

## Mei-Li's Story: Empowering Hep B Positive Moms in China Through Mobile Messaging

China



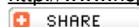
Chari Cohen

**Organization type:**

nonprofit/ngo/citizen sector

**Budget:**

\$500,000 - \$1 million

**Website:**<http://www.hepb.org> SHARE

- [Health care](#)
- [Health education](#)
- [Maternal health](#)
- [Information & communication technology](#)
- [Women's issues](#)
- [Wellness](#)

### Project Summary

#### Elevator Pitch

**Concise Summary: Help us pitch this solution! Provide an explanation within 3-4 short sentences.**

Through mobile messaging and interactive storytelling, we will educate women in China who are diagnosed with hepatitis B about their disease; provide positive messages to encourage women to share their concerns with others; and empower women to seek appropriate medical care to ensure they can enjoy long, healthy lives.

#### About Project

**Problem: What problem is this project trying to address?**

Like Mei-Li, two billion people (1 in 3) have been infected with HBV worldwide and one million die each year from cirrhosis and liver cancer. Hepatitis B is the 10th leading cause of death and is second to tobacco as the deadliest known carcinogen. In China, more than 100 million people suffer from chronic HBV infections and it continues to be a highly stigmatized disease. Infected individuals find it difficult to marry, enter school, or find a job. This stigma can be especially devastating for pregnant women, which has led to many being isolated from their families and discriminated against in the community; being forced to deliver their babies in an "Infectious Disease" hospital which forever stigmatizes their child; and being unmotivated to seek appropriate care for their disease. As a result of this lack of accurate information and emotional support, infected women are at high-risk for progressing to serious health outcomes such as cirrhosis or liver cancer.

**Solution: What is the proposed solution? Please be specific!**

"Need info about HBV? Text 1 for yes or 2 for no." Our Mobile Messaging project utilizes low-cost telephone technology to address a serious disease threat among vulnerable pregnant women in China. Mei-Li was 25 years old when she was diagnosed with a hepatitis B virus (HBV) infection. She was devastated, but didn't know where to turn for information and support. In fact, when she told her husband, he was angry and took their baby to his mother's home. There is no happy ending to this story since Mei-Li is now divorced and lives apart from her child. Sadly, Mei-Li's story is a common one in China where HBV is greatly misunderstood. Those who have it are stigmatized, and often banned from school and employment. Many women choose to hide their diagnosis from their family, and not see a doctor about their infection, which can silently destroy their liver. We will design a one-year mobile messaging campaign that will enroll one-thousand pregnant women in Haimen City, China, who have been diagnosed with hepatitis B infections during their prenatal care. HBV-infected pregnant women are often reluctant to seek appropriate care for this chronic liver infection due to lack of knowledge, fear of stigmatization and discrimination, and lack of support from families and providers. Through the appealing art of storytelling, we will develop an interactive platform to engage women in a non-threatening and supportive manner to educate them about hepatitis B, dispel common myths to reduce stigma and feelings of shame, and encourage them to speak openly with others about their diagnosis. By developing creative narratives that highlight potential knowledge deficits, societal challenges, and importance of regular medical care, our goal is that infected pregnant women in China will be empowered by accurate information and positive messages to seek the care they need to enjoy long and healthy lives with their loved ones.

### Impact: How does it Work

**Example: Walk us through a specific example(s) of how this solution makes a difference; include its primary activities.**

In 1992, our researchers began to study hepatitis B infection in Haimen City, to help reduce the overwhelmingly high hepatitis B infection and related death rate. Since that time, our public health team has been involved in intensive follow-up of 90,000 people. Findings from the study have had a significant clinical impact in the management and treatment of HBV patients worldwide. Today, our researchers still have an important presence in Haimen City, including direct access to over 13,000 infected individuals; and successful partnerships with the Haimen City Centers for Disease Control and Prevention, the Haimen City Center for the Health of Women and Children (HWC), 31 hospitals, and 23 health service centers. The Hepatitis B Foundation (HBF) was established in 1991 to find a cure and improve the lives of those affected worldwide through research, education and patient advocacy. Dr. Baruch Blumberg, who won the Nobel Prize in Medicine for his discovery of the hepatitis B virus (HBV), is one of the co-founders and continues to be actively involved in our work. Our world-class research institute has one of the largest concentrations of HBV scientists who have discovered a new class of compounds that show promise against HBV and serum biomarkers for the early detection of liver cancer, which is one of the deadliest outcomes of HBV. Our outreach program directly touches millions of lives through our website that get more than one million visitors from 180 countries each year, our phone and email helplines, and free patient workshops. Our public health group conducts research-based programs in the U.S. and Haimen City, China to document disease burden and identify barriers to care. Our advocacy program resulted in the first Institute of Medicine report on Hepatitis and Liver Cancer; introduction of the first Hepatitis and Liver Cancer Bill in Congress; recognition of National Hepatitis B Awareness Week in May; and an increase of federal hepatitis funding.

#### About You

**Organization:**

Hepatitis B Foundation

**Section 1: You****First Name**

Chari

**Last Name**

Cohen

**Email**

[Chari.Cohen@hepb.org](mailto:Chari.Cohen@hepb.org)

**Website URL**

<http://www.hepb.org>

**Organization**

Hepatitis B Foundation

**Country**

, PA, Bucks County

**Section 2: Your Organization****Organization Name**

Hepatitis B Foundation

**Organization Phone**

215-489-4900

**Organization Address**

3805 Old Easton Road Doylestown, PA 18902

**Organization Country**

, PA, Bucks County

#### Your idea

**Country and state your work focuses on**

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**Website URL**

<http://www.hepb.org>

#### Innovation

**Do you have a patent for this idea?**

#### Impact

**Actions**

Our project is built on a solid foundation of working in Haimen City, China for over 15 years with the city's public health, government officials and

community leaders. In August 2010, we received a 3-year grant to conduct a comprehensive public education program in Haimen City; we are now uniquely prepared to incorporate a Mobile Messaging project into our current activities. We can create a culturally and linguistically competent project that will use low-cost telephone technology to build on the popular use of text messaging to improve hepatitis B knowledge, reduce stigma, and empower women to seek the medical care they need. Additionally, we are working with KruResearch, a company with expertise in the development of innovative, technology-leveraged health education solutions. KruResearch will assist in the intervention design and development of the mobile technology platform that will support our project. Together, we will develop an interactive messaging and storytelling platform to empower HBV-infected pregnant women. The project will include an evaluation to identify and address barriers in a timely manner, and analyze project outcomes for possible future expansion.

## Results

Our project will help create a community of informed and empowered women living with HBV who will seek the care they need for healthy outcomes. From this project, we expect to see among the infected women an increased knowledge about hepatitis B, reduced feelings of shame or anxiety, enhanced social support, and increased follow-up rates for disease management. These results will be measured by pre- and post-surveys of disease knowledge, feelings of shame or anxiety about an HBV diagnosis, and self-reports of improved emotional support in women's social networks. The number of follow-up visits of this target group will also be measured as an outcome of increased empowerment. Ultimately, this will lead to improved health outcomes for both mothers and their babies. Through evaluation of the mobile technology platform, we will measure the results of the messaging campaign through feedback from the moms (i.e. satisfaction) and quantifiable response rates. Evaluation data will be used to determine the future usability of this type of technology to improve health and foster empowerment in vulnerable populations.

## What will it take for your project to be successful over the next three years? Please address each year separately, if possible.

In year 1, we will work with the Haimen City CDC, Center for the Health of Women and Children, and birthing hospitals to develop a culturally competent messaging and storytelling campaign, and recruit up to 1,000 HBV-infected pregnant women. Information about women's knowledge and feelings about HBV, as well as their current support networks will be surveyed. We will develop our technology platform with KruResearch and recruit at least one cell phone company in China to provide free or reduced cost mobile messaging for our project.

In year 2, we will kick-off our mobile messaging campaign with our partners and engage enrolled women with messages that are relevant to their stage of pregnancy. Feedback will be solicited on a regular basis from participating women so we can refine messages and stories as necessary. Data will be collected to measure response rates to each message or story for evaluation purposes (and to make adjustments if needed). Efforts will be made to retain as many pregnant women as possible throughout the campaign.

In year 3, we will complete the campaign and focus on project evaluation. This will include analyzing data from pre- and post-surveys and analyzing feedback from the mobile messaging campaign to assess how user-friendly the health messaging was and whether participants felt the campaign made a difference in their lives. We will specifically measure their disease knowledge, degree of social support received, comfort level in discussing their infection with others, feelings of stigma and/or isolation, and medical care-seeking behaviors. Final evaluation will include a comparison with non-participating women, with the expectation that women who participated in the mobile messaging campaign will have improved knowledge, social support and care-seeking behaviors. A final report will be prepared with our Haimen City partners and disseminated widely through peer-reviewed publications and professional presentations in China and the U.S.

## What would prevent your project from being a success?

The primary barriers to achieving success in our project include platform development challenges associated with mobile messaging since this is a relatively new technology; lack of cooperation of cell phone companies in China to provide free or reduced cost messaging services for the project participants; and difficulty in enrolling women to participate in this project. Although we do not anticipate that these will be significant obstacles to establishing this program, any problem in one of these key areas would cause a delay in launching the campaign.

## How many people will your project serve annually?

1001-10,000

## What is the average monthly household income in your target community, in US Dollars?

Less than \$50

## Does your project seek to have an impact on public policy?

Yes

## Sustainability

### What stage is your project in?

Idea phase

### In what country?

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### Is your initiative connected to an established organization?

Yes

### If yes, provide organization name.

Hepatitis B Foundation

### How long has this organization been operating?

More than 5 years

### Does your organization have a Board of Directors or an Advisory Board?

Yes

**Does your organization have any non-monetary partnerships with NGOs?**

No

**Does your organization have any non-monetary partnerships with businesses?**

No

**Does your organization have any non-monetary partnerships with government?**

No

**Please tell us more about how these partnerships are critical to the success of your innovation.**

Our proposed project in Haimen City, China is possible because we have developed strong partnerships with the Haimen City CDC and Center for the Health of Women and Children and earned the trust and approval of government officials which is essential to conducting any business in China. Additionally, since we are already conducting a 3-year outreach and education project in Haimen City, our partners will willingly work with us to develop culturally and linguistically competent health messages and appropriate storylines so they will be understood and readily accepted by our target audience. We will also rely on the expertise of KruResearch to develop our technology platform for this project. They will utilize the Frontline SMS platform and Clickatell SMS gateway to both manage and deliver the bulk text messages. With the assistance of KruResearch and our Haimen City partners, we hope to recruit at least one phone company in China to offer free or reduced cost for the campaign's mobile messaging so that the budget for this project does not become burdensome. Without this partnership the cost per text message is between .01 and .10 (US dollars).

**What are the three most important actions needed to grow your initiative or organization?**

To ensure that our project is successful in China we will need to first nurture existing relationships with our Haimen City partners and maintain the support of government officials, who must approve any program in the city. Second, it is important that we generate positive interest and enrollment from our target audience (HBV-infected pregnant women in Haimen City). This step is important to the intervention phase of our project and will involve working with our Haimen City partners to create and promote a campaign that is appealing to pregnant women and the many townships clinics and providers that serve this population. Finally, to enhance success and sustainability of our project, we will develop a plan to secure additional funding from private and public sector sources, as well as seek corporate sponsorships to help support this innovative project.

The Story

**What was the defining moment that led you to this innovation?**

Year after year, we receives emails and phone calls from people infected by hepatitis B, who are desparate for information and support. They cant tell their families for fear of being shunned, they might lose their jobs, they are isolated and alone with nowhere else to turn. The saddest of these stories are told by the pregnant women in China, who know that because they are infected with hepatitis B, they will be treated differently, as if they are shameful and tainted. They will give birth in designated hospitals for infected women, and their children will bear a red mark on their birth certificate that will affect their school entry. When Mei-Li came to visit us from China in 2010, she brought with her dozens of cards and letters from infected women asking us to please help them find a way to live with this infection and still remain active members of society, without shame. When Mei-Li shared her story, and told us that she was living separately from her toddler son, we knew that we had to help. This program stems directly out of that first visit, where we were surrounded by beautiful hand-made cards containings please for help, as a bright. That day, a caring young woman told us how devastated her life had become because of this virus, and people's reaction to it. It is time to act, for Mei-Li and the millions of other people in the world who feel the stigma of hepatitis B infection.

**Tell us about the social innovator behind this idea.**

My name is Chari Cohen, and I was working with the Hepatitis B Foundation for two years when my husband's mother was diagnosed with viral hepatitis and liver cancer. Finally, it all hit home to me. I had worked closely with people who had lost loved ones to this devastating disease, but I never dreamed it would personally affect my family. We faced a host of physicians, some knowledgeable about hepatitis, some not. There were scary appointments and technical medical terms. There were treatments that costed thousands of dollars each month. And, there were people who no longer visited with us because Mom had hepatitis. This was perhaps the most difficult part of all.

After a long and difficult illness, my beloved second mother died. I knew then that for as long as I could, I would dedicate my time to helping those with hepatitis. I want to make sure that they get the medical care that they need for their bodies, the support they need for their minds and hearts, and the unaffected, un-stigmatized love they need from their families and communities.

I am currently the Associate Director of Public Health for the Hepatitis B Foundation, in Doylestown, PA. I work with an incredible team of public health and medical researchers, community partners, and patients, to plan, implement and evaluate public health interventions and research projects. My specific research areas focuse on developing a community-based model to reduce barriers faced by chronically infected individuals in high-risk areas of the world, developing best practices for eliminating perinatal hepatitis B (mother to child transmission), and finding methods of preventing liver cancer. I am an executive member of the National Task Force on Hepatitis B: Focus on Asians and Pacific Islanders since 2005, and am actively involved in national advocacy efforts. I work with organizations around the U.S., and in China, to help them become HBV advocates and learn how to implement HBV-related projects using best practices. I received my Masters of Public Health from Temple University in 2001, and am currently enrolled in the Doctoral program at Drexel University School of Public Health, in Philadelphia. I am passionate about improving the health of HBV-infected and high-risk groups, and I truly believe that this project has the potential to make a grand, positive difference in the lives of millions of infected pregnant women.

**How did you first hear about Changemakers?**

Through another organization or company

**If through another, please provide the name of the organization or company**

KruResearch, Inc., <http://kruresearch.com/>

