

Liver Cancer: Prevalence, Risk Factors and Strategies for Prevention and Treatment

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12:00 PM to 1:00 PM

Rayburn House Office Building, Room 2044

Patient Perspective Remarks:

Phil Shin, Board Member, American Liver Foundation

Good morning. My name is Phil, and I am a national board member of the American Liver Foundation. But I am here today not as a medical expert or policy analyst, but as someone who should not be alive. I am someone who represents both the devastating toll and the preventable tragedy of hepatitis B-related liver cancer in Asian American communities.

In 2018, I was diagnosed with liver cancer. I was seven years younger than I am here before you today, a husband and a father, running marathons, and at what I thought was the peak of my health. I was blindsided. The cancer was caused by chronic hepatitis B—a virus my mother unknowingly passed to me at birth. My mother, Young Ja Shin, immigrated to this country from Korea in 1969, long before routine hepatitis B screening existed. She didn't know she had hepatitis B. She had no symptoms, no reason to think anything was wrong. Neither did I—until cancer appeared decades later. My brother and sister also contracted hepatitis B from my mother at birth.

When we were born, the hepatitis B vaccine didn't exist. We had no protection. This is the silent tragedy of mother-to-child transmission. Without intervention, infants born to infected mothers have up to a 90% chance of developing chronic infection. My siblings and I represent a generation that had no choice—we were born before the tools existed to prevent this. My mother had to carry the unbearable burden of unknowingly passing this virus to all three of her children. I had to endure two cancer surgeries and a liver transplant.

But today's children don't have to share our fate. Since 1991, the birth dose of the hepatitis B vaccine has changed everything—nearly eliminating mother-to-child transmission when given within 24 hours of birth. This is not an unusual story in Asian American families. It is, in fact, the story of hundreds of thousands of us who came before this medical breakthrough.

I had surgery to remove a very large tumor from my liver. Then just five months later, the cancer returned. My only chance at survival was a liver transplant. In September 2019, my friend Mark made an extraordinary sacrifice—he underwent major surgery to donate 60% of his healthy liver to save my life. He chose to endure pain, risk, and a permanent change to his own body so that I could live. That is the profound gift of living organ donation.

Let me share with you why this matters to all of us.

Asian Americans comprise only 6 to 7 percent of the U.S. population, yet we account for 58 percent of all chronic hepatitis B infections in this country. One in ten Asian Americans—that's approximately one million people—is living with chronic hepatitis B. The consequences are deadly. Asian Americans are nearly eight times more likely to die from hepatitis B than non-Hispanic whites. More than 75 percent of liver cancers are attributed to hepatitis B infections. Vietnamese Americans have a liver cancer rate 11 times higher than white Americans.

Yet one in three Asian Americans with hepatitis B doesn't know they're infected.

And now we face a new threat to progress. The Centers for Disease Control and Prevention has ended the highly effective universal hepatitis B birth dose recommendation that has been in place since 1991. The universal birth dose reduced infant hepatitis B infections by 95%. A CDC analysis found that childhood hepatitis B vaccinations prevented over 6 million infections and nearly 1 million hospitalizations in less than 30 years. We are deeply concerned that this policy reversal will undo decades of progress.

My fellow speakers today—the medical experts and patient advocates joining me—will share evidence-based strategies for prevention and treatment, and legislative solutions to improve access to care for marginalized communities like my own.

When I stand before you today, I carry not just my own story but the stories of thousands who didn't survive, who developed liver cancer in their 20s and 30s, who never knew they were at risk until it was too late. As a national board member of the American Liver Foundation, I also carry the collective voice of patients, families, and healthcare providers across this country who are fighting every day to change these outcomes.

Mark's extraordinary sacrifice gave me a second chance at life. Today, I continue to run marathons and ultra marathons. I've run the Boston Marathon four times—all with the American Liver Foundation charity team, helping raise millions of dollars to support our mission. And in 2022, Mark and I ran the Boston Marathon together. It was his first marathon. There we were, sharing that revered course from Hopkinton to Boston—the man who gave me part of his liver and the person whose life he saved, both running 26.2 miles on one of the world's most celebrated courses.

Running and surviving cancer are intertwined journeys of hope. Both require you to believe you can finish even when your body screams to stop. Both demand that you take it one step at a time. Both teach you that setbacks are not failures—they're just part of the course. I run for those who can't. I run to show what's possible. I run to keep going.

But here's the truth: Mark's heroic sacrifice should never have been necessary. We can spare future Marks from having to make that impossible decision. We can prevent mothers from unknowingly passing this virus to their children. We can stop young people from developing liver cancer in their prime. We have the tools. We have the knowledge. What we need now is the will to implement solutions at scale.

This is not just a liver cancer issue. This is not just an Asian American issue. This is about health equity. This is about children who should never inherit a preventable disease. This is about families who should never have to watch their loved ones die from something we knew how to stop.

Thank you for your time, and thank you for the opportunity to turn my survival into advocacy for those who come after me.

So together, we can keep going.