Connecting Liver Patients, Caregivers and Providers With Policymakers

Global Liver Institute announces Liver Action Network to unify and elevate advocates across the United States.

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Global Liver Institute (GLI) today formally announced its Liver Action Network, a national U.S. initiative to connect liver patients, caregivers, and providers with policymakers on urgent policy changes to improve the liver patient experience. The GLI Liver Action Network will provide technical support to liver health community organizations around the country, building grass roots capacity for patient advocates and advocacy groups to shape liver health policy at the federal, state, and local levels from health systems to insurance companies to Congress.

“Devastating and deadly liver diseases are prevalent and rising across the country, and yet we still struggle to get the attention from policymakers that the liver patients and their families deserve,” said Donna R. Cryer, JD, president and CEO of GLI and a 26-year liver transplant recipient. “That has to change. Everyone has a liver, and everyone, from infants to seniors, is at risk for developing one or more types of liver disease. Millions of people are already living with some form, whether fatty liver disease or damage from hepatitis or an inherited condition, most undiagnosed.

“Liver health policy is public health policy, but far too few policymakers see that. Advocates must be better organized, better equipped, and simply louder to communicate the impact of liver health on everything from military service to going to school to getting a COVID-19 vaccine. Forging a more effective liver health advocacy community is the goal of the GLI Liver Action Network.”

The GLI Liver Action Network gives advocates channels to use their voices and insights from lived experiences to advance liver health policy on behalf of all people at risk for or living with liver conditions. Advocates may participate individually or through state or community organizations. The Liver Action Network includes graduates from the GLI Advanced Advocacy Academy (A3) from more than 39 states and four community organizations serving a majority of the country—the Liver Coalition of San Diego, the Liver Wellness Foundation, the Midsouth Liver Alliance, and the Texas Liver Foundation—covering nine states: California, Washington, Oregon, Nevada, Hawaii, Texas, Tennessee, Mississippi, and Alabama.

The Advanced Advocacy Academy (A3) is an annual week-long educational program that equips patients to advocate for liver health policies across the health care ecosystem, building skills and

knowledge in areas such as storytelling and social media, research, drug and device development, regulatory policy, value and reimbursement, and legislative advocacy. The Liver Health Policy Update, an e-newsletter to patients and advocates nationwide, contains updates on pressing policy developments and opportunities for public comment and government committee service. In convening patients nationwide from across the spectrum of liver health, the Liver Action Network will expand the reach of GLI work in cancer, NASH (nonalcoholic steatohepatitis, the advanced form of fatty liver disease), pediatric and rare diseases, and transplants.

The Liver Action Network identifies timely policy priorities and provides easy-to-use tools for advocates to communicate to members of Congress on why those policy priorities will make a difference for patients. Current policy action items include asking Congress to support the Medical Nutrition Equity Act, ensuring access to specialized foods and vitamins necessary for the treatment of children and adults with rare liver diseases, and the Treat and Reduce Obesity Act to expand Medicare coverage of obesity treatment and screening. Obesity is linked to a variety of liver diseases.

Even before its formal announcement, the Liver Action Network successfully influenced policy. The Liver Action Network helped to persuade members of Congress to sign a bipartisan letter to the U.S. Department of Health and Human Services requesting more accountability in the organ procurement organization system. In November 2020, the agency finalized a rule favoring the advocates' position.

Earlier this month, a key congressional subcommittee convened a bipartisan hearing on the problems in the system. The scrutiny prompted six organ procurement groups to leave their trade association, which fought reforms. Key to the effectiveness of the subcommittee oversight was powerful testimony from GLI's Cryer and LaQuayia Goldring, advocates who draw on their own transplant stories to push for change. Goldring testified from her dialysis clinic about waiting six years for a kidney transplant and requiring 12 hours of dialysis each week to stay alive.

"Bringing policy issues to life, making them real and tangible for people, is an important element of cultivating champions for policy positions," Cryer said. GLI's weekly talk show, GLI LIVE, presents clinical and patient experts on a fresh liver health topic each week. On Wednesday, June 2, at 12 p.m. ET, Liver Action Network member organization leaders will discuss their work for the first time. Watch Scott Suckow from the Liver Coalition of San Diego, Farrah Douglas from the Liver Wellness Foundation, and Teresa Davidson from Midsouth Liver Alliance live on Facebook, YouTube, and Twitter.

This opinion by GLI was originally published at GlobalLiver.org.

About Global Liver Institute

GLI was built to solve the problems that matter to liver patients, equipping advocates to improve the lives of individuals and families impacted by liver disease. GLI promotes innovation,

encourages collaboration, and supports the scaling of optimal approaches to help eradicate liver diseases. GLI believes liver health must take its place on the global public health agenda commensurate with the prevalence and impact of liver illness. GLI is the only patient-created, patient-driven nonprofit liver health organization operating globally. Follow GLI on Twitter, Facebook, Instagram, LinkedIn, and YouTube.

For more information, contact Jill Gerber, communications director, at jgerber@globalliver.org.

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