



August 4, 2016

www.citizen.org

Patients' Groups and Big Pharma

Three in Four Patients' Groups That Sided With the
Pharmaceutical Industry Against Medicare Drug Price
Reforms Received Industry Money

Acknowledgments

This report was written by Rick Claypool, research director for Public Citizen's president's office. Anisha Sehgal, intern for Public Citizen's Access to Medicines program, performed much of the research and data collection for the report, and Steven Knievel, campaign coordinator for Public Citizen's Access to Medicines program, provided background information and additional analysis.

About Public Citizen

Public Citizen is a national nonprofit organization with more than 400,000 members and supporters. We represent consumer interests through lobbying, litigation, administrative advocacy, research, and public education on a broad range of issues including consumer rights in the marketplace, product safety, financial regulation, worker safety, safe and affordable health care, campaign finance reform and government ethics, fair trade, climate change, and corporate and government accountability.



Public Citizen
1600 20th St. NW
Washington, D.C. 20009
P: 202-588-1000
<http://www.citizen.org>

© 2016 Public Citizen.

Key Finding

Out of 147 patients' groups that sided with the pharmaceutical industry against the Medicare Part B demonstration project, at least 110 (75%) received funding from the industry.

Patients' Groups and Big Pharma Funding

When patients' groups side with the pharmaceutical industry against proposed policy reforms, they lend credibility and a sympathetic voice to industry lobbying efforts. Where the industry's interest in lobbying for or against particular policies in Congress often is rightly perceived as purely financial, patients' groups present themselves as representing the voices of suffering individuals whose sole interest is to get better.

Identifying policies that industry and patients' groups seem to agree on might seem like a way for lawmakers to find common ground on which to move toward win-win reforms. However, patients' groups frequent reliance on contributions from the pharmaceutical industry in order to fund programs for the patients they serve should complicate the view that patients' groups' interest in such policy battles is categorically different from the industry's financial interest.

While donations from the pharmaceutical industry no doubt enable patients' groups to do work that makes significant, even life-changing impacts in the lives of individuals they serve, it does compromise their independence. It is certainly not the case that every patient group that takes money from Big Pharma is at the beck and call of industry; and, of course, there is a wide variance in groups' dependence on pharmaceutical industry funding. However, it is the case that industry funding tends to make groups more sympathetic to industry positions, and more likely to respond to industry requests to weigh in on policy issues, including matters about which they may have limited expertise. While groups accepting Big Pharma funding should not be foreclosed from participating in public policy debates, the fact of that funding should be disclosed in the context of their policy debate interventions.

The Medicare Part B Demonstration Project

Big Pharma's efforts to derail a Medicare Part B demonstration project proposed by the Centers for Medicare & Medicaid Services (CMS) have been joined by patients' groups. This particular instance of alignment between the industry and patients' groups merits close scrutiny, especially as consumer groups including Public Citizen and AARP voice strong support for the project as one that will benefit patients and taxpayers.

The pharmaceutical industry has a clear financial incentive in its forceful opposition to the proposed demonstration project, as do the doctors' groups that oppose it. The project seeks to lower spending on the priciest treatments under Medicare Part B – spending which has in recent

years doubled from \$11 billion to \$22 billion.¹ The proposed reform would study the effect of modifying reimbursement methods in a manner intended to decrease physicians' perverse incentive to administer the priciest treatments, thus lessening the frequency these drugs are prescribed when lower-priced medicines would treat patients equally well, if not better. Under current CMS reimbursement methods, a doctor who administers drugs in-office (such as for treatments for certain cancers, rheumatoid arthritis and certain common eye diseases that can lead to blindness)² will be reimbursed the average price of a drug plus six percent. Under the new proposal, the reimbursement rate is cut to 2.5 percent plus a modest flat fee. Phase II of the project would test value-based pricing mechanisms, such as reference-based pricing for certain classes of prescription drugs, intended to deliver better outcomes to patients at more affordable prices.

In addition to the pharmaceutical industry and doctors' groups, 147 patients' groups signed letters to Congress and CMS opposing the demonstration project.³ At least 110 (75%) of the patients' groups that signed on to letters opposing the Part B demonstration project received funding from the pharmaceutical industry.⁴ Unfortunately, patients' groups are not required to disclose these conflicts of interest, so this finding is based on voluntary disclosures that patients' groups and drug companies provide on their websites. As such, they likely under-represent the degree to which patients groups receive pharmaceutical industry sponsorship, and how much the groups received from the industry is mostly unknown. Nevertheless, this finding – that the overwhelming majority of patients' groups opposing the Medicare Part B drug pricing reforms have a conflict of interest thanks to funding they receive from the pharmaceutical industry – should make members of Congress, policymakers at CMS and others skeptical of these groups' advocacy on this topic.

Methodology

This report's findings are based on an analysis of patient groups that signed on to letters⁵ organized by the Partnership to Improve Patient Care (PIPC) and the Community Oncology Alliance (COA). Researchers identified 147 of the 388 groups as patients' groups, then visited each group's website to find evidence of pharmaceutical industry sponsorship. Some groups prominently displayed the logos of industry sponsors on their home page; for others, companies sponsored specific events or

¹ Medicare Program; Part B Drug Payment Model; Proposed Rule, Centers for Medicare & Medicaid Services, Federal Register Vol. 81, No. 48 (March 11, 2016), <https://www.regulations.gov/document?D=CMS-2016-0036-0002>

² Drugs for treating these illnesses top Medicare Part B spending, according to CMS data available here: https://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/Dashboard/Medicare-Drug-Spending/Drug_Spending_Dashboard.html.

³ The letter organized by the Partnership to Improve Patient Care is available here: <http://www.citizen.org/documents/pipc-part-b-letter-may-9-2016.pdf>; the letter organized by the Community Oncology Alliance is here <http://www.citizen.org/documents/coa-groups-letter-march-17-2016.pdf>.

⁴ See Appendix I below for a full list of the 110 groups that received industry funding and Appendix II for the 37 for which industry funding could not be identified.

⁵ See footnote 3.

programs or were listed among organizational benefactors in annual reports and other publications. For others, corporate sponsorships were identified via disclosures made on the websites of companies such as Pfizer and Sanofi. Others received funding from the Pharmaceutical Research and Manufacturers of America (PhRMA), an industry trade group, and this funding was revealed through the Center for Public Integrity's Nonprofit Network research tool.⁶ A full list of the industry-sponsored patient groups with links to the source of the report's corporate sponsorship findings appears below as an appendix.

⁶ The Center for Public Integrity's Nonprofit Network research tool compiles reports of transfers of money between nonprofit groups, and is available here:
<https://www.publicintegrity.org/2016/08/02/20030/search-nonprofit-network>

Appendix I

110 patients' groups that received pharmaceutical industry funding and signed the PIPC and/or the COA letter opposing the Medicare Part B demonstration project:

GROUP NAME	LETTER SIGNED	PHARMA SUPPORT SOURCE
1 in 9: The Long Island Breast Cancer Action Coalition	COA	https://www.publicintegrity.org/2016/08/02/20030/search-nonprofit-network
ADAP Advocacy Association	COA	http://www.adapadvocacyassociation.org/support.html
American Association of People with Disabilities	PIPC	http://www.aapd.com/
American Association on Intellectual and Developmental Disabilities	PIPC	http://aaid.org/education/annual-conference/archives/2014-annual-meeting/2014-sponsors-.V6N9347m89Y
American Bechet's Disease Association	COA	http://www.behcets.com/site/c.8oIJRPsGclSF/b.9145371/k.BD9A/Home.htm
American Foundation for the Blind	PIPC	http://www.afb.org/media/pdfs/afb_annual_report_2015.pdf
American Liver Foundation, Upper Midwest Division	COA	http://www.liverfoundation.org/about/corporatepartnerships/corporateroundtable/
Arthritis Foundation	COA	http://www.arthritis.org/about-us/partners-and-sponsors/proud-sponsors/
Asian Americans for Community Involvement	COA	http://aaci.org/bulletin/fy-14-honor-roll/
Asthma & Allergy Foundation of America, New England Chapter	COA	http://asthmaandallergies.org

Brain Injury Association of America	PIPC	http://www.biausa.org/current-sponsors.htm
California Chronic Care Coalition	PIPC	http://www.chroniccareca.org/Websites/chroniccareca/files/Content/5485228/Program handout final 2.9.16.pdf
California Hepatitis C Task Force	COA	http://www.californiahcvtaskforce.org/flashpaper/Summit_Brochure_2008.swf
Cancer Support Community	BOTH	http://www.cancersupportcommunity.org
Cancer Support Community Central Ohio	COA	http://cancersupportohio.org/get-involved/sponsor/
CancerCare	BOTH	https://media.cancercare.org/reports/original/cancercare-2015-annual-report.pdf?1468605099
Caregiver Action Network	COA	http://caregiveraction.org/can-corporate-leadership-council
Caring Ambassadors	COA	http://caringambassadors.org/our-supporters/
Caring Ambassadors Program, Inc.	PIPC	http://caringambassadors.org/our-supporters/
Cascade AIDS Project	COA	https://www.cascadeaids.org
COA Patient Advocacy Network	COA	http://www.communityoncology.org/home/coa-membership/corporate-members/
Coalition of Texans with Disabilities	COA	http://www.txdisabilities.org/ctd-sponsors
Colon Cancer Alliance	COA	http://www.ccalliance.org/about-us/sponsors/
Colorado Gerontological Society	COA	https://www.senioranswers.org/wp-content/uploads/2016/01/2015-Annual-Report.pdf
Community Access National Network	COA	http://www.tiicann.org/partners.html#pp
Community Liver Alliance	COA	http://www.communityliveralliance.org/#!2016-steel-chef-challenge/meugb
Cutaneous Lymphoma	BOTH	http://www.clfoundation.org/ways-to-give/become-

Foundation		corporate-partner
Dia de la Mujer Latina	COA	http://diadelamujerlatina.org/events/sponsors/
Digestive Disease National Coalition	COA	http://www.ddnc.org/Members.html
Easter Seals	PIPC	http://www.easterseals.com/who-we-are/partners/
Easter Seals Massachusetts	COA	http://www.easterseals.com/ma/easter-seals-annual-report.pdf
Eastern Pennsylvania Chapter, National Hemophilia Foundation	COA	http://www.hemophiliasupport.org
Epilepsy Foundation	PIPC	http://www.epilepsy.com/make-difference/ways-give/corporate-partnerships
Epilepsy Foundation Central and South Texas	PIPC	http://www.efcst.org/index.php/help/youth-programs/88-youth-programs/212-studio-e-art-therapy
Epilepsy Foundation Heart of Wisconsin	PIPC	http://epilepsywalk.kintera.org/faf/home/default.asp?event=1129855
Epilepsy Foundation Northwest	PIPC	https://www.epilepsynw.org/programs/camp-discovery
Epilepsy Foundation of Arizona	PIPC	http://epilepsyaz.org/programs/studio-e/
Epilepsy Foundation Of California	PIPC	http://www.epilepsynorcal.org/?page_id=1200
Epilepsy Foundation of Georgia	PIPC	http://epilepsyga.org
Epilepsy Foundation of Greater Chicago	BOTH	http://www.epilepsy-chicago.org/wp-content/uploads/2011/02/Annual-Reportonline.pdf
Epilepsy Foundation of Greater Cincinnati and Columbus	PIPC	http://www.epilepsy-ohio.org/programs/counseling-services/studio-e-the-epilepsy-art-therapy-program/
Epilepsy Foundation of Indiana	PIPC	http://indianaepilepsyfoundation.org/NEWS.html

Epilepsy Foundation of Long Island, A Division of EPIC Long Island	PIPC	http://epicli.org/our-friends
Epilepsy Foundation of Metropolitan New York	PIPC	http://www.efmny.org/events/studio-e-epilepsy-art-therapy-exhibit-2015/
Epilepsy Foundation of Michigan	PIPC	http://www.epilepsymichigan.org/page.php?id=415
Epilepsy Foundation of Minnesota	PIPC	http://www.epilepsyfoundationmn.org/giving/corporate-support-and-sponsorships/
Epilepsy Foundation of Missouri & Kansas	PIPC	http://efmk.org/give/event-sponsorship/
Epilepsy Foundation of New England	PIPC	http://www.epilepsynewengland.org/studio-e-art-program/
Epilepsy Foundation of North/Central IL, IA, NE	PIPC	http://www.epilepsyheartland.org/Resources
Epilepsy Foundation of the Chesapeake Region	PIPC	http://abilitiesnetwork.org/program-sponsorships/
Epilepsy Foundation of Utah	PIPC	http://epilepsyut.org/community-service-awards/
Epilepsy Foundation of Virginia	PIPC	http://www.epilepsyva.com/donors/
Epilepsy Foundation of Western Wisconsin	COA	http://static1.1.sqspcdn.com/static/f/542217/26322786/1459285478790/Annual+Report+2015.pdf?token=L3WatSGDVzXFyZrXirTvCPUn%2BYQ%3D
Epilepsy Foundation Texas-Houston/Dallas-Fort Worth/West Texas	PIPC	http://eftx.org/about-us/sponsors-and-partners/
Epilepsy Foundation Western/Central Pennsylvania	PIPC	http://www.efwp.org/about/2015_EFWCP_Spring_Summer_Newsletter.pdf

Epilepsy-Pralid, Inc.	PIPC	https://epiny.org/downloads/EPI-Matters-2015-Annual-Report.pdf
Fabry Support and Information Group	COA	http://en.sanofi.com/csr/approach/stakeholders/patient_associations/patient_associations.aspx
FH (Familial Hypercholesterolemia) Foundation	PIPC	https://thefhfoundation.org/about-us/sponsors/
Fight Colorectal Cancer	PIPC	http://fightcolorectalcancer.org/about-fight-colorectal-cancer/sponsors/
Florida Allergy, Asthma & Immunology Society	COA	http://www.faais.org/sponsors.php
GBS CIDP Foundation International	COA	http://www.gbs-cidp.org/wp-content/uploads/2011/11/Annual_Report_Final_LR.pdf
Global Colon Cancer Association	COA	http://www.globalcca.org/Sponsors.html
Global Healthy Living Foundation	COA	https://www.ghlf.org/about/our-partners/
HealthHIV	COA	http://www.healthhiv.org/fundersdonate/
Help4Hep	PIPC	https://dennis-simon.squarespace.com/the-support-partnership
Hepatitis C Association	PIPC	https://dennis-simon.squarespace.com/the-support-partnership
Hepatitis Foundation International	BOTH	http://hepatitisfoundation.org/events/hfi-summits/2016-hfi-exhibitor-prospectus/
Immune Deficiency Foundation	COA	http://primaryimmune.org/about/idf-core-service-corporate-sponsors/
International Cancer Advocacy Network	COA	http://askican.org/upcomingevents.html
International Foundation for Autoimmune Arthritis	COA	http://www.walktocurearthritis.org/faf/SponsorASP/ViewSponsors.asp?ievent=1145120&lis=1&kntae1145120=4A9F9B6B9B4A4119B8405990484C3B1C

International Myeloma Foundation	PIPC	https://myeloma.org/Main.action
Kidney Cancer Association	PIPC	http://www.pfizer.com/files/responsibility/grants_contributions/2016_Q1_TIG_06142016.pdf
Lung Cancer Alliance	BOTH	http://www.lungcanceralliance.org/shine-a-light-on-lung-cancer/
LUNgevity	COA	https://www.lungevity.org/sites/default/files/financial-legal/2015-annual-report.pdf
Lupus Foundation of America, Indiana Chapter	COA	http://b.3cdn.net/lupus/9c3bc0ea14942cb531_upm6bbpkj.pdf
Massachusetts Association for Mental Health	COA	http://www.mamh.org/WhoWeAre/Supporters/tabid/157/Default.aspx
Men's Health Network	COA	http://www.pfizer.com/files/responsibility/grants_contributions/2016_Q1_TIG_06142016.pdf
National Alliance on Mental Illness	BOTH	http://www.nami.org/About-NAMI/Our-Finances/Major-Foundation-Corporate-Sponsorships
National Alliance on Mental Illness Greater Des Moines	COA	http://www.namiwalks.org/index.cfm?fuseaction=donorDrive.event&eventID=561
National Alliance on Mental Illness Iowa	COA	http://www.namiwalks.org/index.cfm?fuseaction=donorDrive.event&eventID=561
National Alliance on Mental Illness Texas	COA	http://namitexas.org/corporate-sponsors/
National Association of Hepatitis Task Forces	COA	http://www.nahtf.org/partnerships/index.html
National Blood Clot Alliance	COA	https://www.stoptheclot.org/nbca-corporate-roundtable.htm
National Council on Independent Living	PIPC	http://www.ncil.org/wp-content/uploads/2015/02/2014AnnualReport.pdf
National Infusion Center Association	BOTH	https://infusioncenter.org/partners/

National MPS Society	COA	http://mpssociety.org
National Patient Advocate Foundation	BOTH	http://www.patientadvocate.org/pdf/annual_report/annual13-14/
National Viral Hepatitis Roundtable	PIPC	http://nvhr.org/content/members/sponsors
Neurofibromatosis Mid-Atlantic	COA	http://www.nfmidatlantic.org/?page_id=188
North American Thrombosis Forum	COA	http://www.natfonline.org/corporate-sponsorship/
Patient Services, Inc.	PIPC	https://www.patientservicesinc.org/Portals/0/Patient%20Services,%20Inc.-%202015%20Annual%20Report%20for%20Print.pdf
Patients Rising	COA	https://patientsrising.org/partners-and-supporters
Prevent Blindness	COA	http://www.preventblindness.org/our-partners
Prevent Cancer Foundation	COA	http://preventcancer.org/about-us/alliances/
Prostate Conditions Education Council	COA	https://www.prostateconditions.org/get-involved/sponsorship
Pulmonary Hypertension Association	COA	http://www.phassociation.org/CorporateCommittee
RetireSafe	BOTH	http://www.pfizer.com/files/responsibility/grants_contributions/2016_Q1_TIG_06142016.pdf
Rush to Live	COA	https://www.publicintegrity.org/2016/08/02/20030/search-nonprofit-network
Society for Women's Health Research	COA	http://swhr.org/about/corporate-advisory-council/
State of Texas Kidney Foundation	COA	http://txkidney.org/index.html
StopAfib.org	COA	http://www.stopafib.org/thanks.cfm

Taking Control Of Your Diabetes	COA	https://www.tcoyd.org/index.php/sponsors/corporate-sponsors-section.html
The Mended Hearts, Inc.	COA	http://mendedhearts.org/get-involved/sponsors
The Vasculitis Foundation	COA	http://www.vasculitisfoundation.org/wp-content/uploads/2015/07/Vasculitis_Foundation_Annual-Report-2014-15.pdf
U.S. Hereditary Angioedema Association	COA	http://www.haea.org
U.S. Pain Foundation	PIPC	https://www.uspainfoundation.org/transparency/
United Cerebral Palsy	PIPC	http://ucp.org/getinvolved/corporatepartners/
United Spinal Association	PIPC	http://www.unitedspinal.org/corporate-advisory-council/
Veterans Health Council	COA	http://www.veteranshealth.org/participants.html
Washington State Prostate Cancer Coalition	COA	http://www.prostatewashington.org/advisory-council/
Wellness and Education Community Action Health Network	COA	http://www.wecahn.org/donate/funders-and-sponsors.html

Appendix II

37 patients' groups that signed the PIPC and/or the COA letter opposing the Medicare Part B demonstration project, but for which pharmaceutical industry funding was not identified

GROUP NAME	LETTER SIGNED
Action CF	COA
Advocates for Responsible Care	COA
Alzheimer's and Dementia Alliance of Wisconsin	COA
Autistic Self Advocacy Network	PIPC

Axis Advocacy	COA
Brain Injury Association of Georgia	COA
Cancer Support Community North Texas	COA
Center for Independence of the Disabled, NY	PIPC
Christopher and Dana Reeve Foundation	PIPC
Colorado Gerontological Society	COA
Disability Rights Education and Defense Fund	PIPC
EDSers United Foundation	COA
Epilepsy Foundation of Nevada	PIPC
Epilepsy Foundation of Northeastern New York	PIPC
Epilepsy Foundation of Vermont	PIPC
Georgia Mental Health Consumer Network	COA
H.E.A.L.S of the South	COA
International Institute For Human Empowerment, Inc.	COA
Lakeshore Foundation	PIPC
Lupus Foundation of Colorado	COA
Michigan Lupus Foundation	COA
National Alliance on Mental Illness Kentucky	COA
National Association for Rural Mental Health	COA
National Association of Councils on Developmental Disabilities	PIPC
National Association of State Head Injury Administrators	PIPC
National Disability Rights Network	PIPC
Not Dead Yet	PIPC

Parent to Parent USA	PIPC
Pediatric Congenital Heart Association	PIPC
Prevent Blindness, Ohio Affiliate	COA
South Florida Cancer Association	COA
Spina Bifida Association of Kentucky	COA
The Arc of the United States	PIPC
The Bazelon Center	PIPC
The Crohn's Colitis Effect	COA
The Hepatitis C Mentor and Support Group	PIPC
The Judge L. Bazelon Center for Mental Health Law	PIPC
Wyoming Epilepsy Association	COA