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