



## Board of Directors

### **Victor J. Reyes, MBA**

Deloitte Consulting LLP  
Chair

### **Donna R. Cryer, JD**

President and CEO

### **Lisa Boyette, MD, PhD**

Recursion Pharmaceuticals  
Treasurer

### **Brian Munroe**

Bausch Health Companies, Inc.  
Secretary

### **Nicholas Austin, JD**

Microsoft Inc.

### **Dennis R. Cryer, MD, FAHA**

CryerHealth LLC

### **Gary Deverman, CFRE**

NutriStyle

### **Ben Goodman**

Maine Dept of Economic &  
Community Development

### **Laurie Mobley**

BRG Communications

### **Lewis R. Roberts, MB, ChB, PhD**

Mayo Clinic

### **Amy L. Wright, JD**

Taft, Stettinius & Hollister

Global Liver Institute  
4323 Westover Place NW  
Washington, DC 20016

✉ info@globalliver.org  
🌐 globalliver.com

March 17, 2023

Griffin P. Rodgers, MD, MACP

Director

National Institute of Diabetes and Digestive and Kidney Diseases

National Institutes of Health

9000 Rockville Pike

Bethesda, MD 20892

Dear Dr. Rodgers:

The Global Liver Institute (GLI) appreciates the opportunity to comment on the Report of the Health Disparities and Health Equity Working Group of the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) Advisory Council. GLI is the leading global liver patient advocacy organization with a mission to improve the lives of individuals and families impacted by liver disease through promoting innovation, encouraging collaboration, and scaling optimal approaches to help eradicate liver disease.

GLI appreciates that NIDDK advanced its health disparities and equity research priorities. We also support NIDDK's actions to engage the public on this report, and this opportunity to comment is a promising first step. GLI is generally supportive of NIDDK's recommendations, though we would encourage a more robust focus on liver disease in the report's specific research recommendations and opportunities. Liver disease disproportionately impacts communities of color — which has a rapidly growing impact on quality of life — as well as being increasingly associated with rising rates of liver cancer.<sup>1</sup> We strongly encourage NIDDK to focus on the liver health of Black and Hispanic Americans by ensuring its health disparities and health equity research plan appropriately explores

prevention, diagnosis, and treatment of liver diseases.

---

<sup>1</sup> "Chronic Liver Disease and African Americans" *Office of Minority Health*, U.S. Department of Health and Human Services, 17 Feb. 2023, <https://minorityhealth.hhs.gov/omh/browse.aspx?lvl=4&lvlid=17>

First, GLI would recommend that NIDDK list liver disease as one of the most stigmatized health conditions. In 2020 liver disease was the ninth leading cause of death of African American men aged 45-64,<sup>2</sup> reinforcing evidence of its disproportionate effect on communities of color.

GLI is strongly supportive of your Recommendation 1-1-1, *Authentically engage community perspectives/voices in the research process*. GLI firmly believes that meaningful engagement with communities requires community members to be engaged in the research process from the initial development of investigative questions to be examined in the final research product. For this reason, we have been staunch supporters of engaging patients in the research continuum. For example, we operate an Advanced Advocacy Academy to that ensure liver patients are equipped to meaningfully participate in the research ecosystem. Based on our experience in this arena, we encourage NIDDK to partner with trusted community organizations like GLI, as well as health centers and practicing clinicians that treat communities of color. This approach will ensure that NIDDK is thoughtfully incorporating the perspectives of the affected population and equipping their representatives to participate successfully in the process.

GLI suggests that Recommendation 2, *Advance research on the mechanisms by which biological, behavioral, environmental, and structural factors interact to affect health, disease, and resilience*, is an area in which NIDDK's focus on liver health could yield positive results for health equity. In addition to high rates of chronic liver disease in the Black community, Hispanic Americans are experiencing an increased risk of nonalcoholic fatty liver disease (NAFLD) progressing to nonalcoholic steatohepatitis (NASH).<sup>3</sup>

The prevalence of NASH is increasing rapidly with experts predicting it could increase by over 50% over the next seven years.<sup>4</sup> NASH is underdiagnosed and often untreated, yet preventative lifestyle interventions can have an impact on NASH and even reverse the disease in its early stages.<sup>5</sup> These lifestyle interventions — eating a healthier diet with fewer processed foods and exercising — can be challenging if not impossible for certain populations that may have nutrition insecurity or live in geographic locations that make exercising and a balanced diet difficult or inaccessible. Therefore, it would be worthwhile to incorporate research on NASH patients as you look to determine relationships between social determinants of health (SDOH), genetics, and the effects of each on health disparities and disease heterogeneity. NASH would also be a worthwhile case study as NIDDK seeks to determine promoters and mechanisms of resilience that prevent or lessen disease

---

<sup>2</sup> "Chronic Liver Disease and African Americans" *Office of Minority Health*, U.S. Department of Health and Human Services, 17 Feb. 2023, <https://minorityhealth.hhs.gov/omh/browse.aspx?vl=4&vlid=17>

<sup>3</sup> Rich, Nicole E, et al. "Racial and Ethnic Disparities in Nonalcoholic Fatty Liver Disease Prevalence, Severity, and Outcomes in the United States: A Systematic Review and Meta-Analysis." *Clinical Gastroenterology and Hepatology: The Official Clinical Practice Journal of the American Gastroenterological Association*, U.S. National Library of Medicine, February 2018, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5794571/>.

<sup>4</sup> "The Language of NASH", Global Liver Institute, Washington, D.C., August 2020, [https://globalliver.org/wp-content/uploads/2022/06/GLI\\_TheLanguageofNASH\\_270820.pdf](https://globalliver.org/wp-content/uploads/2022/06/GLI_TheLanguageofNASH_270820.pdf).

<sup>5</sup> "The Language of NASH", Global Liver Institute, Washington, D.C., August 2020, [https://globalliver.org/wp-content/uploads/2022/06/GLI\\_TheLanguageofNASH\\_270820.pdf](https://globalliver.org/wp-content/uploads/2022/06/GLI_TheLanguageofNASH_270820.pdf).

severity. Evidence-based strategies to promote resilience combined with addressing broad SDOH could go a long way to limiting the rapid increase of NASH, now recognized as a looming epidemic.<sup>6</sup>

In response to Recommendation 5, *enhance NIDDK collaboration, structure, and programs to support robust research in health equity*, GLI has several suggestions to strengthen NIDDK's work. Broadly, we would suggest balancing NIDDK's research portfolio to address inequities in resources spent across conditions within NIDDK's mission. Overall, liver disease receives less funding than other comparable conditions, hampering NIDDK's ability to address specific disparities experienced by patients with different types of liver disease. For example, there is a significantly higher prevalence of hepatitis B in Asian Americans<sup>7</sup> and liver cancer in African Americans.<sup>8</sup> Ensuring there is an appropriate level of funding dedicated to liver disease would allow NIDDK to address these diseases from an equity perspective.

There are also opportunities to address equity more holistically in NIDDK's portfolio by recognizing the intersection of liver conditions with other diseases that receive more funding or attention. For example, NASH is closely associated with obesity, diabetes, chronic kidney disease, and cardiovascular disease (CVD). Liver disease is projected to rise in parallel to these diseases,<sup>9</sup> and it has a bidirectional relationship with type 2 diabetes such that NASH develops first, and the patient is likely to develop type 2 diabetes. Conversely, in patients who have type 2 diabetes, NASH is a common comorbid occurrence (37% of people with type 2 diabetes have NASH).<sup>10</sup> Diabetes also contributes to a faster fibrosis progression of NASH and can accelerate the progression to cirrhosis and liver cancer.<sup>11</sup> Understanding the relationship among these co-existing conditions and their impact on disease progression would drive systematic improvements in our health system and significantly reduce the risk of NASH and progression to liver cancer.

In response to 5-2, *provide training for the NIDDK scientific community to enhance knowledge and skills in health equity concepts and community-engaged research*, we would encourage NIDDK to include its grant reviewers in this population. GLI has received feedback from our community that grant applications exploring health equity topics are not fairly scored in light of this priority research area. NIDDK should train its grant reviewers about its goals to not only advance health

---

<sup>6</sup> Kanwal, Fasiha et al. "Preparing for the NASH Epidemic: A Call to Action." *Metabolism: Clinical and Experimental* vol. 122 (2021): 154822. doi:10.1016/j.metabol.2021.154822, <https://pubmed.ncbi.nlm.nih.gov/34289945/>.

<sup>7</sup> Chen MS Jr, Dang J. Hepatitis B among Asian Americans: Prevalence, progress, and prospects for control. *World J Gastroenterol.* 2015 Nov 14;21(42):11924-30. doi: 10.3748/wjg.v21.i42.11924. PMID: 26576081; PMCID: PMC4641114.

<sup>8</sup> "Chronic Liver Disease and African Americans" *Office of Minority Health*, U.S. Department of Health and Human Services, 17 Feb. 2023, <https://minorityhealth.hhs.gov/omh/browse.aspx?vl=4&vlid=17>

<sup>9</sup> Younossi ZM, Koenig AB, Abdelatif D, et al. Global epidemiology of nonalcoholic fatty liver disease meta-analytic assessment of prevalence, incidence, and outcomes. *Hepatology.* 2016; 64:73–84.

<sup>10</sup> Younossi ZM, Golabi P, de Avila L, et al. The global epidemiology of NAFLD and NASH in patients with type 2 diabetes: A systematic review and meta-analysis. *J Hepatol.* 2019; 71:793–801.

<sup>11</sup> McPherson S, Hardy T, Henderson E, et al. 2015. Evidence of NAFLD progression from steatosis to fibrosing-steatohepatitis using paired biopsies: implications for prognosis and clinical management. *Journal of Hepatology* 62(5): 1148-55

equity but give such applications weight as an essential tool for reviewers to understand how to fairly score grant proposals based on the agency’s intentional aim to advance health equity. We would recommend that NIDDK refer to the work of the Patient-Centered Outcomes Research Institute (PCORI) for guidance, especially its emphasis on including merit reviewers from the patient community, associated training and mentorship for new merit reviewers, and inclusion of patient-centeredness criteria as a requirement for all applications.<sup>12</sup>

As an additional note, NIDDK’s report rightfully states that “Advancing health equity calls for changes in the makeup of people involved in the research process.” GLI agrees wholeheartedly and would urge NIDDK to recruit a diverse and representative membership for its Advisory Council. In order to truly understand issues surrounding health disparities and health equity, GLI encourages NIDDK to incorporate more patients of color who have lived experiences to contribute to their work, as well as the clinicians that provide their care.

GLI has a broad network of liver patients trained to engage meaningfully in patient-centered research opportunities and stands ready to be a resource to NIDDK as it continues to build out its health equity research priorities. If you have any questions, or if we can be of assistance, please do not hesitate to contact me at [dcryer@globalliver.org](mailto:dcryer@globalliver.org).

Sincerely,

A handwritten signature in black ink that reads "Donna R. Cryer". The signature is written in a cursive, flowing style.

Donna R. Cryer, JD  
President & CEO  
Global Liver Institute

### **About Global Liver Institute**

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 organization tackling liver health and all liver disease holistically, operating globally. Follow GLI on [Twitter](#), [Facebook](#), [Instagram](#), [LinkedIn](#), and [YouTube](#).

---

<sup>12</sup> “Merit Review” *PCORI*, Accessed March 27, 2023, <https://www.pcori.org/funding-opportunities/merit-review>.