

**Pharmaceutical Links of NGOs
Contributing to the World Health
Organization's Second Public Hearing on
Public Health, Innovation and Intellectual Property**

by

**Essential Action
Washington, DC
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www.essentialaction.org/access

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Introduction

The World Health Organization's Intergovernmental Working Group on Public Health, Innovation and Intellectual Property (IGWG) on November 5, 2007 convened a second hearing to prepare a global strategy and plan of action for improving access to drugs in the developing world and promoting research and innovation for new drugs. The pre-hearing process allowed interested non-governmental parties to submit comments, but the parties were not required to disclose their pharmaceutical or other corporate ties. As a result, many of the organizations erroneously appeared unconnected to pharmaceutical companies that have a financial stake in the outcome of the IGWG process.

Even excluding pharmaceutical trade associations that described themselves as “NGOs,” NGO submissions from groups with links to the pharmaceutical industry outnumbered those from independent groups by a margin of 2 to 1.

Understanding an organization's ties to affected industries is helpful in assessing the merits of comments submitted. Essential Action urges the WHO in the future to request that all authors disclose their financial ties to corporations, including funding sources and whether the author is a consultant, lobbyist or other representative of private industry.

To determine which non-governmental organizations have received pharmaceutical support, Essential Action surveyed the groups that submitted comments to the IGWG. An email request was sent to each organization identified by IGWG as an “NGO,” “Civil Society,” “International Organization,” or “Academia/Research.” (See email in Appendix I.) We did not query trade associations that described themselves as NGOs, since they clearly represent industry views. The email requested whether the organization accepts funding from for-profit corporations or trade associations. In addition, the board of directors and/or advisory committees were scanned for each group to determine any link to the pharmaceutical industry. For organizations that did not respond to the email request, websites and relevant news stories were examined to determine corporate links.

The survey shows 22 NGOs that submitted comments to the IGWG have either accepted funding from pharmaceutical companies and/or employ pharmaceutical representatives on the organization's board of directors or advisory committees. Only eight of the NGOs submitting a total of 11 comments do not receive pharmaceutical industry funding. Thirteen pharmaceutical and biotechnology trade associations or chambers of commerce also submitted comments. A number of academics submitted comments; most do not appear to have pharmaceutical industry ties.

The overall result was an IGWG hearing process dominated on a quantitative basis by pharmaceutical firms and organizations with links to the industry -- a fact not apparent from looking at the names of commenting organizations, or reading the submissions.

A summary of responses appears below. Appendix II contains the full response from organizations that gave more detailed answers.

Summary of Responses from NGOs¹

Gene Copello - Executive Director, the AIDS Institute. Did not respond to Essential Action's request for information. The institute's board of directors includes William Schuyler, vice president of Federal Government Relations with GlaxoSmithKline.²

Catherine Benavidez Clayton - Alliance of Health Disparities, USA. Did not respond to Essential Action's request for information. Clayton is president of the National Association of Hispanic Nurses, Colorado Chapter.³ The group's 2007 conference was sponsored by pharmaceutical and biotechnology companies.⁴

Bishop Council Nedd II - Alliance for Health Education and Development (AHEAD), USA. Did not respond to Essential Action's request for information. Nedd is a former lobbyist for the health care industry and currently president of AHEAD.⁵ He is a spokesman⁶ for the Partnership for Prescription Assistance,⁷ which is sponsored by America's pharmaceutical research companies.⁸ The Partnership advertises on AHEAD's website. Nedd worked for Citizens Against Government Waste (CAGW) during the 1990s. His name surfaced in the Jack Abramoff lobbying scandal when it was disclosed that Nedd, while employed at CAGW, helped the disgraced lobbyist obtain favorable media treatment for his clients.⁹

Marc Wortmann - Alzheimer's Disease International (ADI), UK. ADI accepts pharmaceutical funding, including donations from Pfizer and Eisai.¹⁰

Virginia Ladd - American Autoimmune Related Diseases Association (AARDA), USA. "We do receive corporate and foundation funds from those entities who have an interest in our work for patients. Within established guidelines, I believe this is standard practice in the USA."¹¹

Kelsey Zahourek - Property Rights Alliance, Americans for Tax Reform (ATR). Did not respond to Essential Action's request for information. Pfizer and tobacco companies have financed ATR.¹²

Dr. Milan Hosta - Asthma & Sport Organization, Republic of Slovenija. Dr. Hosta confirmed his organization accepts money from pharmaceutical companies and that "we are aware of the sublime pressure that such policy of private corporations can have on the 'subconscious' of NGOs and other related parties."¹³

¹ Listed alphabetically by organization name.

² The AIDS Institute website: <http://theaidsinstitute.org/downloads/2004%20New%20Board%20Members.doc>

³ National Association of Hispanic Nurses website: <http://thehispanicnurses.org/chapters/viewcat-6.html?Itemid=29>

⁴ National Association of Hispanic Nurses website: <http://thehispanicnurses.org/2007-sponsor-links/>

⁵ AHEAD website: <http://www.ahead-usa.org/leadership.html>

⁶ "Black Activists Criticize Efforts to Politicize Black Churches," Newsblaze.com.

<http://newsblaze.com/story/20060703214823nnnn.np/topstory.html>

⁷ Internet posting by "BishopNedd": <http://www.qubetv.tv/photos/detail/8182>

⁸ Partnership for Prescription Assistance website: <https://www.pparx.org/fourmillion.php>

⁹ Minority Staff Report, Investigation of Jack Abramoff's Use of Tax-Exempt Organizations, Oct. 2006.

<http://www.indianz.com/docs/finance/reportonly.pdf>

¹⁰ ADI's 2006 annual report, p. 12. <http://www.alz.co.uk/adi/pdf/annrep06.pdf>

¹¹ Email from Virginia Ladd, Nov. 1, 2007.

¹² SourceWatch: http://www.sourcewatch.org/index.php?title=Americans_for_Tax_Reform

¹³ Email from Milan Hosta, Oct. 30, 2007

Adrian Koning - Canadian Organization for Rare Disorders, Canada. Did not respond to Essential Action's request for information. The group accepts funding from numerous biotechnology and pharmaceutical companies, including Pfizer, Merck and Novartis.¹⁴

Ronald Cass - Center for the Rule of Law, USA. Did not respond to Essential Action's request for information. Cass is chairman of Cass and Associates, which advises private corporations on trade issues and intellectual property.¹⁵

Randall Maxey - Community Life Improvement Program in Association with the Alliance of Minority Medical Associations (AMMA), USA. Did not respond to Essential Action's request for information. AMMA is not listed in directory assistance and the phone number on AMMA's website¹⁶ is to the National Minority Quality Forum, whose executive director is Dr. Gary Puckrein. Puckrein is also executive director of AMMA.¹⁷ The Forum accepts donations from companies, including Pfizer, Amgen, Abbott Laboratories, AstraZenca, Bristol Myers Squibb, MedImmune, Johnson & Johnson, Sanofi Synthelabo, Biotechnology Industry Organization, and the Pharmaceutical Research and Manufacturers of America. Dr. Maxey is a member of the Forum's scientific advisory board.¹⁸

Durhane Wong-Rieger - Consumer Advocare Network, Canada. Did not respond to Essential Action's request for information. It has accepted funding from Rx&D, Canada's association of research-based pharmaceutical companies.¹⁹

Randall Rutta – Easter Seals, USA. Did not respond to Essential Action's request for information. The group accepts funding from corporations, including Bayer HealthCare, Invacare Corporation, Johnson & Johnson, and Pfizer.²⁰

Harry Kletzko - German Pain League. Did not respond to Essential Action's request for information. Kletzko is vice president of the German Pain League, which is funded by medical equipment manufacturer Medtronic.²¹ He is also chairman of the Neuropathic Pain Network (NPN), which is funded by Pfizer.²² In 2006, the German Pain League successfully worked to defeat proposed government regulations that were opposed by Medtronic. The company heralded the League's success in “negotiating a new, more moderate policy change.”²³ The League is a member of the industry-funded International Alliance of Patients' Organizations.

Peter Munyi - Health Action International Africa, Kenya. “We don't accept any in-kind donations from private corporations.”²⁴

¹⁴ Canadian Organization for Rare Disorders website: <http://www.raredisorders.ca/index.php/site/membership/corporate>

¹⁵ Cass and Associates website: <http://www.cassassociates.net>

¹⁶ AMMA's website: <http://www.ammaonline.org/contactus.htm>

¹⁷ National Minority Quality Forum website: <http://www.nmqf.org/staff.aspx>

¹⁸ National Minority Quality Forum website: <http://www.nmqf.org/ScientificAdvisoryBoard.aspx>

¹⁹ Consumer Advocare website: <http://consumeradvocare.org/index.php/ca/content/view/full/65/>

²⁰ Easter Seals website: http://www.easterseals.com/site/PageServer?pagename=ntl_corporate_sponsors&s_esLocation=pf_v

²¹ Medtronic website: http://www.medtronic.com/foundation/programs_pl_grant_list.html

²² Neuropathic Pain Network website: <http://www.neuropathicpainnetwork.org/english/coalition/index.asp>

²³ Medtronic website: <http://www.medtronic.com/foundation/newsletter/may06/article5.html>

²⁴ Email from Patrick Mubangizi, Health Action International Africa, Nov. 3, 2007.

Christian Wagner - Health Action International, Essential Innovation Campaign: “Health Action International does not accept any funding by pharmaceutical companies.”²⁵

Herbert Perry - Health Care Advocacy Alliance, USA. Did not respond to Essential Action's request for information. In Dec. 2006, Pfizer sponsored a conference held by HCAA regarding the benefits of Medicare's prescription drug coverage.²⁶

Jorge Quel - Hispanic-American Allergy Asthma and Immunology Association, USA. In 2001, CBS News referred to Dr. Quel as a “California allergist and pharmaceutical spokesman.”²⁷ HAAAI An partnered with Aventis Pharmaceuticals to promote its drug Allegra.²⁸ Along with Randall Maxey, Quel is a member of the scientific advisory board for the industry-funded National Minority Quality Forum, headed by Dr. Gary A. Puckrein.

Jeremiah Norris - Center for Science in Public Policy, Hudson Institute, USA. Did not respond to Essential Action's request for information. Hudson's latest online annual report confirms it accepts donations from corporations, including Eli Lilly, Guidant Corp., Merck & Co., Monsanto, Pfizer, and the Pharmaceutical Research and Manufacturers of America.²⁹

Thomas Pogge - Incentives for Global Health, USA, Centre for Applied Philosophy and Public Ethics (CAPPE), Australia. “No ... we accept no such donations; and thanks for doing this. It was clear from many of the other contributions that they could not honestly say the same thing about themselves.”³⁰

Lawrence A. Kogan - Institute for Trade, Standards and Sustainable Development (ITSSD) - “To the extent there are corporate monies donated to support our efforts, all the better.”³¹

Jo Harkness - International Alliance of Patients' Organizations (IAPO), UK. “IAPO does receive funding from companies (including pharmaceutical companies).”³²

Jacqueline Bonisteel - Innovation, Policy and Science program area of the International Development Research Centre (IDRC), Canada. Did not respond to Essential Action's request for information. IDRC accepts funding from private corporations.³³ It's not clear if the organization receives pharmaceutical industry support.

Xuanhao Chan - FIP/International Pharmaceutical Federation, Netherlands. “No, our organization does

²⁵ Email from Christian Wagner, Oct. 29, 2007.

²⁶ “Nevada Experts Educate Seniors on the Benefits of Medicare's Drug Coverage,” PR Newswire/RedOrbit.com, Dec. 1, 2006.
http://www.redorbit.com/news/health/751612/nevada_experts_educate_seniors_on_the_benefits_of_medicares_drug/index.html

²⁷ “Allergy Relief?”, CBS News, May 12, 2001. <http://www.cbsnews.com/stories/2001/05/10/national/main290642.shtml>

²⁸ Hispanic-American Allergy and Immunology Association website:
http://www.haama.org/Pages/Allegra_Pages/press_release.htm

²⁹ Hudson's 2003 Annual Report: http://www.hudson.org/files/publications/2003_Annual%20Report.pdf

³⁰ Email from Thomas Pogge, Oct. 25, 2007.

³¹ Email from Lawrence A. Kogan, Oct. 25, 2007.

³² Email from Jo Harkness, Oct. 31, 2007.

³³ IDRC's website: http://www.idrc.org.sg/uploads/user-S/11071836081PBD_brochure_e.pdf

not accept cash donations or in-kind contributions from for-profit corporations or trade associations.”³⁴

Stephen McMahon - Irish Patients Association, Ireland. Did not respond to Essential Action's request for information. Accepts funding from Merck Sharpe & Dohme (Human Health) Ltd., and Pfizer³⁵.

Daniele Dionisio - Access to Drugs: International Policies, Italian Network for International Fight against AIDS (CLIA). Did not respond to Essential Action's request for information. CLIA's international advisory board includes Eric Noehrenberg, who is the director of International Trade and Market Policy, IFPMA (International Federation of Pharmaceutical Manufacturers & Associations).³⁶

Frederick Modell - Jeffrey Modell Foundation, USA. Did not respond to Essential Action's request for information. Accepts corporate funding and has an industry advisory board comprised of representatives from Baxter BioScience, Octapharma, CSL Behring, Talecris Biotherapeutics, and Grifols USA.³⁷

Spring Gombe, James Love and Manon Ress - Knowledge Ecology International (KEI), USA. “As a matter of policy, because of our involvement in policy debates over innovation and access to medical technologies, KEI does not accept cash or in-kind contributions from the pharmaceutical or biomedical industry. As a general matter, concerning funding, in areas outside of the biomedical field, we may in the future have occasions where we would consider accepting contributions from some for-profit entities. For example, we may decide in the future to consider pro-bono services from law firms, film makers, photographers, accounting firms or public relations firms, in cases that do not present a conflict of interest. However, to date, KEI's only funding has come from private foundations and individuals.”³⁸

Ellen t’Hoen - Médecins Sans Frontières, Campaign for Access to Essential Medicines, France. “I am sure that corporate funding is accepted by MSF but on a small scale. Most of our money comes from individual donors The MSF Access to Essential Medicines Campaign does not accept any donations in cash or kind from outside. The Campaign - being an international MSF project - is financed directly by the MSF sections.”

Thomas Gebauer - Medico International, Germany. Accepts donations from “small-scale for-profit corporations such as lawyer-offices, medical practitioners [sic], or smaller companies.” Does not accept funding from pharmaceutical companies.³⁹

Leroy Watson - National Grange of the Order of Patrons of Husbandry, USA. Does not accept funding from corporations.⁴⁰

³⁴ Email from Xuanhao Chan, Oct. 29, 2007.

³⁵ Irish Patients Association website:

http://www.irishpatients.ie/assets/68/568EA235-491A-4DDD-8949705F60285940_document/EU_Patients_Charter.pdf

³⁶ CLIA's announcement of the “1st CLIA International workshop-Rome-Italy”, <http://translate.google.com/translate?hl=en&sl=it&u=http://www.poloinformativohiv.it/modules.php%3Fname%3DKalender%26op%3Dview%26eid%3D49&sa=X&oi=translate&resnum=2&ct=result&prev=/search%3Fq%3D%2522Daniele%2BDionisio%2522%2Bpfizer%26hl%3Den%26sa%3Dg>

³⁷ Jeffrey Modell Foundation website: <http://www.info4pi.org/jmf/index.cfm?section=jmf&content=directors&CFID=2813523&CFTOKEN=3>

³⁸ Email from James Love, Nov. 6, 2007.

³⁹ Email from Thomas Gebauer, Oct. 31, 2007.

⁴⁰ Telephone call with Leroy Watson, Nov. 2, 2007.

Myrl Weinberg - National Health Council, USA. The Council's corporate partners include Amgen, AstraZeneca, Eli Lilly, GE Healthcare, GlaxoSmithKline, Johnson & Johnson, Merck, Novartis, Novo Nordisk, Pfizer, Roche, Sanofi-Aventis, Schering-Plough and Wyeth Pharmaceuticals.⁴¹

Philip Stevens - On Behalf of a Coalition of 24 Civil Society Groups, UK. Did not respond to Essential Action's request for information. Stevens is the director of policy at the International Policy Network (IPN), a UK-based development think tank.⁴² IPN's Website: "IPN's membership programme allows individuals, foundations and businesses to donate to our activities and our world-wide network."⁴³ The IPN has accepted funding from the Eli Lilly Foundation.⁴⁴

Mohga Kamal-Yanni - Oxfam International, UK. Does not accept funding from the pharmaceutical industry.⁴⁵

Sangeeta Shashikant - Third World Network, Malaysia. "We do not get any funds from companies or from for-profit trade associations."⁴⁶

Caroline Gallant, Universities Allied for Essential Medicines (UAEM), USA. "We haven't received any money from any for-profit corporations or trade associations. We are funded by foundations (our primary source), private gifts and in-kinds and small grants that students get from their school."⁴⁷

⁴¹ National Health Council website: <http://www.nationalhealthcouncil.org/aboutus/membership.htm>

⁴² IPN's website: http://www.policynetwork.net/main/content.php?content_id=6

⁴³ IPN's website: http://www.policynetwork.net/main/content.php?content_id=2

⁴⁴ Eli Lilly and Company Foundation, Form 990-PF, 2005.

⁴⁵ Email from Mohga Kamal-Yanni, Oct. 31, 2007.

⁴⁶ Email from Sangeeta Shashikant, Nov. 4, 2007.

⁴⁷ Email from Ethan Guillen of UAEM, Nov. 6, 2007.

Summary of Responses from Academia

Kevin Outterson - Associate Professor of Law, Boston University, USA. “I certainly didn't receive \$\$ from any one for this IGWG submission, other than my salary as a professor at BU. The only external funding I received this year was a visiting scholar appointment at Seton Hall School of Law, which included funds from Merck. I used the visit to critique Merck's lack of attention to access to its HPV vaccine. I must say that when I saw the groups which submitted, that many of them looked like pharma funded astroturf.”⁴⁸

Jerome Reichman - Duke University School of Law, USA. “We received no funding from pharmaceutical companies that I know of.”⁴⁹

Frederick Abbott - Florida State University College of Law, USA. “The comments Jerry and I submitted to the IGWG process are based very closely on a study we initially prepared for the European Parliament Committee on International Trade, and paid for by the Parliament's Directorate General for External Policy I am not making comments to IGWG on behalf of an NGO. I am making them on behalf of myself as an independent academic employee of a government-funded state university, which presumably accepts contributions from a wide range of sources, which may include some pharmaceutical industry enterprises But, if the question is, do I ever provide consulting services on a paid basis for a trade association, the answer is yes -- but that is disclosed, for example, on my study prepared for the Indian Pharmaceutical Alliance for the Patent Experts Committee (Mashelkar, et al.). I state on the front page that it was prepared on behalf of the IPA.”⁵⁰

Jean-Frederic Morin - The Innovation Partnership, McGill University, Canada. “No, we have not accepted donations from private corporations or trade associations.”⁵¹

Tina Piper - The Innovation Partnership, McGill University, Canada. The partnership accepts no corporate funding.⁵²

Wayne Taylor - McMaster University professor of business and director of the school's Health Leadership Institute, Canada. Did not respond to Essential Action's request for information. Taylor owns a private consulting practice outside of his duties at McMaster. His website says, “President of his own private consulting practice, Dr. Taylor's clients include many of the leading health care organizations, governments, and Fortune 1000 companies in Canada, the United States and Europe.”⁵³

Aidan Hollis - Department of Economics, University of Calgary, Canada. “I work for the University of Calgary. I believe that the university accepts donations from anyone. I think it extremely unlikely that university is able to list all donations, but I may be wrong. If you like, you can ask the University for a list of all corporate donors. You can look for the appropriate administrative department at www.ucalgary.ca. Most likely the university has received donations from most major pharmaceutical corporations. The university does, however, receive massive funding from the

⁴⁸ Email from Kevin Outterson, Nov. 6, 2007.

⁴⁹ Email from Jerome Reichman, Nov. 5, 2007.

⁵⁰ Email from Frederick Abbott, Nov. 2, 2007.

⁵¹ Email from Jean-Frederic Morin, Oct. 26, 2007.

⁵² Email from Tina Piper, Oct. 26, 2007.

⁵³ Wayne Taylor's website: <http://www.degroote.mcmaster.ca/dir/atoz/wtaylor.aspx>

Government of Alberta, which as you can imagine is a major purchaser of pharmaceutical products. I can, however, assure you that the university has in no way whatsoever indicated to me that it would like me to make any submission to IGWG....”⁵⁴

Andrew Farlow - Saïd Business School, University of Oxford, UK. “I am an academic working in a university business school and submitted in that capacity and as a private individual. All my projects are foundation supported, but the report I submitted I did not get a penny from anyone for it whether foundation or private source!”⁵⁵

⁵⁴ Email from Aidan Hollis, Oct. 25, 2007.

⁵⁵ Email from Andrew Farlow, Oct. 25, 2007.

Organizations Not Responding to Survey

Alexander Gershman - American Russian Medical Association, USA.

Felix Rozanski - Director, Asociación de Derechos Intelectuales, Argentina. Director of Intellectual Property Rights Association ASDIN, Argentina.

Margaret De Rooy - Healthcare Evolves with Alliances & Leadership, USA

Ann Sullivan - International Association for Business and Health (IABH), USA.

Hiroko Yamane - Academia/Research, Graduate Institute for Policy Studies, Japan.

Appendix I

Email Sent to NGOs and Academics

Dear :

I am a staff attorney with Essential Action, a nonprofit public interest group based in Washington, DC that works to promote access to essential medicines. We are surveying nonprofit organizations that submitted comments in the IGWG public hearing process to ask if they accept donations from private corporations or trade associations.

Could you please reply and indicate whether your organization accepts, or has accepted, cash donations or in-kind contributions from for-profit corporations or trade associations? If yes, would you be willing to list the companies, date of donation, purpose of the donations if any was specified, and amount? Please mark your answer below.

Information about our project is available at <http://www.EssentialAction.org/access>.

Thank you very much.

Sincerely,

Jim Donahue
Essential Action
Tel. 202-387-8030
Fax. 202-234-5176
jdonahue@essential.org

1. ___ Yes, our organization accepts cash donations or in-kind contributions from for-profit corporations or trade associations.

___ No, our organization does not accept cash donations or in-kind contributions from for-profit corporations or trade associations.

2. If answer to question one is yes:

___ Yes, we are willing to share information about corporate contributions publicly with you. (For each donation, please list below the contributing company, amount of contribution, purpose of the contribution, if any, and date.)

___ No, we are not willing to share information about corporate contributions.

Appendix II

Detailed NGO Responses

Email response from Thomas Gebauer, Executive Director, Medico International

Dear Mr. Donahue,

Thanks for your mail. You will find information about medico international at our website www.medico-international.de. The English section also contains medico's annual report for 2006.

medico international accepts private donations and public grants for specific programmes. Since we are not engaged in what is called "sponsoring" we do not separate between cash-donations given to us by individuals and those coming from small-scale for-profit corporations such as lawyer-offices, medical practitioners, or smaller companies e.g. within the communication and IT-sector. Donations from this side are given to us without any precondition and specific announcement, just showing up on our accounts like donations from individuals. It would be quite difficult and too time consuming to differentiate within these kind of donations.

However, let me make myself perfectly clear: medico never accepted donations offered to us with the purpose to receive any service in return ("sponsoring"). The last time we received cash-donations or in-kind contributions from bigger companies is about twenty years ago. The reason is simple: medico is an outspoken "left-wing" NGO, heavily engaged in criticizing the neo-liberal transformation of the world, e.g. the scandal that healthcare is more and more perceived in the context of profit making instead of responding to the needs of the people. It is the political approach of medico that makes our organisation uninteresting for those who profit from the prevailing neoliberal ideology. Have a look at our website, and you will find all the information to get an understanding of our concept.

Kind regards
Thomas Gebauer
Executive Director
medico international

Email response from Jo Harkness, Chief Executive Officer, International Alliance of Patients' Organizations

Dear Mr Donahue

Thank you for your email. It raises important points regarding the representation of civil society in healthcare debates and regarding how organizations ensure they represent their members appropriately. IAPO considers it essential that non governmental organizations that represent patients and the general public are involved, and have their voice heard, in the WHO IGWG process through for example the submissions.

IAPO believes that all non governmental organizations that participate in these debates should strive towards transparency and accountability regarding their governance, funding and policy-making frameworks whether they receive funding from commercial (such as the pharmaceutical industry), governmental (such as national or regional governments), foundation grants or other sources.

IAPO is concerned that debate around the issues addressed by the IGWG has become polarised by different stakeholders as developed versus developing economies or, more versus less stringent intellectual property regimes. This has the potential to create conflict between patients with chronic illnesses and patients with infectious diseases when, in fact, what should operate to the benefit of all patients, is access to good healthcare, including safe and effective treatments. These different interests have neglected the perspective of the key stakeholder: " patients".

We strongly believe that we should look to where consumers' and patients' organizations have shared interests and where we can work in collaboration for the benefit of all users of healthcare. We are always keen to engage in open discussion of the important issues regarding representation and funding but at the same time we do not want the IGWG to be overtaken by this debate to the detriment of the healthcare needs of patients.

In response to your email we would like to make the following points regarding IAPO's work:

- * As a membership organization IAPO is accountable to its members and its frameworks enable IAPO to represent the patient groups within its membership.

- * IAPO policies and responses to consultations reflect the opinions of IAPO's members and are guided by our Policy Framework www.patientsorganizations.org/policyframework. IAPO's response to the IGWG was based on the results of a consultation with IAPO's members only and with approval of IAPO's Governing Board (elected representatives of member organizations), in line with the methods outlined in our Policy Framework, and directly reflected and represented their views.

- * IAPO does receive funding from companies (including pharmaceutical companies) within the framework of its Healthcare Industry Partners Initiative www.patientsorganizations.org/partners which clearly outlines the benefits and responsibilities of partnership and through project grants whereby funds are provided for a project as outlined in a project proposal with IAPO taking full responsibility for the project design, management and implementation.

- * IAPO provides information on funding and its financial statements on its website (see www.patientsorganizations.org/finances).

Yours sincerely

Jo Harkness
Chief Executive Officer
International Alliance of Patients' Organizations
703 The Chandlery
50 Westminster Bridge Road
London SE1 7QY

Email response from Dr. Milan Hosta, Director, Asthma & Sport Organization, Republic of Slovenija.

Dear Mr. Donahue

Yes, we are willing to share such information. Not only that our work is transparent, but also we are aware of the sublime pressure that such policy of private corporations can have on the 'subconsciouss' of NGOs and other related parties.

In short, our interest at issue is to assure acces to science based HEPA (health enhanced phys. act.) to all asthma patients, and we also seek for supporters in farmacy.

I will reply in couple of days, since I need to collect the data.
For how many years back, do you need the information?

Sincerely,
dr. Milan Hosta

Email response from Lawrence A. Kogan, Esq., President/CEO, Institute for Trade, Standards and Sustainable Development (ITSSD), Princeton, NJ USA

Dear Mr. Donahue,

I am flattered that Robert Weissman, James Love and Ralph Nader, and perhaps even George Soros who funds Essential Action, KEI and other of your group's affiliate organizations are interested in how we fund our work.

In all honesty, our IGWG work was done pro bono, so you needn't be concerned about whether we possess true convictions regarding the positions we have espoused within our comments. You can be rest assured that we also have the facts and the law behind our positions as well.

We understand the objectives of groups like yours and honestly find them reprehensible. If your group had chosen a different tack and sought charitable donations from industry, concerned individuals and governments to facilitate access to medicines we would not have any objections. People and companies are free to donate to whomever and for whatever causes they wish. And, governments are free to pursue charitable foreign aid and humanitarian policies with the support of their citizens.

However, since it is clear that your group and its affiliates and supporters wish to compel individual and corporate intellectual property holders to give up their patents, technical data and trade secrets for less than just compensation and also to replace the private property-based domestic and international intellectual property systems with one based on open source universal access to health and related knowledge, we will aggressively oppose you within each forum in which you promote these agendas. Let me be very clear about this. And, to the extent there are corporate monies donated to support our efforts, all the better.

As concerns the coalition resolution which you so proudly highlight, it is our informed opinion that it is in direct conflict with fundamental US constitutional principles, including private property rights. I would even go so far as to say that, if your groups try to vilify those who disagree, then such groups are also violating constitutionally protected free speech rights.

Lastly, to the extent resolutions like this would persuade the U.S. government (current and/or future) and foreign governments to issue compulsory licenses against U.S. patent, data and trade secret holders, especially for the benefit of third country citizens, no matter the size, wealth and reach of the IP holder, we at the ITSSD would find it to be blatantly contrary to the national economic and technological interests of the United States and its citizens.

For all intensive purposes, therefore, you have our answer to your questions.

Sincerely,

Lawrence A. Kogan, Esq.
President/CEO
Institute for Trade, Standards and Sustainable Development (ITSSD)
Princeton, NJ USA

Email response from Virginia T. Ladd, President, American Autoimmune Related Diseases Association (AARDA)

Dear Mr. Donahue:

You can find the information on our web-site as our IRS report is posted. (www.aarda.org) AARDA has a strict and transparent guidelines for all corporate contributions and only accept funds for general support, educational programs which include basic research (not clinical) scientific meetings, special events, public awareness campaigns and patient forums. We do not accept funds for co-branded or marketing project. We accept no funds for advocacy or policy development work. The public and our members contributions represent over 90 percent of our income. We develop our policy statements through a procedure which involves patients and their families through focus groups and final approval of the Board of Directors. The board has over 75 percent patient representation. We therefore feel confident that our policy development represents the patient and is absent any donor influence.

We do receive corporate and foundation funds from those entities who have an interest in our work for patients. Within established guidelines, I believe this is standard practice in the USA. For example, Toy "R" Us" provides funds to organizations that help children. Foundations interested in the environment fund environmental groups. Entities interested in consumer issues fund groups such as yours. Obviously, health industries, including pharmaceuticals, would fund groups that represent and help patients. I did notice that your organization has received major funding from the Aviation Consumers Action group, but trust that you have guidelines in place that would prevent this donor from influencing your policy development in this interest area. Could you share your major contributions guidelines with us as we are always interested in what other groups do to ensure that a firewall exist between donations and policy development?

Additionally, we believe that the WHO-IGWG discussion and debate should include all stakeholders . As patients are the major stakeholder patients should have a voice. The debate should not be politicized by any group as all patients whether from a developing or developed country should have access to good healthcare.

Best Regards,
Virginia T. Ladd
President
American Autoimmune Related Diseases Association (AARDA)

Appendix III

NGO Submissions Listed by Pharmaceutical Industry Links

NGO's Linked to Pharmaceutical Companies⁵⁶

Catherine Benavidez Clayton - Alliance of Health Disparities, USA

Gene Copello - Executive Director, the AIDS Institute

Daniele Dionisio - Italian Network for International Fight against AIDS (CLIA)

Jo Harkness - International Alliance of Patients' Organizations (IAPO), UK

Dr. Milan Hosta – Director, Asthma & Sport Organization, Republic of Slovenija

Harry Kletzko - German Pain League

Lawrence A. Kogan – Institute for Trade, Standards and Sustainable Development (ITSSD)

Adrian Koning - Canadian Organization for Rare Disorders, Canada

Virginia Ladd – American Autoimmune Related Diseases Associations (AARDA), USA

Randall Maxey – Alliance of Minority Medical Associations (AMMA), USA

Stephen McMahon – Irish Patients Association, Ireland

Frederick Modell - Jeffrey Modell Foundation, USA

Bishop Council Nedd II, Alliance for Health Education and Development (AHEAD), USA

Jeremiah Norris - Director, Center for Science in Public Policy, Hudson Institute, USA

Herbert Perry - Health Care Advocacy Alliance, USA

Jorge Quel - Hispanic-American Allergy Asthma and Immunology Association, USA

Randall Rutta - Easter Seals, USA

Philip Stevens - On Behalf of a Coalition of 24 Civil Society Groups, UK

Wayne Taylor - Health Leadership Institute, Canada

Myrl Weinberg - National Health Council, USA

⁵⁶ Listed alphabetically by author's last name.

Durhane Wong-Rieger - Consumer Advocare Network, Canada

Mark Wortman – Alzheimer's Disease International (ADI)

Kelsey Zahourek - Property Rights Alliance, Americans for Tax Reform (ATR), USA

NGOs Not Linked to Pharmaceutical Companies

Xuanhao Chan – FIP/International Pharmaceutical Federation, Netherlands

Caroline Gallant - Universities Allied for Essential Medicine, Canada

Thomas Gebauer – Medico International, Germany

Spring Gombe, James Love & Manon Ress, Knowledge Ecology International, Switzerland & USA

Peter Munyi - Health Action International Africa, Kenya

Thomas Pogge, Incentives for Global Health, USA

Sangeeta Shashikant - Third World Network, Malaysia

Christian Wagner, Health Action International, Essential Innovation Campaign

Leroy Watson - National Grange of the Order of Patrons of Husbandry, USA

Mohga Kamal-Yanni - Oxfam International, UK

Pharmaceutical Links Uncertain

Jacqueline Bonisteel - Innovation, Policy and Science program area of the International Development Research Centre (IDRC), Canada. IDRC accepts money from corporations but it is unclear whether it receives pharmaceutical donations.

Ronald Cass – Center for the Rule of Law, USA. Ronald Cass' consulting firm, Cass and Associates, works on intellectual property issues but Essential Action was not able to determine whether the firm's clients include pharmaceutical companies.

Ellen t'Hoen - Médecins Sans Frontières (MSF), France. MSF's access to Medicines Campaign does not accept funding from pharmaceutical companies. The campaign is funded by MSF sections, which may accept some corporate money. It is unclear whether any such donations are from pharmaceutical companies.

Appendix IV
Submissions from Academics⁵⁷

Frederick Abbott - Florida State University College of Law, USA

Andrew Farlow - Saïd Business School, University of Oxford, UK

Aidan Hollis - Department of Economics, University of Calgary, Canada

Jean-Frederic Morin - The Innovation Partnership, McGill University, Canada

Kevin Outtersson - Associate Professor of Law, Boston University, USA

Tina Piper - The Innovation Partnership, McGill University, Canada

Jerome Reichman - Duke University School of Law, USA

Wayne Taylor - McMaster University professor of business and director of the school's Health Leadership Institute, Canada

⁵⁷ Note: Contributors from universities may not receive pharmaceutical donations, but the university itself might be tied to corporate funding. For example, McGill University receives pharmaceutical funding but the Innovation Partnership obtains no such funding. Although universities present a special case, generally it makes sense to see whether the individual academic has industry ties or whether their particular program or research center has received funding.

Appendix V
Contributors Not Contacted by Essential Actions⁵⁸

Richard Barker - The Association of the British Pharmaceutical Industry, UK

Harvey Bale (second submission) - NGO, International Federation of Pharmaceutical Manufactures and Associations, Switzerland

Wellcome Trust - Charitable Foundation, UK

Tracy Haller - Private Sector, Novartis, USA

European Generic Medicines Association - International Non-Profit Organisation, Belgium

Daniele Capezzone, Benedetto Della Vedova Veaceslav Untila, European Parliamentarians

Lila Feisee - Private Sector, Biotechnology Industry Organization, USA

Richard Kjeldgaard - Private Sector, Pharmaceutical Researchers and Manufacturers of America, USA

Meri Koivusalo - Government Institution, National Research and Development Centre for Welfare and Health, Finland

Paul Herrling - Private Sector, Novartis International AG, Switzerland

Janet Trunzo - NGO, The Advanced Medical Technology Association. USA

Harald Zimmer - Private Sector, VFA/German Association of Research-based Pharmaceutical Manufacturers, Germany

Brendan Barnes - Private Sector, European Federation of Pharmaceutical Industries and Associations, Belgium

BIO Ventures for Global Health - Public-Private Partnership, USA

David Hirschmann - International Organization, U.S. Chamber of Commerce, USA

Itaru Nitta - General Public, Green Intellectual Property Project, Japan

Daphne Yong-d'Hervé - Private Sector, International Chamber of Commerce, France

Yves Champey - General Public, France

Robert Reinhard - Civil Society, San Francisco Department of Public Health Research Section, USA

⁵⁸ Essential Action did not contact contributors from pharmaceutical companies, trade associations, government bodies or those who submitted as unaffiliated individuals.