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August 13th, 2019

The Honorable Alex M. Azar II
Secretary U.S. Department of Health and Human Services
200 Independence Avenue, SE
Washington, DC 20201

Re: Nondiscrimination in Health and Health Education Programs or Activities [HHS–OCR–2019–0007] [RIN 0945–AA11]

Submitted electronically via federalregister.gov

Dear Secretary Azar,

The Global Healthy Living Foundation (GHLF) is a 20-year-old 501(c)(3) patient organization reaching millions of chronically ill patients and their caregivers across the country through social media, community events and our online support and education. GHLF works to improve the quality of life for patients living with chronic disease by making sure their voices are heard and advocating for improved access to care at the community level. Our patients suffer from chronic conditions including arthritis, psoriasis, gastrointestinal disease, cardiovascular disease and migraine. As a result, these patients incur significant financial burden due to the high cost of the treatments that are necessary to manage their disease. And, it is on behalf of the patients we represent that we are sharing our grave concerns about the proposed changes in implementing section 1557 of the Affordable Care Act (ACA) made in the proposed rule titled *Nondiscrimination in Health and Health Education Programs or Activities (HHS-OCR-2019-0007; RIN 0945-AA11)*.

Section 1557 of the ACA was put in place to ensure that any individual could not be excluded from any health program or activity associated with Federal financial assistance based on race, color, national origin, sex, age, or disability. GHLF is concerned that the current proposed rule is in direct conflict with this intention and as a result, would disrupt care for millions of Americans with chronic diseases.

In particular, GHLF is concerned that the proposed rule would completely eliminate 42 CFR § 92.207 which protects individuals from payers:

- Denying, canceling, limiting, or refusing to issue or renew a health insurance policy;
- Denying or limiting coverage of a health insurance claim;
- Imposing additional cost sharing or other limitations or restrictions on coverage; and
- Using discriminatory marketing practices or insurance benefit designs.

Given that chronic conditions often substantially limit one or more major life activities, many in our community meet the disability criteria specified in Section 1557's regulations. As such, the above prohibitions are crucial to ensure equal access to healthcare for people with chronic conditions, and thus, we oppose their elimination. Doing so will further exacerbate problems with payers designing benefit structures that discriminate against groups of people with specific chronic conditions. As an example, often patients with specific chronic diseases will find that most or all of their treatment options are placed

in high cost tiers which shift significant out-of-pocket costs onto patients who are in most need of care. These plans are unrealistic for patients with chronic disease essentially driving them away and leaving them without proper coverage. This tactic has long been used by payers and was a primary reason for why protections were put into place by the ACA for those with pre-existing conditions. It is not enough to simply prohibit a payer from denying coverage based on a pre-existing condition – those protections outlined at 42 CFR § 92.207 are also needed to ensure that payers are prevented from orchestrating other mechanisms that discriminate against those with chronic conditions. Instead of stripping patients of these protection, we instead urge the Office of Civil Rights to maintain this provision.

Unfortunately, even though the protections outlined at 42 CFR § 92.207 exist, these discriminatory practices are still occurring because enforcement of Section 1557 has been lacking. GHLF supports increased enforcement to ensure that patients are not subject to discriminatory practices. Thus, we oppose the proposed changes to 45 CFR § 92.7 requiring covered entities to establish a grievance procedure for patients to report discrimination, designate a staff person responsible for coordinating Section 1557 responsibilities, and inform people about their right not to be discriminated against. GHLF believes that this change would make it more difficult for patients to learn about and understand their rights and to report violations from payers. Additionally, while GHLF supports the Office of Civil Rights taking a more active role in Section 1557 enforcement, we think this is best accomplished through a comprehensive approach that involves other federal and state regulators. Thus, GHLF also opposes delegating all enforcement authority to the Director of the Office of Civil Rights.

Additionally, our community is diverse – chronic diseases impact all communities and we support access to whatever care they may need to live fuller and more productive lives. Thus, we are concerned that the elimination of the “Definitions” section of the current rule in part because of the removal of definitions of key terms such as “on the basis of sex,” “sex stereotypes,” and “gender identity.” We understand that the Office of Civil Rights currently believes these definitions to be burdensome and unnecessary, but a clear understanding of key terms and situations is of the utmost importance to remedy a history of discrimination. The definitions provided make clear what kinds of practices are considered discriminatory under the law.

For these many reasons, we respectfully urge you to withdraw this proposed rule.

Thank you very much for the opportunity to comment on this proposed change to Section 1557. Please do not hesitate to contact me at snewmark@ghlf.org if the Global Healthy Living Foundation, its arthritis community, CreakyJoints, or our arthritis patient registry, ArthritisPower, can be of further assistance with this proposed rule

Sincerely,



Steven Newmark
Director of Policy and General Counsel
Global Healthy Living Foundation