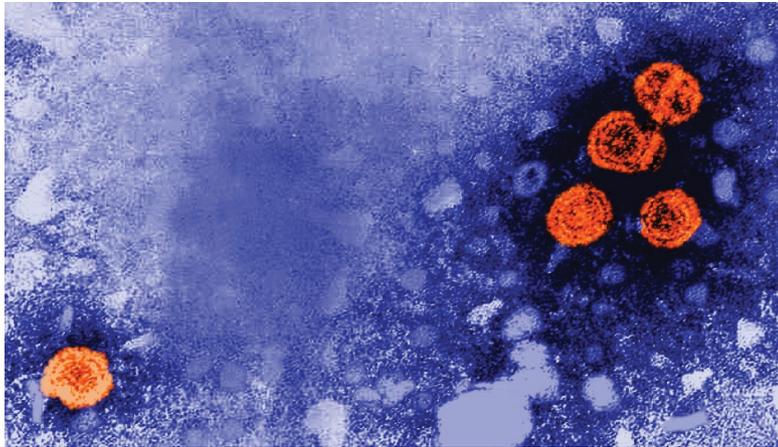


The Public Health Crisis with Liver Disease Affects Everyone



BY DONNA R. CRYER, JD, OPINION CONTRIBUTOR

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Dr. Erskine Palmer/CDC via AP

This electron microscope image made available by the U.S. Centers for Disease Control and Prevention shows hepatitis B virus particles, indicated in orange, or Dane particles. On Nov. 3, 2021, a government advisory committee recommended that all U.S. adults younger than 60 be vaccinated against hepatitis B, because progress against the liver-damaging disease has stalled.

The recent worldwide **outbreak** of acute, severe hepatitis in young children across **16** countries prompted the World Health Organization to begin an investigation of its origin. Globally, up to 14 percent of the 450 children recently diagnosed from ages 1 month to 16 years old have required liver transplants.

In the U.S., following the issuance of a nationwide alert, the Centers for Disease Control and Prevention (CDC) is **investigating** 109 cases of children in 25 states treated for liver injury and liver failure, including five deaths and 15 liver transplants.

The outbreak serves as a stark reminder of the common misconception that children do not get liver disease. This misconception clearly can be deadly. In the U.S. each year, around **15,000** children are hospitalized with over 100 types of liver disease. An estimated **5 percent to 10 percent of children** in the U.S. have nonalcoholic fatty liver disease (NAFLD). **Up to half** of those children have the more severe version of this disease — nonalcoholic steatohepatitis (NASH) — in which the buildup of fat leads to liver damage.

This prevalence has **steadily risen** over the past three decades. Many rare liver diseases are inherited genetically, but these diseases are so rare and receive so little research attention that the data are affected does not exist about how many children. Because of the integral role that the liver plays in the body, liver failure can require a liver transplant to save the child's life — as has been the case for several of the children affected by the recent outbreak.

Today, more than **1.5 billion** people across the globe have chronic liver disease, which causes more than **2 million deaths** each year.

No country or population is exempt. Globally, liver transplantation is the **second-most** common organ transplantation, yet **less than 10 percent** of total organ transplantation needs are met.

The tragic reality is that liver conditions are stigmatized, under-diagnosed, misdiagnosed, untreated and misunderstood. The result is high morbidity rates that could have been prevented. Clearly, many aspects of the story told about liver health need to be changed. Everyone — including children — is at risk for liver disease because everyone has a liver.

Autoimmune disorders can lead to liver disease, particularly in infants and children. Viruses, environmental toxins, and other factors can cause liver disease. The built environment and community access to nutritious food can contribute to liver disease. Still, many see liver disease as a consequence of deliberate choice.



Opinion > Healthcare



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I know this first-hand because the roots of my own liver disease started when I was diagnosed with inflammatory bowel disease at age 13. This progressed into an autoimmune liver disease called primary sclerosing cholangitis, or PSC. At 24, I was told I had only days to live, but my lifesaving liver transplant gave me the second chance that not every child will receive.

I launched **Global Liver Institute** in 2014 with the hope that no one else has to go through the same arduous process of diagnosis and care for liver disease as I did. As president and CEO of the organization, I work with foundations and institutional partners worldwide to improve awareness, education, research, clinical care pathways and policies that impact liver health.

Globally, **up to 90 percent** of liver disease is driven by preventable causes, yet chronic liver damage has risen to the **11th leading cause** of death. Transformation of liver health falls staunchly in the realm of public health, which focuses on this necessary prevention.

The world must prioritize liver health as a public health issue. That is why I launched the global **Liver Health is Public Health** campaign this year. Liver health is tied closely to food policy, to vaccination access, to the built environment, to air quality, and to much more; as a result, it is time to activate the robust array of public health tools.

Public health measures such as surveillance networks will allow experts to evaluate patterns in liver health —

such as the current outbreak — and respond accordingly. Measures such as screening standards will help providers identify liver disease in its earliest stages so that patients have a chance to regain their health. Measures at the systems level, such as health promotion campaigns and urban design, will create communities of people who know how to take care of their livers and have the tools necessary to do so.

In everything from global and federal policies to funding and attention within health systems, the possibility for positive change is enormous. The trajectories of liver disease for millions around the world can — and must — be altered for the better. To start, people need to believe that liver disease is an issue deserving investment of significant time and resources.

This public health crisis of widespread, unacknowledged liver disease affects me and the millions like me whose lives are affected by liver disease, as well as our loved ones and colleagues. It is time to change the story.

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RARE Champions of Hope Founder’s Award and the 2021 American Association for the Study of The Liver Distinguished Advocacy Service Award. She serves on the boards of directors of the Council of Medical Specialty Societies, Sibley Memorial Hospital/Johns Hopkins Medicine, the Innovation and Value Initiative and the Clinical Trials Transformations Initiative.

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