



November 9, 2015

The Honorable Sylvia Mathews Burwell
Secretary of Health and Human Services
200 Independence Avenue SW
Washington, D.C. 20201

Re: Comments on Office for Civil Rights, ACA Non-discrimination Proposed Rule
(RIN 0945-AA02)

Dear Madame Secretary:

We, the undersigned 197 patient and community organizations representing millions of patients and their families, remain dedicated to the successful implementation of the Affordable Care Act (ACA). With the close of the second open enrollment period, an estimated 17.6 million Americans have gained health coverage under the ACA and the number of uninsured in the country has dramatically decreased. While there are numerous provisions in the ACA that protect patient rights, one key provision is Sec. 1557, which prohibits discrimination in the health care system on the basis of race, color, national origin, sex, age, or disability.

We are pleased that the long awaited proposed regulation to implement Sec. 1557 has now been issued. While the proposal does an adequate job of defining discriminatory practices by insurance plans for some individuals, **it does not define discriminatory practices in plan benefit design as it relates to all beneficiaries, particularly those with serious and chronic health conditions who rely on prescription medications and other healthcare services.**

While §92.207(b) mentions in very general terms that plans shall not “(1) ...deny or limit coverage of a claim, or impose additional cost sharing or other limitations or restrictions, on the basis of an enrollee’s or prospective enrollee’s race, color, national origin, sex, age, or disability; [and] (2) Employ marketing practices or benefit designs that discriminate on the basis of race, color, national origin, sex, age, or disability in a health-related insurance plan or policy, or other health-related coverage,” it is not very specific. **Therefore, we strongly urge HHS to better define what discriminatory plan practices are in the final rule.**

Beneficiaries have witnessed discriminatory benefit design by some insurers, particularly in the coverage of prescription medications, which many beneficiaries living with chronic and serious

health conditions rely on to remain healthy and alive. Some marketplace plans are placing all or almost all medications to treat a certain condition on the highest cost tier. In the preamble of the [Notice of Benefit and Payment Parameters for 2016](#) and in the 2016 [Letter to Issuers](#), HHS has gone on record and stated that these practices could be discriminatory. In the *Letter to Issuers*, the Centers for Medicare & Medicaid Services cautions issuers from discouraging enrollment of individuals with chronic health needs and provided examples of discriminatory plan designs. One example identified was “if an issuer places most or all drugs that treat a specific condition on the highest cost tiers, that plan design might effectively discriminate against, or discourages enrollment by, individuals who have those chronic conditions.”

In order to protect beneficiaries and to provide clarity to state and federal regulators, now and in the future, HHS must provide a clear definition of what constitutes discrimination. Therefore, we urge HHS to include in regulatory language the practice of placing all or nearly all medications to treat a certain condition on the highest tier to be discriminatory.

In addition, beneficiaries have experienced other design benefits that amount to discrimination of people with chronic conditions, including not covering certain medications or not following treatment guidelines, imposing excessive medication management tools such as unreasonable prior authorizations and/or step therapy, charging patients high cost sharing, and having narrow provider networks.

Therefore, in the final rule, we recommend that employing these types of practices also be clearly defined as discrimination. Standards and parameters for benefit and plan design should be detailed in the final rule, along with acceptable practices. Unfortunately, the proposed rule is completely silent in this area and regulators, beneficiaries, and insurers are not provided with any clarity on what constitutes discrimination.

Additionally, we believe that HHS needs to clarify that the definition of who is protected under Sec. 1557 is not only limited to beneficiaries who are “disabled” under the definition in the Americans with Disabilities Act (ADA), but to all beneficiaries with chronic health conditions or serious illness. Using the definition under the ADA will include only some individuals or health conditions and overlooks many beneficiaries who may be exposed to discrimination in their health care coverage. These individuals should also enjoy the same patient protections.

Finally, any law or regulation is useless if it is not enforced. We urge HHS and the Office for Civil Rights to properly enforce the law now, and act on any discrimination complaints that have been filed in order to ensure beneficiary rights are protected.

We greatly appreciate all you and the rest of the Department are doing to improve the health of all Americans and look forward to another successful open enrollment period. We thank you for your continued dedication to improving implementation of the ACA so that it meets the needs of patients throughout the country.

Sincerely,

30 for 30 Campaign

ActionAIDS

ADAP Advocacy Association
 Adult Congenital Heart Association
 Adventist Health
 Advocates for Responsible Care
 AIDS Action Baltimore
 AIDS Alabama
 AIDS Alliance for Women, Infants,
 Children, Youth & Families
 AIDS Foundation of Chicago
 The AIDS Institute
 AIDS Project Los Angeles
 AIDS United
 Alabama Alliance for Healthy Youth
 Alliance for Lupus Research
 Alliance for the Adoption of Innovations in
 Medicine (Aimed Alliance)
 Alliance for Patient Access
 Alpha-1 Foundation
 The ALS Association
 Alstrom Syndrome International
 American Academy of HIV Medicine
 American Association on Health and
 Disability
 American Autoimmune Related Diseases
 Association
 American Kidney Fund
 American Liver Foundation
 American Lung Association
 American Society for Metabolic and
 Bariatric Surgery
 APLA Health & Wellness
 Arthritis Foundation
 Asian & Pacific Islander American Health
 Forum
 Association of Asian Pacific Community
 Health Organizations (AAPCHO)
 Association of Nurses in AIDS Care
 Asthma & Allergy Foundation of America,
 New England Chapter
 AXYS
 Best Practice Concepts, LLC
 Bladder Cancer Advocacy Network
 Borinquen Medical Centers of Miami-Dade
 California Hepatitis C Task Force
 Cancer Support Community
 Cardio-Facio-Cutaneous International
 Caregiver Action Network
 Caring Ambassadors Program, Inc.
 Center for Independence of the Disabled,
 NY
 Central Ohio Diabetes Association
 Community Access National Network
 COPD Foundation
 County Behavioral Health Directors
 Association of California
 Crohn's and Colitis Foundation of America
 Depression and Bipolar Support Alliance
 Dystonia Medical Research Foundation
 Easter Seals
 Elder Care Advocacy of Florida
 EPIC Long Island
 Epilepsy Foundation
 Epilepsy Foundation of Alabama
 Epilepsy Foundation Central & South
 Texas
 Epilepsy Foundation Chesapeake Region
 Epilepsy Foundation of Colorado
 Epilepsy Foundation of Connecticut
 Epilepsy Foundation of Delaware
 Epilepsy Foundation of East Tennessee
 Epilepsy Foundation of Florida
 Epilepsy Foundation of Greater Chicago
 Epilepsy Foundation of Greater Cincinnati
 and Columbus
 Epilepsy Foundation of Greater Los
 Angeles
 Epilepsy Foundation of Greater Southern
 Illinois
 Epilepsy Foundation Heart of Wisconsin
 Epilepsy Foundation of Indiana
 Epilepsy Foundation of Kentuckiana
 Epilepsy Foundation of Metropolitan New
 York
 Epilepsy Foundation of Michigan
 Epilepsy Foundation Middle & West
 Tennessee

Epilepsy Foundation of Minnesota
 Epilepsy Foundation of Missouri and
 Kansas
 Epilepsy Foundation of Nevada
 Epilepsy Foundation New England
 Epilepsy Foundation of Northeastern New
 York
 Epilepsy Foundation of North Carolina
 Epilepsy Foundation North/Central Illinois,
 Iowa, Nebraska
 Epilepsy Foundation Northwest
 Epilepsy Association of Oklahoma
 Epilepsy Foundation of Rochester
 Syracuse-Binghamton
 Epilepsy Foundation Texas -
 Houston/Dallas-Fort Worth/West Texas
 Epilepsy Foundation of Vermont
 Epilepsy Foundation of Virginia
 Epilepsy Foundation of Western Ohio
 Epilepsy Foundation of Western Wisconsin
 Fabry Support & Information Group
 Family Voices
 Federation of Families for Children's
 Mental Health CO chapter
 Fight Colorectal Cancer
 FORCE: Facing Our Risk of Cancer
 Empowered
 Frederick HIV/AIDS Group
 GBS|CIDP Foundation International
 Genetic Alliance
 Global Colon Cancer Association
 Global Healthy Living Foundation
 Global Justice Institute
 Global Liver Institute
 Harlem United
 HealthHIV
 Hemophilia Alliance of Maine
 Hemophilia Association of the Capital
 Area
 Hemophilia Federation of America
 Hepatitis B Foundation
 Hep C Connection
 Hepatitis Foundation International
 Hermansky-Pudlak Syndrome Network
 HIV/AIDS Alliance of Michigan
 HIV Dental Alliance
 HIV Medicine Association
 HIV Prevention Justice Alliance
 Hope for a Brighter Day, Inc.
 Howard Brown Health
 IHS Tribal Health
 Immune Deficiency Foundation
 International Foundation for Autoimmune
 Arthritis
 International Myeloma Foundation
 International Pemphigus & Pemphigoid
 Foundation
 International WAGR Syndrome
 Association
 Lakeshore Foundation
 Latino Commission on AIDS
 Leukemia & Lymphoma Society
 Lupus and Allied Diseases Association
 Lupus Foundation of America
 Lupus Foundation of Florida, Inc.
 Lupus Foundation of Southern California
 Lupus LA
 Lupus Research Institute
 The Marfan Foundation
 Men's Health Network
 Mental Health America
 Mental Health America of Colorado
 Mental Health Connecticut
 Mental Health America of Montana
 Metropolitan Community Churches
 Nashville CARES
 National Alliance for Caregiving
 National Alliance for Hispanic Health
 National Alliance on Mental Illness
 National Alliance on Mental Illness
 Alabama
 National Alliance on Mental Illness North
 Carolina
 National Alliance on Mental Illness
 Washington State

National Alliance of State & Territorial
 AIDS Directors
 National Alopecia Areata Foundation:
 NAAF
 National Asian Pacific American Families
 Against Substance Abuse
 National Association of Hepatitis Task
 Forces
 National Association of Hispanic Nurses
 National Black Justice Coalition
 National Council for Behavioral Health
 National Eczema Association
 National Hemophilia Foundation
 National Kidney Foundation
 National LGBTQ Task Force
 National Multiple Sclerosis Society
 National Organization for Rare Disorders
 (NORD)
 National Osteoporosis Foundation
 National Patient Advocate Foundation
 National Psoriasis Foundation
 National Viral Hepatitis Roundtable
 NBIA Disorders Association
 New England Hemophilia Association
 New Jersey Association of Mental Health
 and Addiction Agencies, Inc.
 Obesity Action Coalition
 Obesity Medicine Association
 The Obesity Society
 One in Four Chronic Health
 Ovarian Cancer National Alliance
 OWL-The Voice of Women 40+
 Parkinson's Action Network
 Positively Healthy Coalition
 Positive Women's Network - USA
 Project Inform
 PSC Partners Seeking a Cure
 Pulmonary Hypertension Association
 RAIN Oklahoma
 RetireSafe
 Rush To Live
 Ryan White Medical Providers Coalition
 Sacramento Community Clinic
 Scleroderma Foundation
 Services and Advocacy for GLBT Elders
 (SAGE)
 Society for Women's Health Research
 South Florida Cancer Association
 Specialty Tiers Coalition of Georgia
 The Sturge-Weber Foundation
 Susan G. Komen
 Treatment Action Group
 Urban Health Epidemiology Project
 US Hereditary Angioedema Association
 US Pain Foundation
 Usher 1F Collaborative
 The Veterans Health Council - Vietnam
 Veterans of America
 Virginia Hemophilia Foundation
 Washington Community Mental Health
 Council
 Wellness and Education Community
 Action Health Network
 Wyoming Epilepsy Association