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 WAGb 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