
[lipodystrophy@us.intmedpress.com](mailto:lipodystrophy@us.intmedpress.com)  
[www.intmedpress.com](http://www.intmedpress.com)

**December 16 – 20**  
**HEP DART 2001**  
**Frontiers in Drug Development for Anti-Hepatitis Therapies**  
Informed Horizons  
Co-Chairs: Drs. Raymond Schinazi and Jean-Pierre Sommadossi  
Ritz-Carlton, Maui, Hawaii  
Contact: 678-395-0029 [info@informedhorizons.com](mailto:info@informedhorizons.com)  
<http://informedhorizons.com/HEP-dart2001>

## New Resources

### Hepatitis B Foundation Launches "Chinese Chapter" On Its Website!

The HBF has added a new "Chinese Chapter" to its website with information translated into traditional Chinese. Available in PDF for easy printing. Visit [www.hepb.org](http://www.hepb.org) and click on the Chinese flag!

**"Hepatitis B: The Global Challenge" Video Now Available In Four Languages.** This moving 24-minute documentary chronicles the impact of chronic hepatitis B around the world. Produced by GlaxoSmithKline, it provides easy-to-understand information that is suitable for lay audiences. Available in English, Chinese, Korean and Vietnamese. To order, contact the HBF at [info@hepb.org](mailto:info@hepb.org) or call 215-489-4900.

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

Call anywhere in the U.S. for information, physician referrals and screening sites. GlaxoSmithKline just launched this nationwide toll-free number. Information is available in Mandarin, Cantonese, Korean, Vietnamese and English. Call **1-888-888-0981**.

## Get Out Your Soft Spikes Tee-Up For A Good Cause!

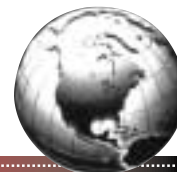
### 2<sup>nd</sup> Annual Joseph Nagy Golf Tournament to benefit the Hepatitis B Foundation

July 16, 2001  
Bunker Hill Golf Course  
Princeton, NJ

For more information or to sign up, please contact:  
Kevin Drake at 908-707-1184

There will be team prizes, door prizes and plenty of refreshments. The winner of a special hole-in-one contest will receive a trip to Las Vegas valued at \$5,000!

## 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](mailto: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.

# Resource Roundup



**Hepatitis B Foundation**  
215-489-4900 [www.hepb.org](http://www.hepb.org)  
[info@hepb.org](mailto: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](http://www.liverfoundation.org)  
[webmail@liverfoundation.org](mailto:webmail@liverfoundation.org)

Information about all liver diseases, including viral hepatitis. Fact sheets, legislative advocacy, research funding, and chapter reports from across the nation.

**Centers for Disease Control, Hepatitis Branch**  
1-888-443-7232

[www.cdc.gov/ncidod/diseases/hepatitis](http://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](http://www.cdc.gov/nip)  
1-800-232-0233 (Spanish)  
[nipinfo@nip1.em.cdc.gov](mailto:nipinfo@nip1.em.cdc.gov)

**Hepatitis B Research List**  
To subscribe, send a blank email to:  
[HBV\\_Research-on@mail-list.com](mailto:HBV_Research-on@mail-list.com)

A free electronic research list maintained by Sheree Martin that provides subscribers with up-to-the-minute research abstracts, reports and notices.

**Hepatitis B Research Archive Website**  
[http://dispatch.mail-list.com/archives/hbv\\_research](http://dispatch.mail-list.com/archives/hbv_research)  
Research bulletins posted on the Hepatitis B Research List, from 1998 until current year, are automatically archived at this website and can be accessed by an easy search engine.

**Hepatitis B Virus Page**  
<http://www.globalseve.net/~harlequin/HBV/index.html>  
Maintained by Robert Garces, Ph.D. Candidate in Virology, at the University of Toronto. Everything you wanted to know about the hepatitis B virus and more.

**Hep C Connection**  
1-800-522-4372 [www.hepc-connection.org](http://www.hepc-connection.org)  
[info@hepc-connection.org](mailto:info@hepc-connection.org)  
Comprehensive information to assist Hep C-challenged individuals and their families.

**Hepatitis Control Report.**  
[www.hepatitiscontrolreport.com](http://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](http://www.hepfi.org)  
[mail@hepfi.org](mailto:mail@hepfi.org)

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

**Hepatitis Magazine**  
1-800-310-7047 [www.hepatismag.com](http://www.hepatismag.com)  
[editor@hepatismag.com](mailto:editor@hepatismag.com)

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

**Hepatitis Neighborhood**  
[www.hepatitisneighborhood.com](http://www.hepatitisneighborhood.com)  
[info@HepatitisNeighborhood.com](mailto:info@HepatitisNeighborhood.com)

Features a Town Hall with a Live Speakers Forum of hepatitis experts. Sponsored by Priority Healthcare Corporation, a nationwide specialty pharmacy.

**HIV and Hepatitis Treatment Advocates**  
[www.hivandhepatitis.com](http://www.hivandhepatitis.com)

Professional online publication with treatment updates, conference reviews, free interactive teleconferences, and a weekly email announcement service.

**Immunization Action Coalition**  
651-647-9009 [www.immunize.org](http://www.immunize.org)  
[medinfo@immunize.org](mailto: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](http://www.nccam.nih.gov)

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

**Parents of Kids with Infectious Diseases**  
1-877-55-PKIDS (toll-free) [www.pkids.org](http://www.pkids.org)  
[pkids@pkids.org](mailto: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.

## Fast Fact


**1991:** National call for "universal infant HBV vaccination" first recommended.

**2001:** 88% of all American infants now routinely vaccinated against hepatitis B.



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## Giving Hope to Millions Is As Easy As Giving...

**... and we've Just Made It Easier!  
Credit Card Donations Can Now Be Accepted**

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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 City \_\_\_\_\_  \$500 Patron  
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 State \_\_\_\_\_ Zip \_\_\_\_\_  Other

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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.



**FOUNDATION**  
700 East Butler Avenue  
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*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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