

# I AM (Still) ESSENTIAL

May 15, 2015

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

Re: Adequate Review of 2016 Qualified Health Plans

Dear Madame Secretary:

We, the undersigned 219 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, millions of Americans now have gained health coverage and the number of uninsured in the country has dramatically decreased. **As you begin to review the Qualified Health Plans (QHPs) for 2016, we want to ensure that the many positive patient protections that were included in the [Notice of Benefit and Payment Parameters for 2016](#) and the [Letter to Issuers](#) are adhered to and strictly enforced.**

As we have detailed to you in the past, many patients have had troubling experiences with some Qualified Health Plans (QHPs). In particular, patients living with chronic conditions have found that some plans offer limited benefits, high cost-sharing and discriminatory plan designs, and lack of transparency. We are very pleased that beginning in 2016, you will require plans to address some of these barriers with new transparency and exceptions provisions. Having accurate, complete, and up-to-date lists of drugs and providers that are easily accessible to patients will help them select the plan that best meets their needs. Plans must also disclose any restrictions, including prior authorization, step therapy, and quantity limits for covered medications. The added exceptions processes will help patients access medically necessary medications prescribed by their providers. The Centers for Medicare and Medicaid Services (CMS) has also stated that plans cannot remove drugs from their formularies mid-year unless it is due to the availability of the drug.

In addition, CMS has stated that it will review plans for adequate drug coverage and discriminatory plan design. CMS has stated in the past that it would conduct these reviews. However, the growing number of plans engaging in discriminatory practices is evidence that thorough reviews have not taken place. In the *Letter to Issuers*, CMS cautions issuers from discouraging enrollment of individuals with chronic health needs and provides examples of discriminatory plan designs. One example is “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 identify discriminatory plan designs, CMS states it will conduct outlier analysis on plan cost sharing, including co-payments and co-insurance, and total out of pocket costs

associated with standard treatment protocols for specific conditions. It will also review any medical management techniques, such as prior authorization and/or step therapy, to ensure they are based on clinical guidance, and analyze formularies to ensure drug coverage is consistent with treatment guidelines for certain conditions.

We strongly urge you to ensure that CMS fulfills its duties and adequately reviews the 2016 plans in accordance with the above stated requirements and reject QHPs that do not meet the ACA's anti-discrimination standards.

There is growing evidence that more plans are placing all medications in certain classes on the highest tier and charging patients high co-insurance. A [recent analysis](#) conducted by Avalere found increases between 2014 and 2015 in the number of formulary tiers used by federally facilitated marketplace plans and in the use of cost-sharing for drugs on specialty tiers. The proportion of bronze and silver plans using specialty tier co-insurance greater than 30 percent increased by 14 percent from 2014 to 2015. In five classes used to treat cancer, MS, and HIV, more than one-fifth of all exchange plans are requiring 30 percent co-insurance or higher for all drugs in the class—a significant increase over 2014.

We are concerned that without meaningful review and enforcement by CMS, these trends will continue and become worse, creating greater barriers for patients to access their health care.

Again, we greatly appreciate all you and the rest of the Department are doing to improve the health of all Americans. 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  
Action CF  
ADAP Advocacy Association (aaa+)  
Adult Congenital Heart Association  
Advocates for Responsible Care  
African American Health Alliance  
AIDS Action Baltimore  
AIDS Alabama  
AIDS Alliance for Women, Infants, Children,  
Youth & Families  
AIDS Foundation of Chicago  
The AIDS Institute  
AIDS Legal Referral Panel  
AIDS Project Los Angeles  
AIDS United  
AIDS Vaccine Advocacy Coalition (AVAC)  
Alabaster  
Alliance for the Adoption of Innovations in  
Medicine (Aimed Alliance)

The ALS Association  
Alzheimer's & Dementia Resource Center  
American Academy of HIV Medicine  
American Association on Health and Disability  
American Autoimmune Related Diseases  
Association (AARDA)  
American Behcet's Disease Association  
American Chronic Pain Association, Inc.  
American Diabetes Association  
American Kidney Fund  
American Lung Association  
American Society for Metabolic and Bariatric  
Surgery  
American Society of Bariatric Physicians  
The Arc of The United States  
Asian & Pacific Islander American Health  
Forum  
Association of Community Cancer Centers  
Association of Nurses in AIDS Care

Behavioral Health & Wellness  
Bladder Cancer Advocacy Network  
Boley Centers  
Brain Injury Association of America  
California Chronic Care Coalition  
California Hepatitis C Task Force  
California Senior Advocates League  
Cancer Support Community  
Caregiver Action Network  
The Cave Institute  
Center for Public Policy Priorities  
Centro de mi Salud  
Citrus Council, National Kidney Foundation of Florida  
Coalition for Pulmonary Fibrosis  
Columbia CARES  
Community Access National Network (CANN)  
County of Santa Clara HIP program  
Crohn's & Colitis Foundation of America  
Delaware HIV Consortium  
Dialysis Patient Citizens  
Easter Seals  
Elder Care Advocacy of Florida  
Epilepsy California  
Epilepsy Foundation  
Epilepsy Foundation Heart of Wisconsin  
Epilepsy Foundation New England  
Epilepsy Foundation North/Central Illinois, Iowa, Nebraska  
Epilepsy Foundation of the Chesapeake Region  
Epilepsy Foundation of Florida  
Epilepsy Foundation of Greater Chicago  
Epilepsy Foundation of Greater Southern Illinois  
Epilepsy Foundation of Indiana  
Epilepsy Foundation of Kentuckiana  
Epilepsy Foundation of Michigan  
Epilepsy Foundation of Minnesota  
Epilepsy Foundation of Missouri & Kansas  
Epilepsy Foundation of Nevada  
Epilepsy Foundation of New Jersey  
Epilepsy Foundation of Western Ohio  
Family Resource Network  
Federation of Families for Children's Mental Health - Colorado Chapter  
Fight Colorectal Cancer  
Florida CHAIN  
Gay Men's Health Crisis (GMHC)  
GBS/CIDP Foundation International

Georgia AIDS Coalition  
GLMA: Health Professionals Advancing LGBT Equality  
Global Colon Cancer Association  
Global Healthy Living Foundation  
Global Liver Institute  
HEALS of the South  
HealthHIV  
Hemophilia Alliance of Maine, Inc.  
Hemophilia Association of the Capital Area  
Hispanic CREO  
HIV Dental Alliance  
HIV Medicine Association  
HIV Prevention Justice Alliance  
HIV/AIDS Services for African Americans in Alaska  
Immune Deficiency Foundation  
Indiana Rural Health Association  
International Foundation for Autoimmune Arthritis  
International Myeloma Foundation  
Jonah's Just Begun  
Kentucky Life Sciences Council  
Kidney Cancer Association  
Knights of Peter Claver - New Orleans  
Lambda Legal  
Latino Commission on AIDS  
Latinos Salud  
Let's Talk About Change  
Leukemia & Lymphoma Society  
Los Angeles LGBT Center  
Louisiana AIDS Advocacy Network  
Louisiana Alumni, Sigma Kappa GNO  
Louisiana Lifespan Respite Coalition  
Louisiana Medicare Checkup Campaign  
Lupus Alliance Long Island/Queens  
Lupus and Allied Diseases Association, Inc.  
Lupus Foundation of America  
Lupus Foundation of America, DC/MD/VA Chapter  
Lupus Foundation of Arkansas, Inc.  
Lupus Foundation of Florida  
Lupus Foundation of Northern California  
Lupus Foundation of Southern California  
Lupus LA  
Lupus Research Institute  
Lupus Society of Illinois  
The Marfan Foundation  
The Mastocytosis Society, Inc.

Maxima Home Health LLC  
 Medical News - Kentucky  
 Mended Hearts of Central Ohio  
 Men's Health Network  
 Mental Health America  
 Mental Health Association of Connecticut  
 Michigan Association of Community Mental Health Boards  
 Michigan Lupus Foundation  
 Minnesota AIDS Project  
 Moveable Feast  
 NAACP  
 Nashville CARES  
 The National Alliance to Advance Adolescent Health  
 National Alliance for Caregiving  
 National Alliance on Mental Illness  
 National Alliance on Mental Illness Alabama  
 National Alliance on Mental Illness Kentucky  
 National Alliance on Mental Illness New Mexico  
 National Alliance on Mental Illness North Carolina  
 National Alliance on Mental Illness of Ohio  
 National Alliance of State & Territorial AIDS Directors  
 National Alopecia Areata Foundation  
 National Asian Pacific American Families Against Substance Abuse (NAPAFASA)  
 National Association of Hepatitis Task Forces  
 National Association of Hispanic Nurses/CMS  
 National Association of Nutrition and Aging Services Programs (NANASP)  
 National Association for Social Workers Texas (NASWTX)  
 National Association of State Head Injury Administrators  
 National Black Gay Men's Advocacy Coalition  
 National Center for Transgender Equality  
 National Coalition for LGBT Health  
 National Community Pharmacists Association (NCPA)  
 National Grange  
 National Health Law Program  
 National Hemophilia Foundation  
 National Hispanic Medical Association  
 National Kidney Foundation  
 National LGBTQ Task Force  
 National Multiple Sclerosis Society  
 National Osteoporosis Foundation  
 National Patient Advocate Foundation  
 National Prostate Cancer Awareness Foundation  
 National Psoriasis Foundation  
 National Viral Hepatitis Roundtable  
 New England Hemophilia Association  
 New Jersey Association of Mental Health and Addiction Agencies, Inc.  
 New Jersey Mayors Committee on Life Sciences  
 Noah's Hope  
 Obesity Action Coalition  
 The Obesity Society  
 Ohio Association of Community Health Centers  
 Ohio Association of County Behavioral Health Authorities  
 One in Four Chronic Health  
 Organize Now  
 Ovarian Cancer National Alliance  
 Parkinson's Action Network  
 Positive Women's Network - USA  
 Prescription Assistance Network of Stark County, Inc.  
 Prevent Blindness, Ohio Affiliate  
 Prevent Cancer Foundation  
 Project Inform  
 Pulmonary Hypertension Association  
 Racial and Ethnic Health Disparities Coalition  
 Rene Rodriguez, M.D.  
 RetireSafe  
 Rio Grande Valley Diabetes Association  
 Rush To Live  
 Ryan White Medical Providers Coalition  
 San Francisco AIDS Foundation  
 Scleroderma Foundation  
 Services and Advocacy for GLBT Elders (SAGE)  
 SisterLove, Inc.  
 S.L.E. Lupus Foundation  
 Society for Women's Health Research  
 Solo Practice  
 South Carolina Advocates For Epilepsy  
 Southern AIDS Coalition  
 Southern HIV/AIDS Strategy Initiative  
 Specialty Tiers Coalition of Georgia  
 Spina Bifida Association  
 The Sturge-Weber Foundation  
 Test Positive Aware Network

Texas Healthcare and Bioscience Institute  
Thrive Alabama  
Treatment Access Expansion Project  
United Cerebral Palsy  
U.S. Pain Foundation, Inc.  
Utah Health Policy Project  
Vasculitis Foundation  
Veterans Health Council

Vietnam Veterans of America  
Virginia Hemophilia Foundation  
Visiting Nurse Associations of America  
(VNAA)  
Women Against Prostate Cancer  
WomenHeart: The National Coalition for  
Women with Heart Disease  
Wound Care Clinic - ESU