Going Global

Personal struggles with liver disease led Donna Cryer to advocacy.

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Donna Cryer is a liver policy wonk par excellence. She’s not only a Harvard graduate and lawyer but also the founder and CEO of the five-year-old Global Liver Institute (GLI), whose aim is to improve the lives of people living with liver disease, which affects up to 30 million Americans.

But Cryer, who lives and works in the Washington, DC, area, came to her work the personal way: via a lifelong, ongoing struggle with inflammatory bowel disease (IBD), an umbrella term for conditions caused by chronic inflammation of the gastrointestinal tract. IBD can also affect the liver. It got so bad that she needed a liver transplant, which plunged her into patient advocacy.

“I don’t look back wishing that things were different,” says Cryer. “I just see that I was able to use what I’ve gone through to develop and grow as both a person and a leader. It has given me a certain resiliency that hopefully pervades everything I do.”

That journey started in Connecticut, where Cryer was one of a few students of color at elite private schools and where she struggled from an early age with the stomach pain and diarrhea of IBD.

“It was so embarrassing and horrible, having to make bathroom stops on bus trips, going to the nurse all the time,” she says. Thankfully, her mother was nurturing, and her father was tough, telling her never to give up the fight—a message that propelled her to Harvard in the late 1980s.

There, her IBD caused increasingly bad liver disease, which causes jaundice (yellowing) in the eyes. “One Halloween, I went as a tiger,” she recalls, “and everyone was like, ‘How did you get your eyes so yellow?’ and I’d say, ‘It’s a secret.’”

Eventually, she was put on a liver transplant list and at one point was told that she had seven days left to live if she did not get the transplant. Thankfully, in 1994, she did—at the Johns Hopkins medical center, with friends from both Harvard and Georgetown—where she was by then enrolled in law school—by her side.

“I saw them at a reunion recently,” she says, “and they confided, ‘We were so scared you were going to die!’”

Although she had to miss her first semester of law school because of the transplant, the surgery was a success. Post-procedure, she considered going into child welfare law, but her doctors, impressed by her burning curiosity about her condition and level of care, urged her to get a job with the United Network for Organ Sharing (UNOS), the nonprofit that manages the U.S. transplant system, including its all-important waiting lists.

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After that, she worked for a clinical trials consulting group, reaching out to Black sororities and fraternities to help recruit more people of color to participate in studies. Then it was on to the public relations firm Hill+Knowlton, where, Cryer says, her intimate knowledge of the patient world allowed her to think innovatively for clients and she often collaborated with grassroots community groups.

But on the 20th anniversary of her transplant, she says, "I sat and thought deeply. Was I confident that other [liver] patients would have the same access to innovations in medicine, surgery and care delivery that saved my life? The answer was no because in general there are low levels of awareness about liver health. And there didn't seem to be a place that represented the large number of liver patients around the world."

So she took a page from the late literary legend Toni Morrison. "She wrote that if you can't find the book you want to read, you were meant to write it," says Cryer. "So that's what GLI is to me, writing the story that I was looking to read."

She launched the organization in 2014, right around the time the new drugs for hepatitis C virus (HCV) were coming out. "I put together a campaign where I sought out a woman who had finally been cured from hep C with the new meds," she says, "and asked her to partner with me and talk to other people being cured of HCV." A dedicated website, YouTube channel and shareable infographics for social media were all part of the push to get the word out.

Other accomplishments include working with hepatitis advocates to craft the LIVER Act and champion it in Congress. If passed, the law would take bold steps to prioritize liver disease, including authorizing an additional $45 million a year for five years for liver cancer and hepatitis B virus research at the National Institutes of Health (NIH), raising the profile of liver disease at the NIH by adding "Liver" to the name of the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) and elevating the Liver Disease Research Branch at NIDDK to its own division, which would report directly to the NIH director.

"We're not even in the room right now," she says of liver health advocates in DC, "so this would get all liver organizations more respect."

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GLI also leads International NASH Day, held annually on June 12, which educates the public about and advocates for the roughly 5 million Americans living with non-alcoholic steatohepatitis, an advanced form of obesity-linked fatty liver disease. GLI oversees related events in 22 countries with 65 partner organizations. NASH is expected to affect 28% of the world by 2030.

Other priorities include getting organ procurement organizations to be more transparent about where donated organs go; raising the amount of money that people can be reimbursed by insurers for donating their own organs, which requires taking time off from work; and growing GLI’s advocacy academy for patients and caregivers who want to become liver policy advocates.

(Start the journey yourself by signing up at globalliver.org/liver-health-policy-updates.)

Cryer’s biggest challenge? “Low levels of awareness about liver health overall,” she says. “We walk into congressional offices and have to educate [lawmakers] about how many people in a district this could impact.”

Despite all the advocacy work, Cryer says she finds time for fun stuff like SoulCycle, yoga and weight lifting. “They help with the pressures and responsibilities of work as well as with my IBD,” which she still battles. “It doesn’t help anybody if I get sick, so I consider this giving my own wellness the recognition I deserve.” And she admits that she may have the Hallmark Channel playing in the background to soothe her nerves—“something really vanilla,” she says—and that she’s a Marvel Comics fangirl.

But despite the burdens she carries, she doesn’t regret that her personal health challenges have determined her career. “It’s a blessing to have found such a clear purpose,” she says, “and know I’m able to have a meaningful impact on so many people’s lives.”