



# INFORMED

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## Hepatitis B and Liver Transplantation

Human organ transplantation has undergone remarkable progress since the pioneering work of **Dr. Thomas Starzl** in the 1960s laid the groundwork for an entirely new field of medicine. In 1967, Dr. Starzl performed the first successful liver transplant and almost 40 years later, with new advances in medical technology and organ allocation, liver transplantation has now become a “routine” life-saving procedure.

### Encouraging Trends

Perhaps the most marked progress in the United States over the past decade has been the sharp drop in the number of people chronically infected with the hepatitis B virus (HBV) who need a liver transplant. As more effective anti-HBV drugs have

become available, the number of individuals with HBV progressing to liver failure is significantly decreasing in the country.

This good news is reflected in the numbers from the United Network of Organ Sharing (UNOS). Among the people waitlisted for a liver transplant, there has been a nearly 30% reduction since 2001 in those with end-stage liver disease related to HBV. And while the number of those waiting for a liver transplant due to HBV-related liver cancer is rising, the increase is not as great as with other causes of liver cancer (eg, hepatitis C and fatty liver disease) and is projected to decrease over the next few decades. This indicates HBV is being better managed with the current treatments and that liver cancer surveillance is identifying liver cancer earlier.

Dr. Thomas Starzl Receives 2014 *Baruch S. Blumberg Prize* from HBF [page 6](#)



Dr. Thomas Starzl

*“The father of modern transplantation”*

### Impact of HBV Drug Therapies

These encouraging trends are largely thanks to the widespread use of oral antiviral therapy for HBV. “Pre-transplant regimens with a single first-line drug, such as tenofovir or entecavir, are wiping out end-stage liver disease due to HBV,” noted **Dr. Robert Gish**, the newly appointed medical director of the Hepatitis B Foundation. “If the patient is treated appropriately, the virus is successfully suppressed and the liver disease does not progress—and reverses in many patients. This underscores the need for not only aggressive treatment but also long-term care and surveillance,” he added.

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HBV-infected patients have one of the **highest** post-liver transplant survival rates.



### Cause for a Cure

The Hepatitis B Foundation is a national nonprofit organization dedicated to finding a cure and improving the quality of life for those affected by hepatitis B worldwide through research, education and patient advocacy.



# From the Editor's Desk

## Hepatitis B in the Spotlight



**HEPATITIS B FOUNDATION**

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**Joan M. Block, Co-Founder and Executive Director**

A lot is going on in the world of hepatitis B, and it's gratifying to see the growing momentum with new hepatitis B screening recommendations (*see In the News* below), exciting advances in research (*see p. 5*), and successful public health initiatives (*see p. 5*).

The U.S. Preventive Services Task Force announced its draft recommendations that approve hepatitis B screening of high-risk communities, which will significantly increase screening efforts and improve care to those affected. And *Hep B United*, the national coalition established by the Hepatitis B Foundation and AAPCHO, continues to energize hepatitis B coalitions across the country as they work to eliminate hepatitis B through community-based programs that increase awareness, screening, vaccination and linkage to care for high-risk populations.

On the research front, with hepatitis C now curable, companies are re-focusing on hepatitis B (*see In the News*). The effectiveness of current HBV treatments has meant a sharp drop in the number of patients progressing to end-stage liver disease (*see front page*). The approved treatments, however, are only effective in about 50% of patients; thus, there is still a tremendous need to find a cure.

Finding a cure takes on new urgency as the World Health Organization announced that liver cancer, which is due primarily to HBV, has moved up to being the 2<sup>nd</sup> deadliest cancer in the world (*see p. 8*). In the U.S., liver cancer is the fastest growing cancer in incidence with a 5-year survival rate of less than 15% and is devastating to patients and their families (*see p. 7*).

So while we celebrate the advances and progress being made, we must keep up the pressure to sustain the momentum. Hepatitis B is now back in the spotlight, and the Hepatitis B Foundation and its many partners intend to make sure it stays there until a cure is finally found.

### Thanks for your donations!

The Hepatitis B Foundation thanks everyone who contributed to our 2013 Annual Fund Appeal. We sincerely appreciate your support and donations to help us continue our valuable work in research, outreach, public health and patient advocacy.

*The Hepatitis B Foundation is a national nonprofit organization dedicated to finding a cure and improving the quality of life for those affected by hepatitis B worldwide through research, education and patient advocacy.*

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\*Baruch S. Blumberg, MD, DPhil (1992-2011)  
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## IN THE NEWS

### Hepatitis B Screening Makes the Grade



In March, the U.S. Preventive Services Task Force (USPSTF) issued a “B” grade recommendation for HBV screening in persons at high risk, including Asian Americans and Pacific Islanders. These communities make up 5% of the total U.S. population, but account for more than 50% of Americans living with chronic hepatitis B. The draft recommendation applies to asymptomatic, nonpregnant adolescents and adults who have not been vaccinated and other individuals at high risk for HBV infection. A “B” grade recommendation means screening may be covered by private and government insurance plans. And HBV screenings can be included in the list of preventive services of the Affordable Care Act. Read the complete recommendations at [www.uspreventiveservicestaskforce.org/uspstf/uspshpb.htm](http://www.uspreventiveservicestaskforce.org/uspstf/uspshpb.htm)

### OnCore for Hepatitis B!



Hepatitis C is now curable, thanks to newly developed antiviral agents. Chief among them is sofosbuvir, the drug named after its inventor, **Mike Sofia, PhD**. Sofosbuvir (approved to be sold as “Sovaldi”) was developed by Dr. Sofia and his team only seven years ago. It is the first HCV treatment that does not require interferon injections and can be taken as a pill with other drugs. This is a revolutionary oral treatment with few side effects that promises a cure for hepatitis C in 12 weeks!

*Dr. Sofia, a faculty member of the HBF's Baruch S. Blumberg Institute, has started OnCore BioPharma to develop new hepatitis B therapies. The HBF wishes Dr. Sofia and his group success as they set their sights on an encore performance...this time, a cure for hepatitis B!*

# Hepatitis B and Liver Transplantation

...continued from Front Page

## Preventing Transplant Rejection

The anti-HBV drug therapies are also preventing infection of the new graft after transplantation (often incorrectly termed “recurrence”). The chance of new graft infection (about 5%) in transplant recipients with HBV is low enough that success is now considered to be routine. HBV-infected patients have one of the highest post-liver transplant survival rates.

Currently, the picture is not so upbeat for transplant candidates infected with the hepatitis C virus (HCV), the leading cause of liver transplants in the U.S., which is due to a greater number of HCV-infected Americans. HCV infection of the new graft is almost 100% and graft loss is about 50%. But with HCV now potentially curable (see “In the News,” p. 2), the transplant community is very optimistic

that graft infection and organ loss can be dramatically reduced in people with HCV. Recently an all-oral regimen containing sofosbuvir for chronic HCV in waitlisted patients with liver cancer had a very high cure rate after liver transplant.

## Raising the Bar

With the availability of effective anti-HBV therapies and optimal surgical and medical care, the average 1-year survival rate after liver transplantation at U.S. transplant centers is now at least 93%, with rejection and infection rates at one month being under 15% and 7%, respectively. “Post-transplant care has been refined to exceptional levels,” Dr. Gish observed, adding, “We are raising the bar higher.”

**With the availability of effective anti-HBV antiviral therapies and optimal surgical and medical care, the average 1-year survival rate after transplantation at U.S. transplant centers is now at least 93%.**

Moreover, the processes for selecting transplant candidates and for distributing the donated organs have also been improved. The revised UNOS policy for liver allocation aims to give candidates broader access to available organs. And centers are adopting regional sharing for patients with MELD scores over 15 and over 35 to help reduce the marked disparity in organ distribution across the country. (The “Model for End-Stage Liver Disease,” or MELD score, is a reliable measure of mortality risk in patients with end-stage liver disease and is used to help prioritize allocation of organs for transplant.)

## Focus of the Future

Addressing the disparity in organ allocation has never been more urgent. In 2012, over 6,000 people received a liver

transplant, but about 16,000 were on the waiting list. And the number of people waiting is expected to increase further as the incidence of liver cancer continues

to rise, putting further strain on the already limited donor pool. Up to 80,000 patients are dying of liver failure each year in the U.S.

The focus is now on increasing the number of available organs by enhanced donation and removing the geographic disparity in distribution. Efforts are ongoing to reduce the cost of transporting and processing the organs because these factors affect transplant success.

But perhaps the biggest impact will come from reducing the need for transplants in the first place. Chronic viral hepatitis infections are among the primary reasons for liver transplantation in the U.S. Now that HCV can be cured, the nation must redouble its efforts to find a cure for HBV.

## In Loving Memory of Arline Loh

Hepatitis B Advocate and HBF Friend



**Ms. Arline Loh**, a passionate hepatitis B advocate who was also a founding member of the Hepatitis B Foundation’s *One Hundred Chinese Families & Friends* campaign and recognized as a “Champion of Change” by the White House, lost

her courageous battle to liver cancer on October 15, 2013.

A former banking information technology expert, Arline was forced into early retirement because of advancing liver disease caused by chronic hepatitis B, which she acquired at birth. Arline spent her life dedicated to educating and informing people about hepatitis B and how to prevent and manage this serious liver disease. The founder of two hepatitis B support groups in New York City, as well as the co-founder of H+EAL (Health and Education for Asian Livers), her advocacy efforts focused on HBV screening, vaccination, and treatment.

Arline will be remembered for her strength, determination, generosity and unwavering love of family. Her dedication to the cause of hepatitis B will live on to inspire the continuing work of the Hepatitis B Foundation as it seeks to eliminate hepatitis B through research, outreach and patient advocacy.

**To learn more about liver cancer, visit the HBF’s [www.livercancerconnect.org](http://www.livercancerconnect.org).**



# DRUG WATCH

SPRING 2014

HBV Compounds in Development

[www.hepb.org/drugwatch](http://www.hepb.org/drugwatch)

FAMILY/DRUG NAME	MECHANISM	COMPANY	WEBSITE	STATUS, USA
<b>INTERFERONS</b> Mimic naturally occurring infection-fighting immune substances produced in the body				
Intron A (Interferon alfa-2b)	Immunomodulator	Merck, Whitehouse Station, NJ	<a href="http://www.merck.com">www.merck.com</a>	FDA Approved 1991
Pegasys (PegInterferon alfa-2a)	Immunomodulator	Genentech, South San Francisco, CA	<a href="http://www.gene.com">www.gene.com</a>	FDA Approved 2005
<b>NUCLEOSIDE ANALOGUES</b> Interfere with the viral DNA polymerase enzyme used for hepatitis B virus reproduction				
Epivir-HBV (Lamivudine)	Inhibits viral DNA polymerase	GlaxoSmithKline, Phila., PA	<a href="http://www.gsk.com">www.gsk.com</a>	FDA Approved 1998
Hepsera (Adefovir Dipivoxil)	Inhibits viral DNA polymerase	Gilead Sciences, Foster City, CA	<a href="http://www.gilead.com">www.gilead.com</a>	FDA Approved 2002
Baraclude (Entecavir)	Inhibits viral DNA polymerase	Bristol-Myers Squibb, Princeton, NJ	<a href="http://www.bms.com">www.bms.com</a>	FDA Approved 2005
Tyzeka (Telbivudine)	Inhibits viral DNA polymerase	Novartis, Switzerland	<a href="http://www.novartis.com">www.novartis.com</a>	FDA Approved 2006
Viread (Tenofovir)	Inhibits viral DNA polymerase	Gilead Sciences, Foster City, CA	<a href="http://www.gilead.com">www.gilead.com</a>	FDA Approved 2008
Clevudine (L-FMAU)	Inhibits viral DNA polymerase	Bukwang, Seoul, Korea, Eisai, Japan	<a href="http://www.bukwang.co.kr">www.bukwang.co.kr</a>	Approved in S. Korea 2006 (Levovir)
Besifovir (LB80380)	Inhibits viral DNA polymerase	LG Life Sciences, Seoul, Korea	<a href="http://www.lgls.com">www.lgls.com</a>	Phase II
AG X-1009	Pro-drug of tenofovir	Agenix, Australia	<a href="http://www.agenix.com">www.agenix.com</a>	Phase I, China
<b>NON-NUCLEOSIDE ANTIVIRALS</b> Interfere with proteins involved in viral reproduction				
NOV-205 (Bam 205)	Small molecule	Novelos, Newton, MA	<a href="http://www.novelos.com">www.novelos.com</a>	Approved in Russia
Myrcludex B	Blocks viral entry	Hepatera, Russia with Myr-GmbH, Germany	Pending	Phase IIa, Russia
ARC520	RNAi gene silencer	Arrowhead Research, Pasadena, CA	<a href="http://arrowheadresearch.com">arrowheadresearch.com</a>	Phase IIa
HAP Compound (Bay 41-4109)	Inhibits viral nucleocapsid	AiCuris, Germany	<a href="http://www.aicuris.com">www.aicuris.com</a>	Phase I
REP 9AC	HBsAg release inhibitor	REPLICor Inc., Montreal, Canada	<a href="http://www.replicor.com">www.replicor.com</a>	Phase I
Alinia (Nitazoxanide)	Small molecule	Romark Labs, Tampa, FL	<a href="http://www.romark.com">www.romark.com</a>	Preclinical
dd-RNAi compound	Gene silencing	Benitec, Australia, Biomics, China	<a href="http://www.Benitec.com">www.Benitec.com</a>	Preclinical
NVR-1221	Capsid inhibitor	Novira Therapeutics, Doylestown, PA	<a href="http://noviratherapeutics.com">noviratherapeutics.com</a>	Preclinical
IHVR-25	ccc-DNA inhibitor	Baruch S. Blumberg Institute, Doylestown, PA	<a href="http://www.blumberginstitute.org">www.blumberginstitute.org</a>	Preclinical
<b>NEW! TKM-HBV</b>	<b>HBsAg inhibition</b>	<b>Tekmira, Vancouver, Canada</b>	<b><a href="http://www.tekmira.com">www.tekmira.com</a></b>	<b>Preclinical</b>
<b>NON-INTERFERON IMMUNE ENHANCERS</b> Boost T-cell infection-fighting immune cells and natural interferon production				
Zadaxin (Thymosin alpha-1)	Immune stimulator	SciClone, San Mateo, CA	<a href="http://www.sciclone.com">www.sciclone.com</a>	Orphan drug approval in U.S. for liver cancer
CYT107 (Interleukin-7)	Immunomodulator	Cytheris, Paris, France	<a href="http://www.cytheris.com">www.cytheris.com</a>	Phase I/IIA
GS-4774	Therapeutic vaccine	Gilead Sciences with GlobImmune, Louisville, CO	<a href="http://www.gilead.com">www.gilead.com</a>	Phase II
DV-601	Therapeutic vaccine	Dynavax, Berkeley, CA	<a href="http://www.dynavax.com">www.dynavax.com</a>	Phase 1B
HBV Core Antigen Vaccine	Therapeutic HBV vaccine	Emergent Europe, UK	<a href="http://www.ebse.com">www.ebse.com</a>	Phase I
GS-9620	TLR-7 agonist	Gilead Sciences, Foster City, CA	<a href="http://www.gilead.com">www.gilead.com</a>	Phase I
<b>POST-EXPOSURE AND/OR POST-LIVER TRANSPLANT TREATMENT</b>				
HyperHEP B S/D	HBV immunoglobulin	Grifols, RTP, NC	<a href="http://www.grifolsusa.com">www.grifolsusa.com</a>	FDA Approved 1977
Nabi-HB	HBV immunoglobulin	Biotest, Boca Raton, FL	<a href="http://www.biotestpharma.com">www.biotestpharma.com</a>	FDA Approved 1999
Hepa Gam B	HBV immunoglobulin	Cangene, Ontario, Canada	<a href="http://www.cangene.com">www.cangene.com</a>	FDA Approved 2006

Thank you to **Timothy Block, PhD** (HBF President), **Nat Brown, MD** (Presidio), **Brent Korba, PhD** (Georgetown U) and **Raymond Schinazi, PhD** (Emory U and RFS Pharma) for their regular review of the HBF Drug Watch.

## For More Information...

- **HBV Clinical Trials** [hepb.org/clinicaltrials](http://hepb.org/clinicaltrials)
- **Resource Round-Up** [hepb.org/resources](http://hepb.org/resources)
- **HBV Info & Support List (adults)** [HBList.net](http://HBList.net)
- **HBV Adoption List (parents)** [groups.yahoo.com/group/hbv-adoption/info](http://groups.yahoo.com/group/hbv-adoption/info)

## Scientists “Shanghaied” to Annual International HBV Meeting

More than 500 scientists from around the world gathered in Shanghai for the 29<sup>th</sup> Annual International HBV Meeting in October 2013, making it the most successful one in history. This reflects the importance of hepatitis B in Asia, and the growing interest internationally.



**2013 International HBV Meeting held in Shanghai**  
L to R: Meeting co-chairs Dr. Shuping Tong, Brown U.; Dr. Zhenghong Yuan, Shanghai Med. College; and Dr. Ju-Tao Guo, Drexel U. and Blumberg Institute. (Oct. 2013)

Plenary speaker **Prof. Wenhui Li**, Chinese National Institute of Biological Sciences, generated a lot of excitement as he discussed identification of sodium taurocholate transporting peptide (NTCP) as the liver HBV “receptor.” The virus binds to this molecule to enter the liver cell. Its identification had eluded scientists for decades. The new knowledge is expected to advance basic science and antiviral drug discovery research.

A provocative report from **Dr. Dieter Glebe**, Justus-Liebig University, on isolating a hepadnavirus (closely related to HBV) from bats raised questions about HBV origins and transmission.

### HBV therapeutics-specific highlights:

- HBV replication may be dependent on autophagy, whereby the infected cell “self digests.” Another target for HBV antivirals? (Dr. Tian, USC, Los Angeles, CA).
- cccDNA can be formed in immortalized mice hepatocytes (Dr. Cui, Penn State U, Hershey, PA) and HBV cccDNA establishment is regulated by core protein (Dr. Fournier et al, INSERM, Lyon, France). Host (cellular) factors and DNA repair enzymes were also reported to regulate cccDNA (Dr. Koeniger et al, University Hospital, Freiburg, Germany).
- Rare cutting endonuclease such as Transcription Activator Like Effector proteins may be designed to attack cccDNA (Dr. Arbouthnot, U. Witwatersrand, Johannesburg, South Africa and Dr. Jerome, Fred Hutchinson Cancer Center, Seattle, WA).
- Might HBV core protein be immunosuppressive, even affecting interferon response genes? (Drs. Zoulim, Durantel, and Gruffaz, CRCL Lyon, France).
- Immuno-targeting using bi-specific antibody (Dr. Bohne, German Cancer Research Center, Heidelberg, Germany).
- Treatment of macrophages with STING agonists induced a robust cytokine response that efficiently suppresses HBV replication in hepatocytes (Dr. Chang, Drexel University, with Blumberg Institute scientists).

## Hep B United Rolls Out National Plan

Entering its 3<sup>rd</sup> year, the *Hep B United* national coalition – established by the Hepatitis B Foundation in partnership with the Association of Asian Pacific Community Health Organizations (AAPCHO) – is making huge strides to leverage the success of local hepatitis B coalitions across the country to increase awareness, screening, vaccination and linkage to care for high-risk populations. At the inaugural summit in August 2012 with its 18 community coalition members and federal partners, *Hep B United* developed the first national community plan to advance the key HBV priorities of the U.S. Health and Human Services Viral Hepatitis Action Plan.

The Hepatitis B Foundation received a timely boost to its resources in Oct. 2013 with a 3-year cooperative agreement from the Centers for Disease Control (CDC) to help *Hep B United* implement its national action plan.

Major components of the *Hep B United* plan are to build the infrastructure of the national coalition and provide technical assistance and training to its coalition members through **monthly conference calls and e-newsletters, training webinars, “Hep B Hangouts”** (live video chats), a **mini-grants** program to fund local coalition activities, and an **Annual Summit** to bring all of the partners together (May 21-23, 2014 in Washington, DC). With assistance from its federal partners, *Hep B United* aims to improve HBV screening and linkage to care nationwide. Visit [www.HepBUnited.org](http://www.HepBUnited.org) to learn more and join the coalition!



**Hep B United is an official partner of the CDC’s Know Hepatitis B campaign.**  
Front row L to R: Kate Moraras (HBF), Jeff Caballero (AAPCHO), Dr. Cynthia Jorgensen (CDC), Daniel Chen (HBF) and Chari Cohen (HBF), center in back row. (Dec. 2013)

## Kate Moraras Joins HBF to Lead *Hep B United*

**Ms. Moraras** joined the HBF in November 2013 as a senior program director to help lead *Hep B United* and work with the community and federal partners. She brings a wealth of knowledge and experience to the position. Most recently, Ms. Moraras served as senior advisor on Health Policy and Community Engagement at the White House Initiative on Asian Americans and Pacific Islanders. In addition, she served as a research fellow at the U.S. Office of Minority Health (OMH), and as an associate manager in government affairs and advocacy at the American Diabetes Association. Ms. Moraras received her BA degree in International Politics from George Mason U. and her Masters in Public Health from George Washington U.



## Dr. Robert Gish Joins Hepatitis B Foundation as New Medical Director



The HBF is proud to welcome **Robert G. Gish, MD**, as its new medical director. An internationally renowned medical researcher in the field of viral hepatitis, Dr. Gish has made invaluable contributions to the understanding and treatment of hepatitis B, the world's leading cause of liver cancer. A longtime supporter of the foundation's mission and a member of the Scientific Advisory Board for almost a decade, Dr. Gish's new role will further strengthen its research and advocacy efforts worldwide.

"Dr. Gish's background is a perfect fit for the work we do here at the Foundation and our Baruch S. Blumberg Institute," said **Dr. Timothy Block**, HBF president and professor of

Microbiology at Drexel University. "We are honored that Dr. Gish has agreed to become our medical director and look forward to many years of collaboration so we can finally put an end to this serious liver infection." Learn more about Dr. Robert Gish at his website: [www.rgishmdliverconsults.com](http://www.rgishmdliverconsults.com).



## Dr. Thomas Starzl Awarded 2014 Baruch S. Blumberg Prize

The Hepatitis B Foundation is proud to have presented its highest award, the *Baruch S. Blumberg Prize* to **Dr. Thomas Starzl**, the "father of transplantation," who performed the first successful human liver transplant in 1967. His pioneering work helped open up an entire new field of medicine and tens of thousands of lives have been saved as a result.

## HBF's Gala Blossoms into a Record Breaker!

The Hepatitis B Foundation's Crystal Ball, which took place on April 11, 2014, at the Warrington Country Club, Warrington, Pa., attracted hundreds of leaders from the community, academic institutions, and government, as well as healthcare and biotech company executives. This year's event, the "Cherry Blossom Extravaganza," raised a record-breaking \$102,000 to help support the Foundation's mission of finding a cure and improving the lives of those affected by hepatitis B.



**Joel Rozen**, HBF board chairman, and **Peggy Farley**, HBF associate director (far right), presented the 2014 *Community Commitment Award* to **Teri and Jim Holton** (left) for their generous sharing of time and resources to nonprofit organizations, including the HBF.

**Thomas Starzl, MD, PhD**, was the 2014 recipient of the *Baruch S. Blumberg Prize*, the HBF's highest scientific honor, for his pioneering work in creating a new field of medicine – organ transplantation, especially of the liver. **Dr. Timothy Block**, HBF president, noted, "Tonight we honor a giant, a living legend. Liver transplantation saves many thousands of lives each year in the U.S. and [around] the world. This is all due to the vision and persistence of Dr. Starzl, whose contributions continue to inspire all of us as we push toward the discovery of a cure."

**Dr. Thomas Starzl** (center), recipient of the 2014 *Baruch S. Blumberg Prize*, is congratulated by **Mrs. Jean Blumberg** (left), wife of the late Dr. Blumberg, and HBF president, **Dr. Timothy Block** (right). (April 11, 2014)



In his acceptance speech, Dr. Starzl remarked, "If we had known then what we know now, we would never have attempted to pursue the concept of liver transplantation... because we would have thought it would be too complicated." He graciously thanked all the attending guests for their support of the Hepatitis B Foundation, "which is doing invaluable work to eliminate a terrible disease."

**U.S. Senator Bob Casey** sent his personal congratulations to Dr. Starzl, noting in his letter, "My father, Governor Robert P. Casey, suffered from a liver-based disorder and Dr. Starzl predicted that a liver transplant would halt progression of his disease. In 1993 [he] underwent a successful combined liver and heart transplant at the University of Pittsburgh. After surgery, my father was able to return to work and enacted important transplant legislation that Dr. Starzl consulted on."

The Foundation thanks presenting sponsor, Uninvest, platinum sponsors Gilead Sciences and SigmaPharm, and emerald sponsors Allure West, deArt Folio, Bugajewski Facility Services, OnCore Biopharma, Furia Rubel, High Swartz LLP, and University of Pittsburgh Medical Center, with media sponsor Bucks County Herald.



**Jeffrey Schweitzer**, president of Uninvest, the presenting sponsor of the Crystal Ball.



## Liver Cancer Killed My 15-Year-Old Sister

**My life as a parent started in 1994 when my eight-year-old sister Adrienne visited me for Christmas.**

Adrienne's two-week vacation became permanent when our mother told me she was ill, tired and no longer capable of being a mother. At 22-years-old, I had little money or job stability, but it never occurred to me to say no.

The initial years were challenging for both of us, as we struggled to define our new relationship. The rules were that I was her parent first, then her sister and eventually her friend.

I had high expectations of Adrienne, and she always exceeded them. She maintained a 4.0 GPA during her first year at Burbank High School and participated in the Gifted and Talented program. Aside from her educational achievements, she was a talented artist. Three galleries displayed her artwork in Los Angeles.

On May 16, 2001, I discovered Adrienne curled up in fetal position and saying she couldn't breathe. Six hours later, our lives changed forever when an ER doctor said, "She has tumors in her liver and lungs."

Tests revealed that Adrienne had hepatitis B and hepatitis C, which the doctors determined she had acquired from our mother during childbirth. A biopsy confirmed that Adrienne had hepatocellular carcinoma (HCC), also known as primary liver cancer. When I told her the news, Adrienne asked, "What's next, chemo? Hey, I'm not going to die."

Throughout the summer, Adrienne endured four rounds of chemotherapy — without an ounce of self-pity. Her spirit was infectious. She was determined to make the most of her situation. When her blood counts were up, we did everything she had ever wanted to do: meet her favorite musician on *The Tonight Show*, attend her first ballet, eat our first set of crab legs, and walk through the mall searching for the perfect dress for her Make-a-Wish day.

By October, her health quickly deteriorated. She slurred her speech and lost track of time. Her brain was not getting enough

oxygen because the tumors in her lungs grew larger every day. Though she could not see the yellow in her eyes, I could. She had developed jaundice; her liver was dying.

Within days, Adrienne died at home in her own bed surrounded by people who loved her. Her last words were, "I love you, Sissy."

I could not save Adrienne from liver cancer, but I have made it my mission to tell her story and to help others suffering from this devastating disease.

I founded *Blue Faery: the Adrienne Wilson Liver Cancer Association* to help prevent, treat and cure primary liver cancer, specifically HCC, through research, education and advocacy. We are the only nonprofit in the United States solely devoted to fighting liver cancer.

In 2003, we created our liver cancer patient education brochure, the first of its kind, which we distribute free to patients, families and healthcare providers. We have also developed research and advocacy programs for doctors and patients, respectively.

In November 2013, Blue Faery participated in the Liver Cancer Roundtable — the first ever national discussion about liver cancer. Organized by the Caring Ambassadors Program in collaboration with the Hepatitis B Foundation, the Liver Cancer Roundtable brought together leading experts in liver cancer, including doctors, government agencies, pharmaceutical representatives and advocacy groups to create a liver cancer action plan.

In January 2014, I lobbied with other groups on Capitol Hill for the Viral Hepatitis Testing Act. This bill changes the Public Health Service Act "to revise and extend the program for viral hepatitis surveillance, education and testing to prevent deaths from chronic liver diseases and liver cancer."

With our numerous partners, Blue Faery will continue to advocate for families facing HCC. Together we can fight and win the war against liver cancer. [For more information, please visit www.bluefaery.org.](http://www.bluefaery.org)



Giving hope to millions is as easy as giving ... and we've made it easier.

Make a secure donation online at [www.hepb.org](http://www.hepb.org)

### YES! I want to support the Hepatitis B Foundation with a tax-deductible gift.

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Please make check payable to: **Hepatitis B Foundation**

Use remittance envelope or mail to: **3805 Old Easton Road, Doylestown, PA 18902 USA**

Donations will be acknowledged in our Annual Report unless otherwise requested.

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



## HEPATITIS B FOUNDATION

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## Liver Cancer Moves Up to 2nd Deadliest Cancer in the World



Liver cancer moved up from being the world's third to the second leading cause of cancer deaths, according to the 2014 World Cancer Report released by the World Health Organization (WHO).

The World Report emphasizes the need for urgent implementation of efficient prevention strategies to curb the disease, because treatments alone cannot solve the problem of cancer.

"The rise of cancer worldwide is a major obstacle to human development and well-being. These new figures and projections send a strong signal that immediate action is needed to confront this human disaster, which touches every community worldwide, without exception," declared **Dr. Christopher Wild**, director of WHO's special agency on cancer. He urged governments to implement prevention and early detection strategies to complement improved treatments because "[they] are an investment rather than a cost."

The Report specifically recommends the greater implementation of preventive measures, including greater use of the hepatitis B vaccine (the world's first anti-cancer vaccine) to reduce the incidence of liver cancer. For more information on the 2014 WHO Report, visit [www.iarc.fr/en/media-centre/pr/2014/pdfs/pr224\\_E.pdf](http://www.iarc.fr/en/media-centre/pr/2014/pdfs/pr224_E.pdf).

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Presented by the Hepatitis B Foundation



B Informed and all back issues are available online at [www.hepb.org/newsletters](http://www.hepb.org/newsletters)

## Calendar of Events 2014

**May 19, 2014**

### National Hepatitis Testing Day

Centers for Disease Control and Prevention  
Testing events across the U.S.  
[www.cdc.gov/hepatitis](http://www.cdc.gov/hepatitis)  
[www.HepBUnited.org](http://www.HepBUnited.org)

**May 21-23, 2014**

### 2<sup>nd</sup> Annual Hep B United Summit

Hepatitis B Foundation and AAPCHO  
Four Points Sheraton, Washington, DC  
[www.HepBUnited.org](http://www.HepBUnited.org)

**June 3-7, 2014**

### International Workshop on Antiviral Drug Resistance

Special Hepatitis Forum!  
Grand Hyatt, Berlin, Germany  
[www.informedhorizons.com/resistance2014](http://www.informedhorizons.com/resistance2014)

**June 26, 2014**

### HBF's Distinguished Bruce Witte Lecturer

Dr. Charles Rice, Rockefeller U  
Hepatitis B Foundation and  
Baruch S. Blumberg Institute  
[www.hepb.org](http://www.hepb.org)

**July 28, 2014**

### World Hepatitis Day 2014

World Hepatitis Alliance with WHO  
Events scheduled around the world  
[www.worldhepatitisalliance.org](http://www.worldhepatitisalliance.org)

**September 3-6, 2014**

### International HBV Meeting 2014

Coordinated by Hepatitis B Foundation  
University of California, Los Angeles, CA  
[www.HBVmeeting.org](http://www.HBVmeeting.org)

**September 15-17, 2014**

### 1<sup>st</sup> International Indigenous Liver Health Meeting

Australian Society for HIV Medicine  
with Hepatitis B Foundation  
Alice Springs, Australia  
[www.hepatitis.org.au](http://www.hepatitis.org.au)

**October 10-11, 2014**

### 2<sup>nd</sup> International Conference on Occult Hepatitis B Infection

Co-organizers: Profs. Chengyao Li and  
Yongshui Fu with Prof. Jean-Pierre Allain  
Guangzhou, PR China  
[www.obi-gzmeeting.com](http://www.obi-gzmeeting.com)

**November 7-11, 2014**

### The Liver Meeting 2014

American Association for the Study of  
Liver Diseases (AASLD)  
Hynes Convention Center, Boston, MA  
[www.aasld.org](http://www.aasld.org)