

Released: October 22, 2015

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.^{1 2} – Reported by a physician

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.

¹The 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.

²The 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.

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.³
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.⁴
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

Colorado AIDS Project
 THRIVE!: The Persons Living With HIV/AIDS Initiative of

Colorado

Treatment Education Network

Connecticut

Liberty Community Services, Inc.

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
 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
 Pozitively Healthy
 The AIDS Institute
 Woodhull Freedom Foundation
Florida
 Dab the AIDS Bear Project
 Okaloosa AIDS Support & Informational Services, Inc. (OASIS)

³This 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>.

⁴ 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

Missouri

Hep C Alliance

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

Nevada

Amy Keller and Associates Consulting

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
 GHAP

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 Política 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