

PATIENTS, PATENTS AND THE PHARMACEUTICAL INDUSTRY:

**THE PHARMACEUTICAL INDUSTRY TIES OF THE ORGANIZATION
"PATIENTS AND PATENTS," AND THE SIGNERS OF THE "PATIENT
DECLARATION ON MEDICAL INNOVATION AND ACCESS"**

**A Report By
Essential Action
Washington, DC
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**Essential Action
PO Box 19405
Washington, DC 20036
www.essentialaction.org/access**

I. EXECUTIVE SUMMARY AND OVERVIEW

An organization called Patients and Patents is circulating a "Patient Declaration on Medical Innovation and Access." This declaration insists on the importance of patient group involvement in the Intergovernmental Working Group on Public Health, Innovation and Intellectual Property (IGWG) or other World Health Organization processes before "recommending changes to international patent protection (IPP)."

Patients and Patents is governed by a seven-member advisory board. Six of the seven members of the advisory board are linked to the brand-name pharmaceutical industry, either directly as an individual or through their primary organization, and the seventh member has at least a weak tie to the industry.

A high proportion of the signers of the Patient Declaration are also connected to the brand-name pharmaceutical industry. We found 61 of 110 of the signers of the Declaration have industry ties.

Those involved in the IGWG negotiating process should evaluate the Patient Declaration, and any other inputs from Patients and Patents, in the context of the organization's deep ties to the brand-name pharmaceutical industry.

This short report offers a brief framework for assessing patient group and NGOs' industry linkages in the context of the debates surrounding the IGWG negotiations. It then identifies the industry ties of Patients and Patents' advisory board. A final section details industry ties for many of the signers of the Patient Declaration.

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The Washington, D.C.-based Essential Action is a nonprofit project that focuses on public health and corporate accountability. Our Access to Medicines Project works to overcome patent and related barriers to affordable medicines, especially in developing countries. We also work on pharmaceutical industry transparency, including documentation of industry funding of NGOs, think tanks and patient organizations. Essential Action's work on pharmaceutical issues is funded by the Open Society Institute and the Ford Foundation.

II. IGWG AND THE ROLE OF INDUSTRY-FUNDED PATIENT GROUPS AND NGOS

The World Health Organization's Intergovernmental Working Group on Public Health, Innovation and Intellectual Property (IGWG) is undertaking very important debates on how to advance the twin goals of improving access to drugs in the developing world and promoting research and innovation for new medical technologies to meet priority health needs.

The breadth of the IGWG project means that many stakeholders are keenly interested in the outcomes of the debate. In addition to official government participants, many industry groups, NGOs, academics and patient groups have participated in negotiations, including through submissions of comments, or otherwise sought to influence the debate.

This robust debate is a good thing.

One issue that has shadowed the IGWG negotiations and surrounding debate, however, is the extent to which debate participants portray themselves or convey the impression of independence, when in fact they are linked to corporations with a perceived financial interest in the outcome of the negotiations.

Understanding an organization's ties to affected industries is helpful in assessing the merits of inputs to the debate. This does not mean that organizations should be prohibited from receiving corporate funding or otherwise maintaining corporate ties. Nor does it mean that organizations with corporate ties should be prohibited from participating in the IGWG process. It does mean that those involved in the IGWG negotiation process -- including, most importantly, the government officials undertaking the actual negotiations -- as well as the media and the broader public, should be aware of the financial entanglements of organizations participating in the broad IGWG debate. This is particularly important in cases where seemingly independent organizations that receive funding from, or are otherwise tied to, brand-name pharmaceutical companies advance an agenda consonant with the priorities of the brand-name pharmaceutical industry.

In 2007, WHO held web-based "public hearings" on IGWG issues. In November 2007, Essential Action released a report detailing the brand-name pharmaceutical industry ties of NGOs submitting comments to the second public hearing. The report found that 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 1.¹

¹"Pharmaceutical Links of NGOs Contributing to the World Health Organization's Second Public Hearing on Public Health, Innovation and Intellectual Property," Essential Action, November 7, 2007: <http://www.essentialaction.org/access/index.php?/archives/82-Pharma-Links-of-NGOs-in-the-WHO-IGWG-process.html>

This short report focuses on the patient groups signing on to Patients and Patent's "Patient Declaration on Medical Innovation and Access." Other civil society groupings will surely be issuing statements around the May IGWG negotiation. Essential Action has focused on the Patients and Patents' statement because a) we have seen it in advance of the IGWG meeting, and b) although its recommendations are very general, the statement's focus on defending the existing patent system aligns it with the posture of the brand-name pharmaceutical industry.

III. THE PATIENTS AND PATENTS-BIG PHARMA NEXUS

Patients and Patents says it "is a patient-driven and patient-focused resource whose goal is to inform and engage patient groups, advocates and other stakeholders from around the world on issues surrounding medical innovation and access to treatments." Patients and Patents' primary project appears to be maintaining its website as "a centralized information resource."²

"The content and focus of www.patientsandpatents.com is directed by the Patient and Patents Advisory Board," according to the website. There are seven members of the advisory board: Gene Copello, Elizabeth Helms, Hussain Jafri, Virginia Ladd, Dr. Kristina Lybecker, Stephen McMahon and Durhane Wong-Rieger. Copello, Helms, Ladd, Lybecker, McMahon and Wong-Rieger are all connected to the brand-name pharmaceutical industry, through personal or organizational ties. Jafri has at least one weak tie to industry. Information on these ties follows.

Gene Copello is the executive director of The AIDS Institute in the United States. The institute's board of directors includes William Schuyler, vice president of Federal Government Relations with GlaxoSmithKline.³

Elizabeth Helms is president and CEO of the TMJ and Orofacial Pain Society of America. Helms is a former public relations executive with Perry Communications,⁴ whose clients include pharmaceutical companies.⁵ She also is a former director and founder of Citizens for the Right to Know Coalition;⁶ the group's website is defunct and its web address, www.rtk.org, now re-directs to the website of PhRMA, the U.S. pharmaceutical industry trade association. In 2000, Helms represented Citizens for the Right to Know before Congress in testimony that defended industry drug prices. "What her audience did not hear," reported the New York Times, "was that she also works full time for a public relations company whose clients include the Pharmaceutical Research and Manufacturers of America, the drug industry's trade group."⁷ When Helms left Perry Communications in 2006, Perry's website said it will "look forward to working closely with her in her new capacity" as the president and CEO of TMJ & Orofacial Pain Society.

Hussain Jafri is founder of Alzheimer's Pakistan, and serves on the governing board of the industry funded International Alliance of Patients' Organizations.⁸ He runs his own tourism company and also works as a consultant in the medical field.⁹

² http://www.patientsandpatents.com/index.php/us/who_we_are

³ The AIDS Institute website: theaidsinstitute.org.

⁴ "Top Health Care Advocate Takes Lead Role Representing The Patient Community In California," Perry Communications press release, Dec. 13, 2006 (Perry bids farewell to Helms).

⁵ Perry Communications client list: perrycom.com/clients_list.php.

⁶ Google cached version of Citizens Right to Know Coalition website: www.rtk.org.

⁷ Jeff Gerth and Sheryl Gay Stolberg, "Medicine merchants/Cultivating Alliances; With Quiet, Unseen Ties, Drug Makers Sway Debate," New York Times, p. A1, Oct. 5, 2000.

⁸ Email to Jim Donahue from Jo Harkness, International Alliance of Patients' Organizations, Oct. 31, 2007.

⁹ <http://www.patientsorganizations.org/showarticle.pl?id=26>

Virginia Ladd, president and executive director of the American Autoimmune Related Diseases Association, confirmed to Essential Action that “We do receive corporate and foundation funds from those entities who have an interest in our work for patients.”¹⁰

Dr. Kristina Lybecker is assistant professor at Colorado College. According to her curriculum vitae, Professor Lybecker is presently a consultant for the brand-name pharmaceutical industry trade association, PhRMA -- the Pharmaceutical Research and Manufacturers of America, and a consultant to Ward Health Strategies, a communications firm that works for the industry. She has held several other consultancies for brand-name pharmaceutical companies, including Sanofi-Aventis, Merck (via a consultancy with The Madison Group) and Astra-Zeneca, and received research grants from brand-name pharmaceutical companies.¹¹

Stephen McMahon is chair of the Irish Patients Association, which receives funding from Merck Sharpe & Dohme (Human Health) Ltd., and Pfizer.¹²

Durhane Wong-Rieger is chair of the Consumer Advocare Network, funded by Canada's pharmaceutical industry trade association Rx&D.¹³ Wong-Reiger is also president of the Canadian Organization for Rare Disorders, which is funded by Actelion Pharmaceuticals, Amicus Therapeutics, Apo Pharma, BioMarin Pharmaceutical, BIOTECCanada, Debiovision, Genzyme Canada, Hoffmann-LaRoche (Roche), Merck Frosst Canada, Neurochem, Novartis, Orfagen, Ortho Biotech, Pfizer, Rare Disease Therapeutics, Shire Human Genetics Therapies, Sigma-Tau Pharmaceuticals and YM Biosciences.¹⁴

¹⁰ Email to Jim Donahue, Essential Action, from Virginia Ladd, Nov. 1, 2007.

¹¹ faculty1.coloradocollege.edu/~klybecker/CV.pdf

¹² Irish Patients Association website: http://www.irishpatients.ie/assets/68/568EA235-491A-4DDD-8949705F60285940_document/EU_Patients_Charter.pdf

¹³ Consumer Advocare Network website: consumeradvocare.org.

¹⁴ Canadian Organization for Rare Disorders, “The Link” newsletter, Vol 1., Issue 2, Winter 2007/Spring 2008. See also: raredisorders.ca/index.php/site/membership/corporate

IV. THE INDUSTRY TIES OF THE SIGNERS OF THE PATIENT DECLARATION ON MEDICAL INNOVATION AND ACCESS

The Patients and Patents website highlights that more than 100 patients and advocates from more than 20 countries have signed the Patient Declaration on Medical Innovation and Access. Essential Action has identified brand-name pharmaceutical industry ties for 61 of the 110 individuals who had signed the statement as of mid-day April 24.

To identify industry ties, we searched organizations' websites, the Internet, news clips and information from brand-name pharmaceutical companies and their foundations. Many of the organizations receiving industry funding or maintaining ties with industry disclose these relationships on their own websites. They should be complimented for those disclosures.

For our November 2007 report on organizations submitting comments to the IGWG public hearings, we contacted each submitting organization directly. Time constraints did not permit us to replicate that effort for this report.* For this reason, as well as the incompleteness of available public or web-based information, our information certainly undercounts and underreports the industry ties of the signers of the declaration.

We present directly the information we have collected on the Declaration signers' industry ties, without distinguishing between different kinds of linkages. Information on industry ties of signers of the declaration follows:

Silvia Castillo de Armas, Association of Patients with Chronic Leukemia Mieloide in Guatemala (ASOPALEU), funded by Novartis.¹⁵

Kathleen A. Arntsen, Lupus Foundation of Mid & Northern New York, funded by Abbott Laboratories, Aspreva Pharmaceuticals, Biogen Idec, Bristol Myers Squibb, Encysive Pharmaceuticals, Genentech, General Electric, GlaxoSmithKline, La Jolla Pharmaceuticals, Partnership for Prescription Assistance/PhRMA and Pfizer.¹⁶

Mary Lou Ballweg, Endometriosis Association, funded by Gynecare, Ethicon, Johnson & Johnson, Purdue Pharma,¹⁷ and TAP Pharmaceuticals.¹⁸ A member of the group's advisory board, Stephen Kennedy, is a medical advisor to Bayer, Ferring Pharmaceuticals, Pfizer, Schering-Plough, TAP Pharmaceuticals and Takeda Pharmaceuticals.¹⁹

* In a few cases, we drew on information provided by e-mail by groups in connection with our previous report; these are noted in the footnotes as "e-mail to Jim Donahue."

¹⁵"Aguilla Health Brazil and Novartis announced the finalists of the Oncology Health Awards Latin America," Aguilla Health Institute Brazil, April 19, 2006 (ASOPALEU won \$5,000 from Novartis).

¹⁶Lupus Foundation of Mid and Northern New York, Lupus Communique newsletter, Vol. 6, No. 3, Spring 2007.

¹⁷"Women report chronic pelvic pain not taken seriously, survey shows," OBGYN.net, *Women's Health Weekly*, Nov. 14, 2002.

¹⁸Endometriosis Association website: <http://killercramps.org/media.html>

¹⁹World Endometreosis Research Foundation website: endometriosisfoundation.org/board-kennedy.php.

Aleksandra Baranowska, Urszula Jaworska Foundation, funded by Bristol Myers Squibb.²⁰

Anna Bordiuk, Urszula Jaworska Foundation, funded by Bristol Myers Squibb.²¹

Cristina C. Caballero, president, Dialogue on Diversity, funded by the Pharmaceutical Research & Manufacturers of America (PhRMA).²²

Amanda Caballero-Holmes, National Latina Health Network USA (NLHN), funded by Abbott Laboratories, AstraZeneca, Pfizer, and the Pharmaceutical Research & Manufacturers of America (PhRMA).²³ PhRMA advertises on NLHN's website. AstraZeneca and NLHN jointly sponsor "Heart Healthy Day."²⁴

Maira Caleffi, Brazilian Federation of Institutions Filantrópicas of Support for Breast Health (FEMAMA), funded by AstraZeneca and Roche Laboratories.²⁵

Jacqueline Cahill, Canadian Continence Foundation, funded by Astellas Pharmaceuticals, Depend Products (Kimberly-Clark), Gynecare, Johnson & Johnson, Laborie Medical Technologies, Medtronic, Paladin Labs Inc., Pfizer, Purdue Pharma, Q-Med and Triton Pharma.²⁶

Candida Carvalheira, president of the Associação Brasileira de Ostomizados (ABRASO), funded by ConvaTec (Bristol Myers Squibb) and medical equipment maker Coloplast Group.²⁷ Both companies also advertise on ABRASO's website.²⁸

Marilia Casseb, Associação Brasileira do Câncer (ABCâncer), funded by Roche Laboratories.²⁹

²⁰"Foundation and Corporate Philanthropy: Grant to Polish Groups Focuses on Establishing Patient and Family Psychosocial Support," Bristol Myers Squibb website, undated (Bristol Myers donated \$375,000 to the Urszula Jaworska Foundation).

²¹"Foundation and Corporate Philanthropy: Grant to Polish Groups Focuses on Establishing Patient and Family Psychosocial Support," Bristol Myers Squibb website, undated (Bristol Myers donated \$375,000 to the Urszula Jaworska Foundation).

²²"Dialogue on Diversity Announces 2007 Awards Laureates: The Genius of the Americas: Crafting a Future Society," press release, Aug., 28, 2007 (PhRMA sponsored Dialogue on Diversity's "2007 Entrepreneurial and International Awards" to recognize leaders in entrepreneurship).

²³National Latina Health Network website: nlhn.net/sponsors.php.

²⁴Snejana Farberov, "Latinas Can Take Heart During Health Event," *Daily News* (New York), Feb. 24, 2006.

²⁵FEMAMA website: femama.org.br.

²⁶Canadian Continence Foundation website: continence-fdn.ca.

²⁷"Relatório de Atividades" ("Report of Activities"), Associação Brasileira de Ostomizados (ABRASO), 2007.

²⁸ABRASO website: abraso.org.br.

²⁹ABCâncer's website contains a banner advertisement for Roch Oncologia (Roche Laboratories): abcancer.org.br.

Alicia Diaz, National Latina Health Network, funded by Abbott Laboratories, AstraZeneca, Pfizer and the Pharmaceutical Research & Manufacturers of America (PhRMA).³⁰ PhRMA advertises on NLHN's website. AstraZeneca and NLHN jointly sponsor "Heart Healthy Day."³¹

Gene Copello, the AIDS Institute and Patients and Patents advisory board member. The institute's board of directors includes William Schuyler, vice president of Federal Government Relations with GlaxoSmithKline.³²

Mensura Dražić, Coalition of Associations in Healthcare, Croatia. Dražić heads the Croatian Diabetes Association (Hrvatska Dijabeticka Udruga),³³ funded by Novo Nordisk and Croatian firm MediLab,³⁴ which represents BBRAUN, Bayer Diabetes Care, Siemens MSD, and Diesse.³⁵ Both Novo Nordisk and MediLab advertise on the group's website.

Dominique Etienne, Canadian Organization for Rare Disorders, funded by Actelion Pharmaceuticals, Amicus Therapeutics, Apo Pharma, BioMarin Pharmaceutical, BIOTECCanada, Debiovision, Genzyme Canada, Hoffmann-LaRoche (Roche), Merck Frosst Canada, Neurochem, Novartis, Orfagen, Ortho Biotech, Pfizer, Rare Disease Therapeutics, Shire Human Genetics Therapies, Sigma-Tau Pharmaceuticals, and YM Biosciences.³⁶

John Foreman, executive director of the New Zealand Organisation for Rare Disorders. Foreman is the chairman of Lysosomal Diseases New Zealand, whose funders include biotechnology firm Genzyme and Actelion Pharmaceuticals.³⁷

Elisabeth Fowler, Canadian Organization for Rare Disorders, funded by Actelion Pharmaceuticals, Amicus Therapeutics, Apo Pharma, BioMarin Pharmaceutical, BIOTECCanada, Debiovision, Genzyme Canada, Hoffmann-LaRoche (Roche), Merck Frosst Canada, Neurochem, Novartis, Orfagen, Ortho Biotech, Pfizer, Rare Disease Therapeutics, Shire Human Genetics Therapies, Sigma-Tau Pharmaceuticals, and YM Biosciences.³⁸

³⁰National Latina Health Network website: nlhn.net/sponsors.php.

³¹Snejana Farberov, "Latinas Can Take Heart During Health Event," *Daily News* (New York), Feb. 24, 2006.

³²The AIDS Institute website: theaidsinstitute.org.

³³Croatian Diabetes Association website: diabetes.hr.

³⁴Id.

³⁵MediLab website: medilab.hr.

³⁶Canadian Organization for Rare Disorders, "The Link" newsletter, Vol 1., Issue 2, Winter 2007/Spring 2008. See also: raredisorders.ca/index.php/site/membership/corporate

³⁷Lysosomal Diseases New Zealand website: www.ldnz.org.nz.

³⁸Canadian Organization for Rare Disorders, "The Link" newsletter, Vol 1., Issue 2, Winter 2007/Spring 2008. See also: raredisorders.ca/index.php/site/membership/corporate

Haydee Benoit de Garcia, Fundacion de Apoyo al Hemofílico (FAHEM), is partnered with pharma-funded LA Kelley Communications,³⁹ whose sponsors include Baxter International, Bayer Healthcare, CSL Behring, Novo Nordisk, New England Biolabs, NuFactor Specialty Pharmacy, Talecris Biotherapeutics and Wyeth Pharmaceuticals.⁴⁰

Cesar Garrido, Asociacion Venezolana para la Hemofilia (AVH), funded by Bayer Healthcare.⁴¹ Garrido is a member of the World Federation of Hemophilia, which is funded by Baxter BioScience, Bayer, Biotest Pharma GmbH, CSL Behring, Green Cross Corporation, Grifols S.A., Kedrion, Novo Nordisk, Octapharma, Talecris Biotherapeutics and Wyeth.⁴²

Elizabeth Helms is president and CEO, TMJ and Orofacial Pain Society of America, and Patients and Patents advisory board member. Helms is a former public relations executive with Perry Communications,⁴³ whose clients include pharmaceutical companies.⁴⁴ She also is a former director and founder of Citizens for the Right to Know Coalition;⁴⁵ the group's website is defunct and its web address, www.rtk.org, now re-directs to the website of PhRMA, the U.S. pharmaceutical industry trade association. In 2000, Helms represented Citizens for the Right to Know before Congress in testimony that defended industry drug prices. "What her audience did not hear," reported the New York Times, "was that she also works full time for a public relations company whose clients include the Pharmaceutical Research and Manufacturers of America, the drug industry's trade group."⁴⁶ When Helms left Perry Communications in 2006, Perry's website said it will "look forward to working closely with her in her new capacity" as the president and CEO of TMJ and Orofacial Pain Society.

Milan Hosta, Asthma & Sport Organization, Republic of Slovenija. 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."⁴⁷

Gail Hunt, National Alliance for Caregiving, funded by Johnson & Johnson, Kimberly Clark and Pfizer.⁴⁸ Representatives from the three companies serve on the Alliance's board of directors.⁴⁹

³⁹Laureen A. Kelley, "Journeys of Hope," Parent Empowerment Newsletter, Nov. 2005, Vol. 15, Issue 4.

⁴⁰LA Kelley Communications website: kelleycom.com.

⁴¹"Con el patrocinio de Bayer Health Care: Niños con hemofilia disfrutaron campamento en Higuero," Grupo Open Mind, Sept. 17, 2007 (article in Portuguese describes Bayer Healthcare's sponsorship of Asociacion Venezolana para la Hemofilia).

⁴²World Federation of Hemophilia website: wfh.org.

⁴³"Top Health Care Advocate Takes Lead Role Representing The Patient Community In California," Perry Communications press release, Dec. 13, 2006 (Perry bids farewell to Helms).

⁴⁴Perry Communications client list: perrycom.com/clients_list.php.

⁴⁵Google cached version of Citizens Right to Know Coalition website: www.rtk.org.

⁴⁶Jeff Gerth and Sheryl Gay Stolberg, "Medicine merchants/Cultivating Alliances; With Quiet, Unseen Ties, Drug Makers Sway Debate," New York Times, p. A1, Oct. 5, 2000.

⁴⁷Email to Jim Donahue, Essential Action, from Milan Hosta, Oct. 30, 2007.

⁴⁸National Alliance for Caregiving website: caregiving.org/members.

⁴⁹Id.

Tunde Kazda, CML and GIST Patient's Association, funded by Novartis.⁵⁰

Mary Kim, Canadian Arthritis Patient Alliance, funded by Pfizer.⁵¹

Harry Kletzko, Deutsche Schmerzliga e.V. (German Pain League), funded by medical equipment manufacturer Medtronic.⁵² Kletzko is chairman of the Neuropathic Pain Network (NPN), which is funded by Pfizer.⁵³ 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."⁵⁴ The League is a member of the industry-funded International Alliance of Patients' Organizations.

Adrian Koning, Canadian Fabry Association, funded by Amicus Therapeutics, Genzyme and Shire Pharmaceuticals.⁵⁵

Joyce A. Kullman, Vasculitis Foundation, funded by Astellas Pharmaceuticals, Bristol Myers Squibb and NeilMed Pharmaceuticals.⁵⁶

Virginia Ladd, American Autoimmune Related Diseases Association and Patients and Patents advisory board member. Ladd confirmed to Essential Action that "We do receive corporate and foundation funds from those entities who have an interest in our work for patients."⁵⁷

Anne Lyddiatt, Patient Partners, funded by Pfizer.⁵⁸ Lyddiatt appeared as a spokesperson in an advertisement for Pfizer Canada's "Patient Partners" program.⁵⁹

Maria Cecilia Magalhaes Pinto, Centro dos Hemofilicos do Estado Sao Paulo (CHESP), funded by private corporations and represented by public relations firm Hill & Knowlton,⁶⁰ whose other clients include GlaxoSmithKline, Pfizer, Procter & Gamble and Roche Laboratories.⁶¹

⁵⁰"Patient Group Support," Novartis website: corporatecitizenship.novartis.com.

⁵¹Canadian Arthritis Patient Alliance website: arthritis.ca/capa.

⁵²Medtronic website: http://www.medtronic.com/foundation/programs_pl_grant_list.html

⁵³Neuropathic Pain Network website: <http://www.neuropathicpainnetwork.org/english/coalition/index.asp>

⁵⁴Medtronic website: <http://www.medtronic.com/foundation/newsletter/may06/article5.html>

⁵⁵Canadian Fabry Association Newsletter, Vol. 2, Issue 1, Spring 2008.

⁵⁶Vasculitis Foundation, First European Vasculitis Foundation Meeting Program, Sept. 14, 2007.

⁵⁷Email to Jim Donahue, Essential Action, from Virginia Ladd, Nov. 1, 2007.

⁵⁸Patient Partners website: arthritis.ca.

⁵⁹"Successful Innovative Arthritis Education Program Expands," Pfizer Canada website, June 14, 2000 ("This has been such a positive experience for me," said Anne Lyddiatt from Ingersoll, Ontario, who has been a Patient Partner since 1996.).

⁶⁰"CHESP completa 40 anos em grande estilo," CHESP press release, Sept. 2006.

⁶¹"Clients Successes," Hill & Knowlton website: hillandknowlton.com/index/case_studies.

Nicole Massicotte, Alpha-1 Canada, funded by Baxter International, Pfizer and Talecris Biotherapeutics.⁶²

Sergio Metzger is deputy director of the Associação de Diabetes Juvenil (ADJ), which is funded by Abbott Medsense (Abbott Laboratories), BD-Bom Dia (Becton Dickinson), Johnson & Johnson, Medtronic, Merck, Novo Nordisk, Roche, and Sanofi-Aventis.⁶³

Vlastimil Milata, Association of Czech Diabetics, Czech Republic. Mr. Milata works for medical equipment maker Medtronic.⁶⁴ The Association of Czech Diabetics is funded by Johnson & Johnson, Medtronic and Novo Nordisk.⁶⁵

Juan Guillermo Millan, Asociación Mexicana de Lucha contra el Cáncer, funded by Roche Vida (Roche Laboratories). Roche advertises on the group's website.⁶⁶

Denis Morrice, Bone and Joint Decade of Canada, funded by Abbott Laboratories, Amgen Canada, Biomet, Bristol Myers Squibb, Hoffmann-La Roche Ltd., Janssen Ortho Inc., Johnson & Johnson, Juvent, Inc., MEDEC, Merck Frosst, Pfizer, Procter & Gamble, Schering-Plough, Smith & Nephew Inc., Stryker, Synthes, Sanofi-Aventis, Wright Medical Technology Canada Ltd., Wyeth Pharmaceuticals and Zimmer Canada.⁶⁷ Morrice is the former president of the industry-funded Arthritis Society.⁶⁸

Kati Németh, Oszteoporozis Betegek Magyarországi Egyesülete (OBME, Hungarian Osteoporosis Patient Association), funded by Novartis.⁶⁹

Martha Nolan, vice president of public policy, Society for Women's Health Research, funded by Abbott Laboratories, Advamed, Amgen, Astrazeneca, Barr Laboratories, Bayer, Becton Dickinson, Biogen Idec, Biotechnology Industry Organization, Boston Scientific, Bristol Myers Squibb, Cytoc, Digene Corp., Dow Chemical, Dow Corning, Edwards Lifesciences Corp., Eli Lilly, GE Healthcare, Genentech, GlaxoSmithKline, Johnson & Johnson, Medtronic, Merck, Novartis, Novo Nordisk, Ogilvy Public Relations Worldwide, Ortho McNeil Pharmaceuticals, Pfizer, Pharmaceutical Research & Manufacturers of America (PhRMA), Pharmavite, Procter & Gamble, Roche Laboratories, Sanofi-Aventis, Serono, St. Jude Medical, Wyeth and medical equipment maker Zimmer Inc.⁷⁰ Nancy Walker, Johnson & Johnson's director of Global Pharmaceutical Communications, serves on the Society's board of directors.⁷¹ The Society's Corporate Advisory Council is comprised of representatives from Abbott Laboratories, Amgen, AstraZeneca, Barr Laboratories, Bayer, Boston Scientific, Bristol-

⁶²Alpha-1 website: alpha1canada.ca.

⁶³ADJ website: adj.org.br.

⁶⁴Medtronic website: minimed.cz/team.php.

⁶⁵Association of Czech Diabetics website: diaktiv.eurosystem.cz.

⁶⁶Asociación Mexicana de Lucha contra el Cáncer website: amlcc.org.

⁶⁷Bone and Joint Decade of Canada website (Google cached).

⁶⁸Canadian Orthopaedic Foundation website, canorth.org/en/about/pdf/DMorrice.pdf.

⁶⁹"Patient Group Support," Novartis website: corporatecitizenship.novartis.com.

⁷⁰Society for Women's Health Research, Sexx Matters Newsletter, Vol. 2, 2007.

⁷¹Society for Women's Health Research website: womenshealthresearch.org.

Myers Squibb, Eli Lilly, EMD Serono, Endo Pharmaceuticals, GE Healthcare, GlaxoSmithKline, Gynecare, Hologic, Medtronic, Merck, Novartis, Pfizer, Procter & Gamble, Roche Laboratories, Sanofi Aventis, Schering-Plough, Shire Laboratories, Wyeth, and Zimmer, Inc.⁷²

Stella De Carli Cardoso de Oliveira, Lagrima Brasil, funded by Allergan, GlaxoSmithKline, Novartis, medical equipment maker Alcon Brasil, and biopharmaceutical company Actelion.⁷³

Ana Maria Padovan, of the Associação Brasileira de Linfoma e Leucemia (ABRALE), funded by Roche Laboratories.⁷⁴ A campaign by ABRALE and Roche Laboratories, titled "Lymphoma is Cancer," was the result of the partnership established between ABRALE and Roche. ABRALE is also a member of the Lymphoma Coalition, funded by Roche.⁷⁵

Stella Pavlides, American Vitiligo Research Foundation, funded by Astellas Pharmaceuticals, Roche Laboratories and Valeant Pharmaceuticals.⁷⁶

Tania Maria Pietrobelli, National Health Counselor for the Federação Brasileira de Hemofilia (FBH), funded by Novo Nordisk Haemophilia Foundation, who advertises on FBH's website.⁷⁷

Lenka Rejlová, Association of Czech Diabetics, is funded by Johnson & Johnson, Medtronic and Novo Nordisk.⁷⁸

Jakub Sliwa, Fundacja "Na ratunek dzieciom z chorobą nowotworową" (Foundation "To Rescue Children With Cancer"), Poland. The group is funded by Poland's nationwide pharmaceutical distributor PGF Urtica,⁷⁹ whose partners include AstraZeneca⁸⁰ and by Unilever, whose venture capital business owns pharmaceutical companies.⁸¹

María Isabel Gómez de Soriano, Asociación de Ayuda a Pacientes Hemato-Oncológicos (ASAPHE), funded by Novartis through its ownership⁸² of the GIPAP Program which is

⁷²Id.

⁷³Lagrima Brasil website: lagrima-brasil.org.br.

⁷⁴"Campanha de conscientização - 'Linfoma é Câncer'," ABRALE website: abrale.org.br, Nov. 12, 2007 (article discusses the partnership between ABRALE and Roche Laboratories).

⁷⁵"Global patient organisation launched to help millions of patients with cancer of the lymphatic system," PR Newswire, Sept. 8, 2003.

⁷⁶American Vitiligo Research Foundation newsletter, Vol. 1, No. 1, 2004; Vol. 3, No. 1, 2006.

⁷⁷Federação Brasileira de Hemofilia website.

⁷⁸Association of Czech Diabetics website: diaktiv.eurosystem.cz.

⁷⁹website: naratunek.org.

⁸⁰Urtica's website: urtica.com.pl.

⁸¹"Vectura and Unilever Ventures announce the spin out of Pharmakodex, a new speciality pharmaceutical company," Vectura press release, May 15, 2006.

⁸²Giora Sharf, CML Advocates Network:

http://www.cmladvocates.net/index.php?option=com_content&task=view&id=42&Itemid=45

administered by the Max Foundation. The Max Foundation is funded by Novartis and Cephalon.⁸³

Juares Pires de Souza, of the Associação Brasileira de Linfoma e Leucemia (ABRALE), funded by Roche Laboratories.⁸⁴ A campaign by ABRALE and Roche Laboratories, titled "Lymphoma is Cancer," was the result of the partnership established between Abrale and Roche. ABRALE is also a member of the Lymphoma Coalition, funded by Roche.⁸⁵

Andrew Sperling, National Alliance on Mental Illness (NAMI), funded by Abbott Laboratories, AstraZeneca, Bristol-Myers Squibb, Eli Lilly, Forest Laboratories, GlaxoSmithKline, Janssen Pharmaceuticals, McNeil Consumer Healthcare, Otsuka America Pharmaceutical, Pfizer, PhRMA, Solvay Pharmaceuticals, Vanda Pharmaceuticals and Wyeth Pharmaceuticals.⁸⁶

Merula Steagall, Associação Brasileira de Linfoma e Leucemia (ABRALE), funded by Roche Laboratories.⁸⁷ Steagall is president of two organizations: the Associação Brasileira de Linfoma e Leucemia (ABRALE) and the Associação Brasileira de Talassemia (ABRASTA). A campaign by ABRALE and Roche Laboratories, titled "Lymphoma is Cancer," was the result of the partnership established between ABRALE and Roche. ABRALE is also a member of the Lymphoma Coalition, funded by Roche.⁸⁸

Joan Stevie, Cure Arthritis Now USA, is co-founder⁸⁹ of the Citizens for the Right to Know Coalition,⁹⁰ the group's website is defunct and its web address, www.rtk.org, now re-directs to the website of PhRMA, the U.S. pharmaceutical industry trade association.. Stevie is also director of advocacy and outreach at the TMJ and Orofacial Pain Society of America,⁹¹ which is headed by Elizabeth Helms.

Jarosław Tanaś, Fundacja "Na ratunek dzieciom z chorobą nowotworową" (Foundation "To Rescue Children With Cancer"), Poland. The group is funded by Poland's nationwide pharmaceutical distributor PGF Urtica,⁹² whose partners include AstraZeneca,⁹³ and by Unilever, whose venture capital business owns pharmaceutical companies.⁹⁴

⁸³Max Foundation website: maxaid.org.

⁸⁴"Campanha de conscientização - 'Linfoma é Câncer'", ABRALE website: abrale.org.br, Nov. 12, 2007 (article discusses the partnership between ABRALE and Roche Laboratories).

⁸⁵"Global patient organisation launched to help millions of patients with cancer of the lymphatic system," PR Newswire, Sept. 8, 2003.

⁸⁶National Alliance on Mental Illness, Annual Report, 2007.

⁸⁷"Campanha de conscientização - 'Linfoma é Câncer'", ABRALE website: abrale.org.br, Nov. 12, 2007 (article discusses the partnership between ABRALE and Roche Laboratories).

⁸⁸"Global patient organisation launched to help millions of patients with cancer of the lymphatic system," PR Newswire, Sept. 8, 2003.

⁸⁹zoominfo.com.

⁹⁰Google cached version of Citizens Right to Know Coalition website: www.rtk.org.

⁹¹TMJ and Orofacial Pain Society of America website: tmjsociety.org.

⁹²website: naratunek.org.

⁹³Urtica's website: urtica.com.pl.

⁹⁴"Vectura and Unilever Ventures announce the spin out of Pharmakodex, a new speciality pharmaceutical

Wayne Taylor, Asthma Society of Canada, funded by AstraZeneca, GlaxoSmithKline, Merck, National PharmaCom, Novartis, Nycomed (ALTANA Pharma), Synavant, and medical equipment makers Auto Control Medical and Respironics (Royal Philips Electronics).⁹⁵

Shaleena Theophilus, Canadian AIDS Society. Companies donating over \$100,000 each to the Canadian AIDS Society are Abbott Laboratories, GlaxoSmithKline, Pfizer and Shire Biochem. Other funders include Boehringer Ingelheim (Canada) Ltd., Hoffman-La Roche Ltd. (Roche), Bristol-Myers Squibb and Gilead Sciences.⁹⁶

Carlos Varaldo, Grupo Optimismo de Apoio ao Portador de Hepatite, is vice-director of the World Hepatitis Alliance, funded by Bristol Myers Squibb, Gilead Sciences, Janssen-Cilag, Novartis, Roche Laboratories and Schering-Plough.⁹⁷

Artur Dr. Vasvari, Magyar Rákellenes Liga (Hungarian League Against Cancer), funded by Novartis.⁹⁸

Julie Venners, Lupus Foundation of America, funded by Abbott Fund (Abbott Laboratories),⁹⁹ Amgen,¹⁰⁰ Bristol Myers Squibb,¹⁰¹ Johnson & Johnson¹⁰² and Novartis.¹⁰³

Karen Vicari, Alliance for Better Medicine – Steering Committee includes Bryan R. Luce, Director of Science Policy at pharmaceutical services firm United BioSource Corporation.¹⁰⁴

Cynthia Wainscott, mental health advocate. Wainscott chairs the advisory board of the Fuqua Center for Late Life Depression at Emory University.¹⁰⁵ Other members of the board include Brad Bailey, a regional manager at Pfizer, Stacey Losin, an area account manager at Wyeth Pharmaceuticals, and Edward Crumbley, associate director of medical science liaison at Janssen Pharmaceuticals.¹⁰⁶ Wainscott also serves on the board of directors of Mental Health America,¹⁰⁷ funded by AstraZeneca, Bristol Myers Squibb, Cyberonics, Cephalon, Eli Lilly, GlaxoSmithKline, JestaRx Group, Novartis,

company,” Vectura press release, May 15, 2006.

⁹⁵Asthma Society of Canada website: asthma.ca.

⁹⁶Canadian AIDS Society website: cdnaids.ca.

⁹⁷“World Hepatitis Day 2008 Countdown” newsletter, World Hepatitis Alliance, Issue 1, Dec. 2007.

⁹⁸“Patient Group Support,” Novartis website: corporatecitizenship.novartis.com.

⁹⁹Abbott Fund, IRS Form 990-PF, 2006.

¹⁰⁰Amgen Foundation Charitable Contributions Report, 2004.

¹⁰¹Bristol Myers Squibb Foundation, IRS Form 990-PF, 2002.

¹⁰²Johnson & Johnson Family of Companies Contribution Fund, IRS Form 990-PF, 2000.

¹⁰³“Patient Group Support,” Novartis website: corporatecitizenship.novartis.com.

¹⁰⁴Alliance for Better Medicine website: allianceforbettermedicine.org.

¹⁰⁵Fuqua Center website: psychiatry.emory.edu/PROGRAMS/fuquacenter.

¹⁰⁶Id.

¹⁰⁷Mental Health America website: nmha.org.

Neuronetics, Ortho-McNeil-Janssen Pharmaceuticals, Otsuka Pharmaceuticals, Pfizer, Pharmaceutical Research & Manufacturers of America, Solvay Pharmaceuticals and Wyeth.¹⁰⁸

Joseph Witalis, Canadian Organization for Rare Disorders, funded by Actelion Pharmaceuticals, Amicus Therapeutics, Apo Pharma, BioMarin Pharmaceutical, BIOTECanada, Debiovision, Genzyme Canada, Hoffmann-LaRoche (Roche), Merck Frosst Canada, Neurochem, Novartis, Orfagen, Ortho Biotech, Pfizer, Rare Disease Therapeutics, Shire Human Genetics Therapies, Sigma-Tau Pharmaceuticals and YM Biosciences.¹⁰⁹

Durhane Wong-Rieger, chair of the Consumer Advocare Network and Patients and Patents advisory board member. The Consumer Advocare Network is funded by Canada's pharmaceutical industry trade association Rx&D.¹¹⁰ Wong-Reiger is also president of the Canadian Organization for Rare Disorders, which is funded by Actelion Pharmaceuticals, Amicus Therapeutics, Apo Pharma, BioMarin Pharmaceutical, BIOTECanada, Debiovision, Genzyme Canada, Hoffmann-LaRoche (Roche), Merck Frosst Canada, Neurochem, Novartis, Orfagen, Ortho Biotech, Pfizer, Rare Disease Therapeutics, Shire Human Genetics Therapies, Sigma-Tau Pharmaceuticals and YM Biosciences.¹¹¹

Joan Young, Platelet Disorder Support Association, funded by Baxter International and GlaxoSmithKline.¹¹²

Klári Zalatnai, Oszteoporozis Betegek Magyarországi Egyesülete (OBME, Hungarian Osteoporosis Patient Association), funded by Novartis.¹¹³

Cassia Regina Zappelini de Souza, Centro dos Hemofilicos do Estado Sao Paulo (CHESP), funded by private corporations and represented by public relations firm Hill & Knowlton,¹¹⁴ whose other clients include GlaxoSmithKline, Pfizer, Procter & Gamble and Roche Laboratories.¹¹⁵

¹⁰⁸Mental Health America annual report, 2006.

¹⁰⁹Canadian Organization for Rare Disorders, "The Link" newsletter, Vol 1., Issue 2, Winter 2007/Spring 2008. See also: raredisorders.ca/index.php/site/membership/corporate

¹¹⁰Consumer Advocare Network website: consumeradvocare.org.

¹¹¹Canadian Organization for Rare Disorders, "The Link" newsletter, Vol 1., Issue 2, Winter 2007/Spring 2008. See also: raredisorders.ca/index.php/site/membership/corporate

¹¹²Platelet Disorder Support Association newsletter, Vol. 8, No. 4, Winter 2007.

¹¹³"Patient Group Support," Novartis website: corporatecitizenship.novartis.com.

¹¹⁴"CHESP completa 40 anos em grande estilo," CHESP press release, Sept. 2006.

¹¹⁵"Clients Successes," Hill & Knowlton website: hillandknowlton.com/index/case_studies.

