

I AM (Still) ESSENTIAL

July 28, 2014

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

Dear Madame Secretary:

We, the undersigned patient and community organizations representing millions of patients and their families, have been and continue to be committed to the successful implementation of the Affordable Care Act (ACA). Many people, who have been denied access to health insurance in the past because of denials and exclusions for pre-existing conditions, as well as unaffordable premiums, can now gain meaningful access to quality and affordable care. We are encouraged by high enrollment numbers in the new Health Insurance Marketplace, and by early data showing low-income people who were previously uninsured are taking advantage of premium and cost-sharing assistance.

At the same time, we are increasingly aware of evidence that new enrollees, especially those with chronic health conditions, are still facing barriers to care. As implementation continues, assuring that all enrollees in Qualified Health Plans (QHPs) are able to realize the benefits of health insurance must be a top priority.

We urge you to take action now in order to improve benefit designs and guarantee that there is plan transparency for enrollees. We believe the suggested actions, outlined below, are critical steps to assure that all enrollees have access to the medications, providers, and services they need to improve and maintain their quality of life as intended by the ACA.

Based on reports of enrollee experiences during the first year of Marketplace implementation, we have identified a number of concerns. These include discriminatory benefit designs that limit access, such as restrictive formularies and inadequate provider networks; high cost-sharing; and a lack of plan transparency that may deprive consumers of information that is essential to making informed enrollment choices.

Limited Benefits: Due to the manner in which Essential Health Benefits (EHBs) are defined for plan years 2014 and 2015, select plans do not include all the medications that enrollees may be prescribed to address their health care needs. Plans are further restricting access to care by imposing utilization management policies, such as prior authorization, step therapy and quantity limits. Tying plan formulary requirements to the number of drugs in each class in the state benchmark has resulted in some plans not covering critical medications, including combination therapies. Additionally, there is no requirement for plans to cover new medications and plans can remove medications during the plan year as long as the plan continues to meet the state's benchmark requirements. Narrow provider networks and a lack of access to specialists are also negatively impacting access to quality care for enrollees.

These design elements appear to affect certain patient populations disproportionately – many of the same populations that were subject to pre-existing condition restrictions prior to ACA implementation.

High Cost-Sharing: Despite enrollee out-of-pocket limits that are included in the ACA and reduced cost-sharing for people with very low income levels, some plans are placing extremely high co-insurance on lifesaving medications, and putting all or most medications in a given class, including generics, on the highest cost tier. This creates an undue burden on enrollees who rely on these medications. Unlike employer-sponsored plans, where enrollees usually experience reasonable co-pays, enrollees in the Marketplace are being subject to plans that impose 30%, 40% and even 50% co-insurance per prescription. Such high co-insurance is shocking enrollees and will lead to reduced medication adherence and medical complications as people are unable to afford to begin or stay on medications. Some plans are also imposing high deductibles for prescription medications and high cost-sharing for accessing specialists.

We believe these practices are highly discriminatory against patients with chronic health conditions and may, in fact, violate the ACA non-discrimination provisions.

Transparency and Uniformity: Individuals must have access to easy-to-understand, detailed information about plan benefits, formularies, provider networks, and the costs of medications and services. Unfortunately, individuals cannot access this information easily through an interactive web tool such as a plan finder or benefit calculator that matches an individual's prescriptions and provider needs with appropriate plans (such as the one utilized by the Medicare Part D program). Most troubling is the practice of requiring co-insurance without information for an individual to understand what their actual cost-sharing will be. Transparent, easy-to-navigate grievances and appeals processes are needed, along with special enrollment procedures when patients lose access to a medication due to formulary changes during a plan year.

These issues need attention if the ACA is to deliver on its promises for people with chronic health conditions. Actions should include enforcing the ACA non-discrimination provisions, prohibiting restrictive formularies and inadequate provider networks; addressing high cost-sharing, including inappropriate use of coinsurance; and improving plan transparency so that consumers can make informed decisions. We look forward to working with you as efforts are made to revise the EHB standards for future plan years, implement a strong oversight system, and continually improve meaningful access to medications and providers.

Thank you very much.

Sincerely,

A Support Alliance
ACCSES
ActionAIDS
Addario Lung Cancer Foundation
The Advocacy Center
Advocates for Responsible Care
AIDS Action Baltimore
AIDS Action Coalition
AIDS Action Committee of Massachusetts
AIDS Alabama
AIDS Alliance for Women, Infants, Children,
Youth & Families
AIDS Assist
AIDS Foundation of Chicago

The AIDS Institute
AIDS Legal Referral Panel
AIDS Network of WNY
AIDS Research Consortium of Atlanta
AIDS Task Force of the Upper Ohio Valley
AIDS United
Aimed Alliance
Alabama Council of CMHB
Alabama Council of Community Mental Health
Boards
Alliance of AIDS Services - Carolina
ALPHA Pittsburgh, Inc.
Alzheimer's & Dementia Resource Center
American Association on Health and Disability

American Autoimmune Related Diseases Association
American GI Forum of California Veterans Outreach Program
American GI Forum Women of California
The American Kidney Fund
American Liver Foundation Rocky Mountain Division
American Lung Association
American Society for Metabolic and Bariatric Surgery
The Arc of the United States
Arthritis Association of Louisiana
Association of Community Cancer Centers
Asthma and Allergy Foundation of America, New England Chapter
Aunt Rita's Foundation
Autoimmune Advocacy Alliance
BDD Consulting
Behavioral Health & Wellness (TM)
Big Bend Cares Inc.
Birmingham Health Care
Bladder Cancer Advocacy Network
Bleeding Disorders Alliance Illinois
Blue Ribbon Advocacy Alliance
Brain Injury Alliance of Connecticut
Breathe California
California Asian Pacific Chamber of Commerce
California Hepatitis C Task Force
California Senior Advocates League
Callen-Lorde Community Health Center
Cancer Support Community
Caring Ambassadors Program
Cascade AIDS Project
Center for Lawful Access and Abuse Deterrence
Central Florida Behavioral Health Network
Chicago House and Social Service Agency
City of Hartford Commission on HIV/AIDS
Coalition of Texans with Disabilities
Colon Cancer Alliance
Colorado AIDS Project
Combined Health Agencies
Community Access National Network (CANN)
Community AIDS Resource and Education Services (CARES)
Community Health Action Network
Community Health Center of Central Missouri
Community Health Charities of Florida
Community Health Charities of Iowa
Community Health Charities of Kentucky
Community Health Charities of Nebraska

Community Health Charities of Oklahoma
Community Health Charities of the National Capital Area
Community Health Charities of Wisconsin
Community Volunteers Association
Commwell Health
Concilio Latino de Salud, Inc.
Cutaneous Lymphoma Foundation
Cystic Fibrosis Foundation
Delaware Academy of Medicine
Delaware Ecumenical Council on Children and Families
Delaware HIV Consortium
Delaware Public Health Association
Depression and Bipolar Support Alliance
Dialysis Patient Citizens
Disability Policy Consortium
Easter Seals
Easter Seals Central Texas
Easter Seals Colorado
Easter Seals Massachusetts
Elder Advocacy of Florida
Embracing Latina Leadership Alliances (ELLAS)
Epilepsy Association of Central FL
Epilepsy Association of Oklahoma
Epilepsy Foundation
Epilepsy Foundation Central & South Texas
Epilepsy Foundation Heart of Wisconsin
Epilepsy Foundation Louisiana
Epilepsy Foundation Northwest
Epilepsy Foundation of Alabama
Epilepsy Foundation of Arizona
Epilepsy Foundation of the Chesapeake Region
Epilepsy Foundation of Colorado
Epilepsy Foundation of Connecticut
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 of Indiana
Epilepsy Foundation of Kentuckiana
Epilepsy Foundation of Long Island
Epilepsy Foundation of Metropolitan New York
Epilepsy Foundation of Michigan
Epilepsy Foundation of Minnesota
Epilepsy Foundation of Mississippi
Epilepsy Foundation of Missouri and Kansas

Epilepsy Foundation of New England
 Epilepsy Foundation of New Jersey
 Epilepsy Foundation of North Central Illinois,
 Iowa, Nebraska
 Epilepsy Foundation of Northeastern New York
 Epilepsy Foundation of Northern California
 Epilepsy Foundation of San Diego County
 Epilepsy Foundation of Texas-Houston/Dallas-
 Fort Worth/West Texas
 Epilepsy Foundation of Vermont
 Epilepsy Foundation of Virginia
 Epilepsy-Pralid Inc.
 Equality Maryland
 EveryLife Foundation For Rare Diseases
 FAIR Foundation
 Familia Unida Living with MS
 Family Health Center of Boone County
 Fight AIDS for LIFE Foundation
 Fight Colorectal Cancer
 Filipino American Service Group Inc. (FASGI)
 Firehouse Family Ministries
 Florida CHAIN
 Florida Hemophilia Association
 Florida State Hispanic Chamber of Commerce
 FMS Pharmacy
 Frannie Peabody Center
 Friends For Life
 GBS/CIDP Foundation International
 Global Colon Cancer Association
 Global Healthy Living Foundation
 GMHC (Gay Men's Health Crisis)
 Good Samaritan United Methodist Church
 Granny Connection
 GT23 Foundation
 H.E.A.L.S. of the South
 Hawaii Island HIV/AIDS Foundation
 HEAL International
 Health People: Community Preventive Health
 Institute
 HealthHIV
 Healthy African American Families
 Heartland Alliance for Human Needs & Human
 Rights
 Hemophilia Alliance of Maine, Inc.
 Hemophilia Association of the Capital Area
 Hemophilia Foundation of Greater Florida
 Hep C Connection
 Hepatitis Foundation International
 HIV a Southern Epidemic!
 HIV ACCESS
 HIV and the Aging
 HIV Dental Alliance
 HIV Medicine Association
 HIV Prevention Justice Alliance
 HIV/AIDS Law Project
 HomeCare For The Carolinas
 Human Rights Campaign
 Huntington's Disease Society of America
 (HDSA)
 Illinois African American Coalition for
 Prevention
 Immune Deficiency Foundation
 Interfaith Community Health Center
 International Foundation for Autoimmune
 Arthritis
 International Institute For Human
 Empowerment, Inc.
 International Myeloma Foundation
 International Pemphigus & Pemphigoid
 Foundation
 The Jewish Federations of North America
 Jonah's Just Begun-Foundation to Cure
 Sanfilippo Inc.
 Joshua Tree Feeding Program, Inc.
 Kansas Association of Osteopathic Medicine
 Keeping It Real Neighborhood Institute, Inc.
 Lambda Legal
 Latina Breast Cancer Agency
 The Leukemia & Lymphoma Society
 The Leukemia & Lymphoma Society,
 Connecticut Westchester Hudson Valley
 Chapter
 The Leukemia & Lymphoma Society,
 Mississippi/Louisiana Chapter
 Loaves & Fishes Community Services
 Lone Star Chapter of National Hemophilia
 Foundation
 Los Angeles County HIV Drug & Alcohol Task
 Force
 Los Angeles LGBT Center
 Louisiana A.I.D.S. Advocacy Network
 Lupus Alliance of Long Island/Queens, Inc.
 Lupus Alliance of Upstate New York
 Lupus and Allied Diseases Association, Inc.
 Lupus Foundation of America
 Lupus Foundation of America, Florida Chapter
 Lupus Foundation of America, Georgia Chapter
 Lupus Foundation of America, Indiana Chapter
 Lupus Foundation of America, Texas Gulf Coast
 Chapter
 Lupus Foundation of Florida
 Lupus Foundation of Genesee Valley NY, Inc.

Lupus Foundation of Southern California
 Lupus Research Institute
 Lupus Society of Illinois
 Lutheran Services in America
 The Marfan Foundation
 Maryland Women's Coalition for Health Care Reform
 Massachusetts Association for Mental Health
 MedChi, The Maryland State Medical Society
 Medical AIDS Outreach of Alabama
 The Medical Oncology Association of Southern California, Inc.
 Medical Society of Northern Virginia
 Medical University of South Carolina/Lowcountry AIDS Services C.A.B.
 Men's Health Network
 Mental Health & Addiction Advocacy Coalition
 Mental Health Action
 Mental Health America
 Mental Health America of Colorado
 Mental Health Association of Minnesota
 Mental Health Systems
 Minnesota State Grange
 Missouri Family Health Council, Inc.
 Missouri Health Advocacy Alliance
 MLD Foundation
 Mother & Child Health Coalition
 Nashville CARES
 National Alliance of State & Territorial AIDS Directors
 National Alliance on Mental Illness
 National Alliance on Mental Illness Alabama
 National Alliance on Mental Illness Colorado
 National Alliance on Mental Illness Florida
 National Alliance on Mental Illness Illinois
 National Alliance on Mental Illness Maryland
 National Alliance on Mental Illness Minnesota
 National Alliance on Mental Illness North Carolina
 National Alliance on Mental Illness South Carolina
 National Alliance on Mental Illness South Dakota
 National Alliance on Mental Illness Tennessee
 National Alliance on Mental Illness Washington
 National Alliance on Mental Illness Wyoming
 National Association of Hepatitis Task Forces
 National Association of Hispanic Nurses
 National Association of Hispanic Nurses El Paso Chapter
 National Association of Social Workers
 National Coalition for LGBT Health
 National Community Pharmacists Association (NCPA)
 National Council for Behavioral Health
 National Council of Negro Women Inc. View Park
 National Fibromyalgia & Chronic Pain Association
 National Gay and Lesbian Task Force
 National Grange
 National Hemophilia Foundation
 National Kidney Foundation
 National Kidney Foundation of Florida
 National Minority Quality Forum
 National MS Society, Alabama-Mississippi Chapter
 National Osteoporosis Foundation
 National Patient Advocate Foundation
 National Psoriasis Foundation
 National Stroke Association
 National Viral Hepatitis Roundtable
 Neurofibromatosis, Inc. Mid-Atlantic Neuropathy Action Foundation
 New England Hemophilia Association
 New Jersey Association of Mental Health and Addiction Agencies, Inc.
 New Jersey Mayors Committee on Life Sciences
 New Orleans Council on Aging
 The Noonan Syndrome Foundation
 Obesity Action Coalition
 The Obesity Society
 Ohio Council of Behavioral Health & Family Services Providers
 OK AIDS Care Fund
 Open Door Clinic
 Ovarian Cancer Coalition of Greater California
 Ovarian Cancer National Alliance
 OWL - The Voice of Women 40+
 Parkinson's Action Network
 The Parkinson's Association
 Partnership Project
 Pediatric AIDS Chicago Prevention Initiative
 Philadelphia Center
 Plaza Community Services
 Positive Effect Outreach Ministry
 Positive Life Series
 Power of Pain Foundation
 Prevent Blindness
 Prevent Blindness, Iowa Affiliate
 Prevent Blindness, Ohio Affiliate
 Prevent Blindness, Texas Affiliate

Prevent Cancer Foundation
Private Advocate for PLWH
Program for Wellness Restoration
Pulmonary Hypertension Association
PWA Coalition Colorado
RAIN
RAIN Oklahoma
Renal Support Network
Resource Center
RetireSafe
Rush to Live
S.L.E. Lupus Foundation
Scleroderma Foundation
Sickle Cell Disease Association of Florida
Sickle Cell Foundation Incorporated
Sjogren's Syndrome Foundation
Society for Public Health Education
Society for Women's Health Research
Solidarity Project Advocacy Network
Southwest CARE Center
Southwest Center for HIV/AIDS

St. Louis Effort for AIDS
START at Westminster
Suicide Awareness Voices of Education
Sunburst Projects
Tech Council of Maryland
Tennessee Association of People With AIDS
Texas Bleeding Disorders Coalition
Texas Central Hemophilia Association
Transformation Birmingham
Tuberous Sclerosis Alliance
Umass Memorial
United Cerebral Palsy
United Spinal Association
Veterans Health Council of Vietnam Veterans of
America
Vietnamese Social Services of Minnesota
Virginia Hemophilia Foundation
The Wall Las Memorias Project
Windows of Hope
Women Against Prostate Cancer
Wyoming Epilepsy Association