An Open Appeal to Turing Pharmaceuticals:

We, the under-signed organizations, are concerned that despite a commitment by Turing Pharmaceuticals to lower the price of Daraprim (pyrimethamine) more than a month ago, the price has not been reduced nor have distribution issues been sufficiently addressed.

The controlled distribution system requiring purchase of Daraprim (pyrimethamine) through Walgreen’s Specialty Pharmacy and its classification as a “specialty drug” also continues to create high and unreasonable hurdles for a medication that previously was widely available through local pharmacies to providers and their patients.

As a result, many individuals with toxoplasmosis in the United States are left without access to the preferred treatment for a condition that if not effectively treated can cause blindness, brain and organ damage or death. Patients already affected by the failure of Turing Pharmaceuticals to act on its commitment include pregnant women, children, infants, people with HIV and others with compromised immune systems across the country, for example:

*Within the last month I was seeing a child recently diagnosed with toxoplasmosis and was unable to obtain pyrimethamine as all contacted pharmacies had it listed as discontinued by their distributors. I had to change to trimethoprim/sulfamethoxazole despite the fact that data on that therapy in pediatrics is thin.* – Reported by a physician

*A patient with toxoplasmosis retinitis was quoted a price of $26,000 so we had to change his medication to Bactrim. A second patient had cerebral toxoplasmosis and was unable to get medications refilled by Medicaid. The patient was switched to a second line therapy. Neither therapy is ideal.* – Reported by a physician

*Currently, we have two inpatients on pyrimethamine for cerebral toxoplasmosis. We have two days left of pyrimethamine. A single bottle of 100 pills is the smallest the hospital can buy and will thus cost $75,000. Both patients will have to be switched to trimethoprim/sulfamethoxazole.*

*Yes, we have had a major issue getting pyrimethamine initially for a pregnant woman, and then for her baby following delivery.* – Reported by a physician

We call on Turing Pharmaceuticals to take the following immediate actions regarding Daraprim (pyrimethamine):

1. Lower the price to a level comparable to the price prior to the August 5000% increase.
2. Provide parity on pricing for inpatient and outpatient settings.

† The Department of Health and Human Services guidelines on the Prevention and Treatment of Opportunistic Infections in HIV-infected Adults and Adolescents were updated on October 19th to offer guidance on the use of alternative therapies due to limited access to pyrimethamine.

‡ The Department of Health and Human Services guidelines on the Prevention and Treatment of Opportunistic Infections in HIV-infected Adults and Adolescents recommend a course of acute therapy for a minimum of six weeks followed by maintenance therapy for at least six months. Following their treatment recommendations, a minimum of 486 pyrimethamine tablets are required to effectively treat immunocompromised patients. Available online at: https://aidsinfo.nih.gov/contentfiles/lvguidelines/Adult_OI.pdf.

For more information, contact Andrea Weddle with the HIV Medicine Association at aweddle@hivma.org.
3. Offer support under the patient assistance program to patients with incomes at the level of at least 500 percent of the federal poverty level.

4. Provide complete transparency regarding eligibility and documentation requirements for the patient assistance and co-pay assistance programs.

5. Cover the maximum out-of-pocket costs ($6,600 for an individual plan and $13,200 for a family plan in 2015) on co-insurance and copayments allowable under the Affordable Care Act. The co-pay assistance program should be front-loaded to ensure that coinsurance amounts, which can be between 25 and 50 percent of the retail drug cost, are fully covered until the out-of-pocket limit is reached.

6. Ensure same day and direct access to the drug in the communities where patients live.

The unjustifiable actions taken to leverage the value of an effective 70-year old medication are jeopardizing the health of individuals with a serious, life-threatening condition. These individuals do not have the luxury of time to wait for promised new treatments – which also will likely be priced out of reach.

Endorsed by the 152 organizations listed below representing 29 states, the District of Columbia and Puerto Rico:

**Alabama**
- AIDS Alabama
- AIDS Alabama South
- Blue Faery: The Adrienne Wilson Liver Cancer Association
- Health Services Center
- University of Alabama at Birmingham, 1917 Outpatient HIV/AIDS Clinic
- Selma AIR
- West Alabama AIDS Outreach

**Arizona**
- El Rio Special Immunology Associates
- HIV/AIDS Law Project

**California**
- AIDS Healthcare Foundation
- AIDS Project Los Angeles
- Berkeley Free Clinic
- Correlia Biosystems, Inc.
- Cure for AIDS Coalition
- Infectious Diseases Associates Medical Group, Inc.
- Natural Wholistic Health & Wellness Research Center
- Pangaea Global AIDS
- Positive Life Series Palm Springs
- Positive Women's Network - USA
- Project Inform
- San Francisco AIDS Foundation
- San Francisco Hepatitis C Task Force
- SumOfUs.org
- The Ihangane Project
- Tom Waddell Urban Health Center
- WEB.PsyD

**Colorado**
- Treatment Education Network
- Liberty Community Services, Inc.

**Connecticut**
- 340B Health
- ADAP Advocacy Association (aaa+)
- AIDS United
- Alliance for Retired Americans
- American Academy of HIV Medicine
- American Federation of State, County and Municipal Employees
- Community Access National Network (CANN)
- DC Fights Back
- Fair Pricing Coalition
- GLMA: Health Professionals Advancing LGBT Equality
- HealthHIV
- Human Rights Campaign
- National Alliance of State and Territorial AIDS Directors
- National Black Justice Coalition (NBJC)
- National Center for Lesbian Rights
- National Center for Transgender Equality
- National Coalition for LGBT Health
- National Latina Institute for Reproductive Health
- National Latino AIDS Action Network (NLAAN)
- NMAC
- Positively Healthy
- The AIDS Institute
- Woodhull Freedom Foundation

**District of Columbia**
- 340B Health
- ADAP Advocacy Association (aaa+)
- AIDS United
- Alliance for Retired Americans
- American Academy of HIV Medicine
- American Federation of State, County and Municipal Employees
- Community Access National Network (CANN)
- DC Fights Back
- Fair Pricing Coalition
- GLMA: Health Professionals Advancing LGBT Equality
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- National Center for Lesbian Rights
- National Center for Transgender Equality
- National Coalition for LGBT Health
- National Latina Institute for Reproductive Health
- National Latino AIDS Action Network (NLAAN)
- NMAC
- Positively Healthy
- The AIDS Institute
- Woodhull Freedom Foundation

**Florida**
- Dab the AIDS Bear Project
- Okaloosa AIDS Support & Informational Services, Inc. (OASIS)

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1. This is in line with the policies of manufacturers of other HIV-related medications. See National Alliance of State and Territorial AIDS Directors. Pharmaceutical Company Patient Assistance Programs and Cost-sharing Assistance Programs. Online at: https://www.nastad.org/sites/default/files/HIV-PAPs-CAPs-Resource-Document.pdf.

2. IBID.
Georgia
AIDS Research Consortium of Atlanta
Emory University
Georgia AIDS Coalition
Georgia Equality
HIV Dental Alliance
HOPE CARE FOUNDATION

Hawaii
The CHOW Project

Illinois
AIDS Foundation of Chicago
HIV Prevention Justice Alliance
Howard Brown Health Center
Recovery 2000, Inc.
TACTS-The Association of Clinical Trial Services
Test Positive Aware Network
The Legal Council for Health Justice
University of Chicago Infectious Disease

Indiana
Mohammad Sharief, MD

Louisiana
Aspirations

Massachusetts
Boston Healthcare for the Homeless Program
Community Research Initiative
David Morris Nutritionist
Fenway Health
Search For A Cure
Treatment Access Expansion Project

Maryland
AIDS Action Baltimore
LIGHT Health & Wellness Comprehensive Services, Inc.
PeterCares House
Racial and Ethnic Health Disparities Coalition
The Veterans Health Council of Vietnam Veterans of America

Minnesota
Positive Care Center, Hennepin County Medical Center

New Jersey
Buddies of NJ, Inc
New Jersey Association on Correction
Sandra Palleja, MD

New Mexico
Albuquerque Pride
H.O.P.E. Alliance
New Mexico Hepatitis C Coalition
Southwest CARE Center

New York
ACRIA
AIDS Treatment Activists Coalition (ATAC)
Albany Damien Center
American Association for the Treatment of Opioid Dependence
AVAC
COPE
Division of Infectious Diseases, New York University School of Medicine
Doctors of the World USA Inc.
End AIDS Now

GMHC
Marriage Equality USA
National Queer Asian Pacific Islander Alliance (NQAPIA)
The Center for HIV Law and Policy
The Hepatitis C Mentor and Support Group
Treatment Action Group
Unity Fellowship of Christ Church NYC
VOCAL-NY

North Carolina
Division of Infectious Diseases, Department of Pediatrics, Duke University Medical Center
Southern HIV/AIDS Strategy Initiative
Warren-Vance Community Health Center, Inc.

Ohio
Association of Nurses in AIDS Care
Cincinnati Exchange Project
Nightsweats & T-cells, Co

Oregon
Caring Ambassadors Program
Cascade AIDS Project
Health Education Network

Pennsylvania
ACT UP Philadelphia
AIDS Resource Alliance
ALPHA Pittsburgh, Inc.
Prison Health News
Reading Health System

Puerto Rico
Pacientes de SIDA pro Politica Sana

Rhode Island
American Academy of Addiction Psychiatry
The Center for Prisoner Health and Human Rights
The Miriam Hospital Immunology Center

Tennessee
National Health Care for the Homeless Council
Vanderbilt Comprehensive Care Center

Texas
Gordon Crofoot, MD PA
Migrant Clinicians Network

Virginia
American Medical Student Association
HIV Medicine Association
Infectious Diseases Society of America
Pediatric Infectious Diseases Society
Ryan White Medical Providers Coalition

Washington
defeatHIV Community Advisory Board
Fred Hutch- defeatHIV CAB
Hepatitis Education Project
Point Defiance Aids Projects
Young Activists Against AIDS

Wisconsin
AIDS Resource Center of Wisconsin
Steven Schwimmer, DO, SC

No State Affiliation
Engender Rights Centre for Justice (ERCJ)
FAM-CRU, Stellenbosch University
JAPETI
Public Union Against AIDS
Southern AIDS Coalition
Stop Tuberculose Bouaké