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The pharmaceutical industry-- A global survey of patient groups Part 2



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Patient groups' perspectives of the pharmaceutical industry

Part II

The way forward

About the previous issue of *HSCNews*

The previous issue of *HSCNews International* (November 2008, issue 46) released the findings of a global survey that aimed to discover the latest views held by patient groups on the pharmaceutical industry.

The survey received responses from 384 patient groups in 49 countries. The respondent groups keep differing relationships with pharma. Some, for instance, maintain regular contact with the industry, while others have no connection at all. Some are dependent on pharmaceutical companies for large amounts of their income. Others take no money from industry.

Although the respondent patient groups hold both positive and negative perceptions of pharma, most share one common attitude. As advocates of compassion, the cut-throat world of commerce inhabited by pharma

appears largely incomprehensible to them.

The survey findings reported in issue 46 can be summarised as follows:

Pharma trustworthiness

Only a minority of respondent groups believe that pharma companies are good at being trustworthy, at managing conflicts of interest, and at managing adverse news about their products. Groups that are more familiar with the industry have greater confidence in pharma, but not when it comes to the management of adverse news. However, most respondent groups judge that the industry, despite its failings, is trying to improve its standing in the health advocacy community.

Pharma's pricing policies

Drug pricing turns out to be the most divisive issue between pharma and patient groups. Respondents' comments emphasise again and again that they really do not understand why the industry cannot be more altruistic.

Pharma's marketing to doctors

The respondents are more or less evenly split on the issue of whether marketing to doctors benefits patients, or just pharma. Many groups regard doctors as a vehicle for bolstering the sales of pharma products.

Pharma's record of innovation

Patient organisations have traditionally been



About the respondents to this *HSCNews International* survey on patient group perspectives of the pharmaceutical industry

✓ During October and November 2008, 384 groups from 49 countries completed *HSCNews*' short questionnaire of six open-ended questions. [The names of organisations asking to be listed as survey participants can be found on pages 39-41 of this issue.] The US, with 86 respondent groups, generated the highest single response rate.

✓ A wide array of disease conditions are represented among the respondents.

✓ 30% of the respondent groups report deriving some portion of their income from pharma.

✓ 57% receive no pharma funding—either because they choose not to, or because pharma is uninterested in funding them.

✓ 58% of the respondent groups have regular or occasional contact with pharma. Being in contact with pharma is not the same as taking money from pharma, however. Many groups meet repeatedly with pharma companies to discuss the latest drug developments in their disease area. Others only come across pharma executives at conferences. 29% of the respondent body has no contact with pharma. Some in this latter category say that they would like to have contact with pharma.

supportive of pharma's efforts to produce innovative treatments. The survey finds that respondent groups remain concerned, though, about industry's reluctance to take more notice of what patients actually want from R&D.

Pharma's ability to help patients comply with treatments

Most of the survey respondents (apart from groups specialising in diabetes or neurological conditions) are

unimpressed with pharma's ability to support patient compliance.

Patient information and patient safety

Pharma wins plaudits from most respondent groups for its ability to supply good information, and for ensuring that its products are safe. However, a few groups put these achievements down to the highly-regulated nature of the industry.

Top rankings

The survey asked respondents to rank ten of the world's leading pharma companies in four categories. The companies receiving the largest number of votes: Johnson & Johnson is ranked best for trustworthiness; Novartis is ranked best at handling relationships with patient groups; while Pfizer is ranked best in two categories—supplying patient information, and understanding patients' needs.

In this issue of *HSCNews*: Overview of results

This issue of *HSCNews* is devoted to analysing the results generated by the survey's final question: "**Apart from offering funds to your organisation, is there any other way that pharmaceutical companies could help your organisation achieve its goals?**"

Respondents answered that question with hundreds of suggestions [almost all are listed in the Appendix, pages 14-38], from which emerges a clear set of recommendations to pharma:

1. Be truthful and factually accurate.
2. Improve research by making innovation more relevant to patients.
3. Become more involved with patient groups.
4. Provide patients and patient groups with informational events, speakers, and conference services.
5. Support patient groups' campaign activities.
6. Offer goods and services.
7. Produce more—and better—informational material.
8. Promote greater patient/public involvement in the delivery of healthcare.
9. Adopt some strategic changes in outlook.

1. Be truthful and factually accurate

Groups emphasise the importance of pharma companies being open and honest about their own and competitors' products, and about research results.

- **Transparency about own products.**
Four groups mention the importance of being transparent about the performance of products. A Swedish cancer organisation that does not draw any of its income from pharma asks the industry to:
"Create clearness about their products."
- **Transparency about rivals' products.**
One German local kidney-donor organisation that draws a small proportion of its income from pharma believes that research-based pharmaceutical companies ought to be more up-front about the availability of generic alternatives to their branded products (and be less evasive about parallel imports).
- **Transparency and accuracy about research results.**
Eight groups give the following advice: when companies promote products, data should be presented in a clear, statistically-valid way, and not contain any misleading 'spin' on clinical results; the risks, as well as the benefits of treatment, should be emphasised; all trial results, both positive and negative, should be published; and more transparency is required about whether clinical researchers are in receipt of funds from pharma.

2. Improve research by making innovation more relevant to patients

At first glance, a contradiction is apparent in the respondents' advice about R&D. On the one hand, many organisations request that pharma spend more on innovation. Others, however, accuse the industry of over-spending on R&D, and thereby forcing up the price of medicines. On closer reading, however, respondent groups are requesting that pharma manage its R&D spend more *effectively*, and in subject areas which, thus far, have largely been side-lined by the industry (such as paediatric medicine, or rare diseases).

In addition, a number of groups appeal for the industry to find cures, rather than mere palliatives. Jim Byrne, a member of the Diabetes Federation of Ireland (which draws a moderate proportion of its income from pharma), is among respondents who suspect that the industry's vested interests will prevent such endeavour, since drug companies lose sales if patients are cured of disease:

"More support in research funding. (But, would cures benefit pharmaceutical companies?)"

Eleven of the respondent groups discuss the importance of making R&D more relevant to patients, through such means as:

- Raising clinical questions that "patients want answered about major drugs".
- Undertaking clinical research among people who truly represent the patient population.
- Improving standards of clinical trials, so that patients are well informed about the process in which they are partaking, and so that individuals in trials are not left abandoned after the completion of research programmes.

The Vancouver Advanced Prostate Cancer Support Group, which does not draw any of its income from pharma, stipulates that companies should be encouraged to provide patients with special access to products when test results are especially positive (even before the products are formerly approved):

"Improve patient access to drugs on a 'special-access' basis after good results have been obtained from stage-II clinical trials, but before completion of lengthy stage-III trials."

A number of patient groups believe that pharma innovation could be made more user-friendly if organisations such as themselves (and member patients) are more fully engaged in R&D activities.

3. Become more involved with patient groups

Although the industry maintains close ties with many leading patient organisations worldwide, survey respondents consider that much more could be done:

- Pharma could have more grassroots-level contact with groups.
- Pharma typically favours medical societies over patient-led organisations—but should not discriminate against the latter.
- Pharma should try to gain a better understanding of patients' opinions

and needs, and take them more seriously.

- Pharma should explore more innovative forms of partnership between itself and patient groups [for more on innovative partnerships, see below]. These ought to be adopted for the long haul.

4. Provide patients and patient groups with informational events, speakers, and conference services

Respondents suggest many ways in which pharma can supply help with informational activities—with meetings, conferences, speakers, and training events. The aim would be to allow patient advocates (and their members) to become more informed, and to better promote the patient voice. The suggestions assume far greater liaison at local levels.

- Have leading speakers—medical experts, pharmacists and other health professionals—make presentations at the workshops, forums and conferences of patient organisations. Subjects could include medication, pain management, and drug interactions.
- Help patient group representatives attend other conferences and meetings.
- Offer training events. Subjects could include: training patients in self-monitoring of their condition; training parents and carers in the medical needs of patients (particularly in the field of mental health); and training

health professionals, to enable them to understand patients' perspectives.

- Run seminars on advocacy.
- Run forums that enable all stakeholders to exchange views.
- Provide information about drugs and future prospects in the R&D pipeline (including data about the risks versus the benefits of medication).
- Invite patient groups to R&D laboratories and production plants, to help them gain insight into the process of innovation.

Acción Solidaria, a Venezuelan HIV/AIDS group that draws a small or tiny proportion of its income from pharma, summarises the various opportunities as follows:

“ 1.) Training in issues related to the research and production processes is important. 2.) As well, instead of just inviting doctors, bring members of patient organisations to conferences and symposia, in order to help them keep up to date in terms of advances in treatments, and in prevention strategies (among other issues). 3.) Regular meetings with top specialists (and even visits to production plants) could also help patients understand the complex processes behind innovative medicines and the need for fair pricing.”

A US national genetic disorder organisation that draws a significant proportion of its income from pharma cautions, however, against pharma involvement becoming sales-oriented:

“When patient-educational meetings are attended by pharma personnel who cannot adhere to privacy policies, patients can perceive the meeting and our organisation as being sales-driven, and can question whether our commitment is to the patients, or to pharma.”

5. Support patient groups' campaign activities

Pharmaceutical companies have always helped some patient groups campaign. These efforts, though, usually occur when pharma recognises a subject of interest to itself, and then asks a patient group to lead a campaign built around that subject. Many of the survey's respondent organisations say, though, that they would like pharma to be more ready to support patient-group-inspired initiatives instead—particularly in the areas of raising disease awareness, access to medicines, and patient educational activities. The groups offer ideas on the directions that such support could take:

- Boosting public awareness of patient educational materials (for instance, through public-service announcements).
- Alerting the media to support patient groups' campaigns.
- Working on a political level on behalf of patient groups' activities.
- And, above all, supporting efforts to increase the credibility of patient groups' voices. A German national cancer group that draws a small or tiny proportion of its income from pharma gives an example:

"Campaign against the media's impression that patient organisations are the speaking tube of, and dependent upon, pharmaceutical companies. It's not possible to work without financial security, but also not without pharma collaboration. Hopefully, the answers are helpful."

6. Offer good and services

The respondent groups identify a number of ways in which pharma companies can help them in practical and tangible ways—without entering into relationships that involve money. Pharma can, for instance, provide goods and services, such as office materials, specialist staff, access to corporate discounts, infrastructure support, arranging for the printing of patient group publications, or distributing patient group informational materials to healthcare professionals.

7. Produce more—and better—informational material

The previous issue of *HSCNews* indicated that patient groups consider pharma to be good at producing information. Even so, the respondents still feel able to suggest numerous areas worthy of further improvement and expansion, such as the following:

- Perhaps the largest factual gap pointed out by group after group is information about companies' medications (including details on dosages, side effects, reimbursement status, and new products)—but supplied on a regular basis. Jackie Cajolais, a member of the Sackville Seniors Advisory Council, a Canadian local health-promotion organisation that specialises in older people, and which does not draw any income from pharma, explains the value to her group of such routine informational flow:

"I think that the pharmaceutical industry needs to become more involved with the smaller non-profit organisations that work

with seniors, and with people with a disability. By this, I mean they need to contact and work with these groups to assist them in offering informed choices to their clients regarding medications (whether cross-counter or prescription) Also, since my group deals with seniors, and, being a small charity organisation, it would be seen as good PR for large pharmaceutical companies to help us support the clients who use their products on a daily basis. We are all looking out for the best interests of our clients. Working with groups dedicated to improving the lives of our clients is the most important part of our work with seniors, and being kept abreast of new medications and new ideas would go a long way towards helping us to meet our goals."

- Groups ask to be notified by pharma about the latest R&D developments (especially the results of clinical trials, and related research topics, including prevention).
- Groups request that pharma-generated information for patients be couched in simple, easily-digestible, layman's language.
- Groups with an interest in disability would like more patient information in formats suitable for people they represent. Thus, a UK national organisation specialising in deafness, and which does not draw any income from pharma, notes:

" 1.) Pharmaceutical companies can offer more deaf-friendly services by having their websites accessible for users of BSL (British Sign Language). Sign language is these people's first or preferred language. This would mean that deaf people would have full access to information and services relating to health issues—information that hearing people take for granted every day. 2.) Producing leaflets in plain English would

make for a huge change for the local deaf community. 3.) Pharmacy staff could be trained in deaf awareness. It would go a long way in helping deaf customers if pharmacies have at least one or two staff members who can use BSL. This would allow deaf customers to know that they could go to a local pharmacist for advice, and will be able to communicate in their first language, and be understood. The British Deaf Association would be able to offer our services to carry out an audit access. This would be beneficial for local chemists in improving their services to the local deaf community."

- Groups suggest that health professionals would benefit from more information about the tangential aspects of medications (such as off-label usage).

8. Promote greater patient/public involvement in the delivery of healthcare

Across Europe, in particular (and, to some extent, in Australia and New Zealand), governments are trying to include patients and the public in national-level and local-level healthcare policymaking decisions (and, sometimes, even in the implementation of these decisions). The trend towards patient and public involvement (PPI) is welcomed by user groups. Survey respondents say that they would like pharma companies to encourage PPI in healthcare policymaking. They propose several initiatives, including the following.

- Louisa Di Pietro, Community Educator of Thalassaemia Australia Inc, which draws a moderate proportion of its income from pharma, invites pharma to extend PPI into R&D:

“Without consumer participation, pharma's product development and improvement can only go so far. The efficacy, user-friendliness, access, cost, and understanding of medicines is imperative to consumer loyalty (regardless of the fact that some medicines are a captured market). An interest in consumer needs and concerns rates very highly on consumer priority lists.”

- A US local hepatitis organisation that does not draw any of its income from pharma recommends that companies underwrite many more surveys to understand the individual needs of patients.
- The Danish Society of Obesity, which does not draw any of its income from pharma, advises the industry to involve patients and patient groups in educational activities intended for GPs and other health professionals.
- Some groups wish that pharma could help them build closer relationships with doctors.
- One respondent would like pharma to assist it in the recruitment of members.

9. Adopt strategic changes in outlook

Although the pharmaceutical industry must inevitably be driven by profit motives, a number of survey respondents recommend companies take a more long-term view of their investments.

- Some groups believe that industry's need for quick returns on investment has adversely affected R&D. Pharma seems to have largely abandoned basic research that either might uncover new approaches to treating diseases, or that might move company

R&D into subject areas not normally tackled. The National Council for the Blind of Ireland, which draws a small proportion of its income from pharma, advises the industry:

“Not be overly specific in the conditions for which they supply treatments. A bigger-picture view would be welcome. Progress is being made with a couple of the companies, but there is clearly a reluctance to get involved in an area if they don't have a specific treatment—despite the fact that awareness on the overall issue would benefit them in the long run.”

- Issues of inequity in healthcare continue to loom. The Health Global Access Project, for example, a US HIV/AIDS organisation that does not draw any income from pharma, calls for a more compassionate approach in the distribution of patent and other intellectual property rights.
- As the pharmaceutical industry aligns more closely with patients, it needs to look at problems from the patients' perspective. Medicines are only one part of the patient journey, and a few groups believe that companies should acknowledge (and even support) non-drug medical interventions.
- Furthermore, some groups think that pharmaceutical companies ought to be more willing to consider the social implications of certain disease areas when they market treatments. For example, the promotion of anti-obesity drugs implies that fat people are ill, societal misfits, thereby perpetuating a public myth that can lead to discrimination.

- Drug pricing remains a contentious subject for some of the respondent groups. Twelve of them single out the issue, and counsel the industry to make greater efforts to lower the price of medicines and diagnostics tests.

The way forward

Patients and their representatives are set to play an ever-larger role in healthcare. As governments and other healthcare payers struggle to balance budgets, the public will need to be engaged more fully in decisions about what should, or should not, be paid for by the state or by managed-care systems.

Furthermore, if healthcare spending is to become more effective, patients and the public will have to be allowed a greater say in R&D processes, to ensure that the output of innovations satisfies their needs.

Healthcare users, however, unlike other healthcare stakeholders, have no single union or spokesperson through which they can articulate their desires. Even health advocacy—which, in any case, is a relatively new, and still-fragmented, phenomenon—is still relatively naïve about the mechanisms and tools required to bring about political change.

The pharmaceutical industry has long been, and will remain, an important stakeholder in healthcare markets. It could do much to help patients gain the influence and professionalism required to put health advocacy centre-stage.

Patients and the users of medicines, meanwhile, form one of the few categories of people who sometimes (though not always) regard pharma companies as their natural allies. And the drug industry is in desperate need of friends. As the power and influence of patients increases, their impact on the drug industry could only be beneficial.

However, as this survey finds, the industry has to make changes to its approach to patients and health advocates if relationships are to flourish.

The Schizophrenia Fellowship of NSW Inc, an Australian state-wide mental health group that draws a small or tiny proportion of its income from pharma, illustrates the range of options that pharma could explore if it is to improve its chances of working usefully with health advocates:

- 1.) "For our part, we provide education through professional and consumer speakers to pharma staff." [*Become more involved with groups generally.*]
 - 2.) "Various pharma staff have provided voluntary labour for us in different projects/activities, including manual work (such as painting our offices)." [*Offer goods and services.*]
 - 3.) "We have also been able to partner in other activities, such as advocacy campaigns to increase the level of funding in direct-service provision for people with a mental illness." [*Support groups' campaigns, or campaign along similar themes.*]
 - 4.) "The provision of up-to-date information about (non-pharma) research into mental illness for consumers and carers." [*Produce more and better informational material.*]
- Our major goal is to reduce the stigma associated with mental illness, and we have had very successful partnerships around this task."

Appendices I.-X.

Appendix I. Truthfulness and factual accuracy.

[This category crosses over somewhat with both Appendix II, 'Research', and Appendix VII, 'Information'. Respondents' comments are placed in Appendix I when *veracity* seems to be the main thrust of the request from the groups.]

Appendix II. Improving research and development.

Appendix III. Becoming more involved with patient groups.

Appendix IV. Providing a wider range of services to patient groups and their members.

Appendix V. Supporting patient groups' campaign activities.

Appendix VI. Offering goods and services.

Appendix VII. Producing more and better informational material.

Appendix VIII. Promoting patient and public involvement.

Appendix IX. Introducing strategic changes in outlook.

Appendix X. Organisations happy to be named in this report.

Truthfulness and factual accuracy

Truthfulness and accuracy about products

"Pharma companies can be more transparent with patients and groups about their products."

Northwest Louisiana Chapter of the Sickle Cell Disease Association of America, Inc., a local branch of a US national sickle-cell disorder organisation. Does not draw any income from pharma.

"Improving transparency of information."

US national organisation. Does not draw any income from pharma.

"Transparency rates very highly on consumer priority lists."

Louisa Di Pietro, Community Educator of the Thalassaemia Australia Inc (formerly the Thalassaemia Society of Victoria Inc.), an Australian national organisation specialising in blood disorders (including haemophilia and thalassaemia). Draws a moderate proportion of income from pharma.

"Create clearness about their products."

Swedish cancer organisation. Does not draw any income from pharma.

Truthfulness and accuracy about research results

"We should be happy if the statistics and other information are according to the truth, and not shown in such way that one can miscalculate (for example, the rating numbers of cured people after a certain treatment)."

LHC-Västra Götaland, Swedish local liver and hepatitis-C organisation. Does not draw any income from pharma.

"By providing clear, honest information on any new research or development of their drugs. One has to rely on media reports or Internet surfing to try to discover the truth about some developments in drugs. Even doctors are not clear on the risks, if any, which have been uncovered."

Member of the Diabetes Federation of Ireland, an Irish national diabetes organisation.

"Greater accessibility to in-house research results (rather than the 'spin') would, in my view, considerably enhance my currently-dark suspicions of what may not be getting disclosed."

New Zealand local mental health organisation. Does not draw any income from pharma.

"By accurately reflecting independent research on drug effects on pregnant/breastfeeding moms in the product monograph."

US national breastfeeding organisation. Does not draw any income from pharma.

"They could be open about not only what the benefits of taking a particular drug are, but also the side effects, how extensively it has been tested, and the cost."

Advocacy Initiative Network of Maine, a US local mental health organisation. Does not draw any income from pharma.

"Companies should furnish the results of all trials, and should report all side effects as percentages of patients (0.0001% of death is worse than 100% of many side effects that are typically listed). There should be quicker and more complete post-marketing side effects listings."

Australian national organisation. Does not draw any income from pharma.

"Yes, by being honest and providing real research information."

New Zealand local organisation. Does not draw any income from pharma.

Truthfulness and accuracy about competitor products

"Be more honest on generics offered from other companies. Be more honest on reimports. Don't play around with rumours on transport problems."

German local kidney donor organisation. Draws a small or tiny proportion of income from pharma.

Improving research and development

More emphasis on research in general

"Bring to market products that work."

Anonymous US-based global cancer organisation. Does not draw any income from pharma.

"Initiate research."

Föreningen Autism i Uppsala Län, a Swedish local autism organisation. Does not draw any income from pharma.

"Research for a cure."

Anonymous.

"Focus on donating to objective research that draws honest conclusions. These companies should not 'head' any research, or hire the doctors. Nor should they pay off anyone in government involved in the donation allocation process, or dictate the process through lobbying. This leads to the 'manufacturing' of data, which is bad for patient health. The only valid 'lobby' groups should be patient-driven organisations. That goes for any disease, not just IC."

Anonymous.

"Constant scientific experimentation and development to improve drugs—for instance, move toward investigating for less side effects."

New Zealand local liver organisation. Does not draw any income from pharma.

"I think that pharmaceutical companies should stop spending money on marketing, and increase their research efforts. I am really irritated by ads for prescription drugs, and by knowing that companies woo doctors with treats to influence them to prescribe their products."

Member of the ACOR Carcinoid Cancer Online Support Group, a US national cancer organisation. "The regional carcinoid support groups that plan conferences are supported in part by Novartis."

More emphasis on research for specific conditions

"They could develop a medication which addresses the causes of ALS, not just its symptoms."

Member of a Canadian national neurological organisation specialising in ALS.

"Continue to research new treatments for brain disorders."

US local organisation specialising in mental health. Draws a moderate proportion of income from pharma.

"We'd like to see more research on drugs that could be beneficial to individuals who sustain traumatic brain injury."

Brain Injury Association of America, a US national brain injury organisation. Does not draw any income from pharma.

"They could do increased R&D on pediatric formulations."

Health Global Access Project, a US-based global HIV/AIDS organisation. Does not draw any income from pharma.

"More R&D resources and greater effort could be devoted finding new drugs, vaccines, or treatments to cure pediatric cancers and blood diseases. Currently, manufacture of drugs that prove effective can be terminated because the profit margins are not in line with company earnings goals. It would be helpful if the companies in question would consider licensing the manufacture of those non-profitable drugs to an organisation to manage and distribute to medical facilities."

America's Baby Cancer Foundation, a US national cancer organisation. Does not draw any income from pharma.

"Research more—mechanisms of vomiting, triggers, etc."

Australian CVS Association, a national gastrointestinal disorder organisation. Does not draw any income from pharma.

"By researching treatments for mitochondrial disease and dysfunction."

US national mitochondrial disease organisation. Does not draw any income from pharma.

More emphasis on research for specific conditions (Continued)

"Early and intensive research into, and development of therapies for, mucopolysaccharidoses and related diseases."

Japanese Society of the Patients and Families with Mucopolysaccharidoses (the Japanese MPS Society), a national metabolic organisation. Draws a moderate proportion of income from pharma.

"Yes, they could do some research into the long-term effects of psychotropic drug use, including effects on older adults and children."

Kathleen Piche, member of a US local mental health organisation. Does not draw any income from pharma.

"Work around early intervention with psychosis."

Neami, an Australian national mental health organisation. Does not draw any income from pharma.

"Down syndrome is a complex syndrome with no quick fix. Since leukemia and heart problems are more common in this population, it might be useful to do some more research in these areas."

Louise McGoey, member of a Canadian local Down syndrome organisation. Does not draw any income from pharma.

"Tinnitus (ringing noise in the head or ear) affects some 50 million people in the US, with two million of those incapacitated by the malady. This is a significant number of people who could be helped by pharmaceutical discoveries. Pharmaceutical companies could also donate money to continue researching the causes of tinnitus, and how to cure such a symptom."

American Tinnitus Association, a US national organisation. Does not draw any income from pharma.

"Find the cure for MS."

MS forbundet i Sog og Fjordane, a Norwegian national multiple sclerosis organisation. Does not draw any income from pharma.

"Continued research into therapies for rare disorders."

US national organisation. Draws a small or tiny proportion of income from pharma.

"We are trying to obtain a steroid injectable that would be ready for use. With Addison's being a rare disease, the \$s are not lucrative enough for a pharmaceutical company to prepare a speciality product. But a product such as this could be a life saver for a individuals with Addison's disease."

Francisca Swist, member of a Canadian national adrenal insufficiency organisation. Does not draw any income from pharma.

"Most pharmaceuticals are not interested in Tay-Sachs and other ultra-rare diseases because the patient population is too small to generate a profit. More should be researching ultra-rare diseases."

Kim Kubilus, Director of Member Services, National Tay-Sachs and Allied Diseases Association, Inc. (NTSAD), a US genetic diseases organisation. Draws a moderate proportion of income from pharma.

"Support orphan-disease drug research. Emphasise the value of pharma's research and development activities, and not the embarrassing excesses of their marketing groups."

US national organisation. Does not draw any income from pharma.

"They could do research for a drug to help the 1-in-4 women who miscarry, and the sad percentage who have multiple miscarriages."

New Zealand national organisation. Does not draw any income from pharma.

"More support in research funding. (But would cures benefit pharmaceutical companies?)"

Jim Byrne, member of the Diabetes Federation of Ireland. Draws a moderate proportion of income from pharma.

"In the case of diabetes, they could actually find a cure. However, given the fact that diabetes care and treatment represents nearly \$225 billion annually in the US alone, we know that there won't be a cure in the next 20 years. There is simply too much money in treating the disease, so why cure it? It simply isn't in their best interest."

Defeat Diabetes Foundation, a US national diabetes organisation. Does not draw any income from pharma.

Involve patient groups in research

"Incorporate patient advocates into research programmes."

Gunter Feick, chair of the Bundesverband Prostatakrebs Selbsthilfe e. V. (BPS), a German national prostate cancer advocacy organisation. Draws a small or tiny proportion of income from pharma.

"Involve us in the development of anti-obesity drugs from the beginning, not just when we hear the FDA Advisory Committee presentation."

Council on Size and Weight Discrimination, a US national advocacy organisation specialising in attitudes to weight. Does not draw any income from pharma.

"Include patient organisations' opinions into R&D strategies (innovation vs. me too)—including patient organisations' opinions at ethical committees for clinical studies (non-doctor members are usually irrelevant in decisions)."

Grupo de Enlace, Investigación y Soporte - Enfermedades Raras (GEISER Foundation), an Argentinean national rare disease organisation. Draws a small or tiny proportion of income from pharma.

Make clinical trials more patient-considerate

"We would like to see greater consumer participation in cancer drug clinical trials—from the development stage on. These trials do not always ask the questions that patients need to have answered about major drugs."

Cancer Voices NSW, an Australian state-based cancer organisation. Does not draw any income from pharma.

"Design clinical trials that fairly examine the drug's performance with the sorts of people who will take the drug once it is approved. For example, the people who are the most sick (including those with co-morbidities) are usually excluded from the trials, but will be the first to take the drug once it's on the market."

US-based global cancer organisation. Does not draw any income from pharma.

"Formulate blind-study trials in a way so that those not receiving the drug are not left to die when it becomes apparent that the drug has merit."

Lora Bennett, member of a US local sarcoma organisation.

"Improve due diligence in selection of trial sites, especially for phase-I and bioequivalence trials. Solicit feedback from bioethicists, advocates, and research subjects to improve consent forms. Develop company policies for authorising clinical trials (that is, make sure nobody in the marketing department can commission trials)."

US national organisation specialising in ethics in human research. Does not draw any income from pharma.

"Recruit the patients for the trials from patient groups, not from the doctors' 'favourites'."

Romanian national cancer organisation. Draws a significant proportion of income from pharma.

"If we could obtain trial drugs locally, rather than having to travel long distances, more people would benefit during trial periods. Pharmaceutical companies could help fund travel for patients who are enrolled in clinical trials."

US organisation. Does not draw any income from pharma.

"Improve patient access to drugs on a 'special-access' basis after good results have been obtained from stage-II clinical trials, but before completion of lengthy stage-III trials."

Vancouver Advanced Prostate Cancer Support Group, a Canadian local prostate cancer organisation. Does not draw any income from pharma.

"Provide more test samples through doctors."

Canadian national organisation. Does not draw any income from pharma.

Becoming more involved with patient groups

Make contact with patient groups

"Get involved at the grassroots level. Come out and introduce yourselves to the people at large."

Member of Helping Spirit Lodge Society, a Canadian local organisation specialising in family safety and health. Does not draw any income from pharma.

"Be aware of our existence. Introduce themselves to us. Collaborate with us."

Beka Serdars, RN, MS, NP, member of Care4Dystonia, US-based global dystonia organisation. Draws a small or tiny proportion of income from pharma.

"Perhaps make contact. We are open for discussion."

Asthma and Allergy Association Halmstad, a Swedish local asthma and allergy organisation. Draws a small or tiny proportion of income from pharma.

"The local representatives may look for closer contacts. These are very different from pharma employee to employee."

German local kidney-donor organisation. Draws a small or tiny proportion of income from pharma.

"Better liaison with not-for-profits, etc."

New Zealand national organisation. Draws a small or tiny proportion of income from pharma.

"Be more open to talk and to listen. Understand and observe the patient groups. Do not discriminate between medical societies and patient groups, etc."

Romanian national cancer organisation. Draws a significant proportion of income from pharma.

"Accepting, understanding, and recognising our input in helping parents."

Association PANDA Lanaudière Nord, a Canadian local ADHD/ADD organisation. Does not draw any income from pharma.

"We do not ask, but it seems to me that they have a great obligation to offer to assist organisations [like ours] without asking. After all, they receive millions from patients buying their drugs."

US-based global primary immunodeficiency organisation. Does not draw any income from pharma.

Learn more about patients through the patient groups' own expertise

"Liaise with us, to gain a better understanding of patients' needs and opinions."

Jeannie May, member of Living Sphere (Herpes Support and Awareness), an Australian national herpes organisation. Draws a small or tiny proportion of income from pharma.

"Come to our public education days."

Patients' Rights Advocacy Waikato Incorporated (PRAWI), a New Zealand national advocacy organisation specialising in patients' rights. Does not draw any income from pharma.

Partner with patient groups in activities

"Create relationships with patient advocacy groups for the purposes of improving patient assistance programmes, patient educational materials, and learning about the disease groups' healthcare priorities for research purposes."

Anonymous US national congenital adrenal hyperplasia organisation / Draws a moderate proportion of income from pharma.

"Partner with the organisation (even in name and reputation) for various activities."

Canadian national asthma and allergy organisation. Draws a small or tiny proportion of income from pharma.

"Become aware of what our group of diseases is, and the challenges we face. Support patient programmes, and partner with us for the long haul on worthy projects."

Cicatricial Alopecia Research Foundation, a US national organisation specialising in permanent hair loss. Draws a moderate proportion of income from pharma.

Partner with patient groups in activities (Continued)

"Longer-term relationships. Help programmes be more effective. Often, a programme changes with the pharma staff. Clear goals set forth allow us to best pick programmes that will be mutually successful."

Wendy Poage, President of the Prostate Cancer Education Council, a US national prostate cancer organisation. Draws a moderate proportion of income from pharma.

"We should work hand in hand, to get the best result."

Swedish national organisation. Draws a small or tiny proportion of income from pharma.

"Help by working together with organisations and branches on a local level."

Peggy Scholdei, member of an Irish local diabetes organisation. Does not draw any income from pharma.

"It is necessary to create a code for transparency of relationships in Latin America."

Grupo Otimismo de Apoio ao Portador de Hepatite, a Brazilian national hepatitis organisation. Draws a small or tiny proportion of income from pharma.

Providing patients and patient groups with informational events, speakers, and conference services

Offer informational events for patients

"Yes, by giving presentations about the medications we take, and the options that are better for us in the long run."

Member of the Vancouver/Richmond Mental Health Network, a Canadian local mental health organisation. Does not draw any income from pharma.

"Workshops available in local communities, on medications, pain management, and common interactions."

Canadian local organisation specialising in addiction and sexually-transmitted diseases. Does not draw any income from pharma.

"Organising educational events."

FibroAction, a UK national organisation specialising in fibromyalgia. Draws a moderate proportion of income from pharma.

"Yes, they should conduct forums for individuals (and/or organisations), to explain their products—especially the newer psychotropic meds."

Dr Gordon Bopp, President of the Washington affiliate of a US national mental health organisation. Draws a small or tiny proportion of income from pharma.

"Offer our families training to understand their mental-health pharmaceutical needs, and the complexities of why taking certain meds is important and helpful to them."

North Carolina Families United, Inc., a US local organisation specialising in mental health and families. Does not draw any income from pharma.

"Provide education."

Swedish national organisation. Does not draw any income from pharma.

"By offering lectures on medication (including the bad and good effects of the medicine) that they are manufacturing."

Allan Jørgensen, member of Landsforeningen Bedre Psykiatri, a Danish national mental health organisation specialising in families. Does not draw any income from pharma.

"Organise patient meetings."

Jordan Hemophilia Society. Draws a small or tiny proportion of income from pharma.

"Bring in the world's leading experts, and train patients about what the disease is, how it should be monitored, the gold standards of treatment, other treatment options, and new treatment medications that are in the pipeline."

US local organisation. Does not draw any income from pharma.

Offer informational events for patient groups

"Maybe have an event with people from the company itself [for organisations and branches on a local level]."

Peggy Scholdei, member of an Irish local diabetes organisation. Does not draw any income from pharma.

"We as a self-help group like to provide information. Visits by pharma companies could help us evaluate the pros and cons of psychiatric medication versus possible side effects."

German local mental health organisation specialising in manic-depressive disorder. Does not draw any income from pharma.

"Pharma can provide training services to the groups, instead of funding."

US national congenital adrenal hyperplasia organisation. Draws a moderate proportion of income from pharma.

"Organise regular meetings with our organisation for exchanging information on: 1.) the availability and cost of medication; 2.) patient satisfaction, and patients' experiences of the effects and side-effects of pharmaceuticals; and 3.) research objectives."

Gunter Feick, chair of the Bundesverband Prostatakrebs Selbsthilfe e. V. (BPS), a German national prostate cancer advocacy organisation. Draws a small or tiny proportion of income from pharma.

Offer informational events for patient groups (Continued)

"Yes, by making regular presentations to my group about their drugs and on future prospects in their 'pipeline'."

US local organisation. Does not draw any income from pharma.

"Have pharma representatives willing to come out and present to targeted patient support groups."

Dystonia Medical Research Foundation Canada, a Canadian national dystonia organisation.

"Run a seminar on a topic such as advocacy."

Canadian Arthritis Patient Alliance, a Canadian national arthritis organisation. Draws a significant proportion of income from pharma.

"In-kind services, such as facilitating meetings."

National Association For Continence, US. Draws a moderate proportion of income from pharma.

Offer informational events for a variety of audiences

"By offering training and information days for a variety of healthcare professionals. Could be held in-house."

Irish national cancer organisation. Does not draw any income from pharma.

"Offer sponsorship for scientific seminars, forums for patients, and public-education outreach activities organised by our organisation."

National Kidney Foundation of Malaysia. Does not draw any income from pharma.

"Non-commercial sponsorship for educational events, training activities, etc, aimed at healthcare providers, as well as at non-branded patient-awareness programmes."

The Allergy and Asthma Institute, Pakistan. Does not draw any income from pharma.

"Hold informative sessions on their products, to inform our organisation and its members."

Canadian Treatment Action Council (CTAC), a Canadian national HIV/AIDS organisation. Draws a moderate proportion of income from pharma.

"Organise open and honest forums that bring together patients, medical staff (doctors included), and the pharmaceutical industry (not just one company). These would help people with a chronic disease."

Canadian local organisation / Draws a small or tiny proportion of income from pharma.

"1.) Training in issues related to the research and production processes is important. 2.) As well, instead of just inviting doctors, bring members of patient organisations to conferences and symposia, in order to help them keep up to date in terms of advances in treatments, and in prevention strategies (among other issues). 3.) Regular meetings with top specialists (and even visits to production plants) could also help patients understand the complex processes behind innovative medicines and the need for fair pricing."

Acción Solidaria, a Venezuelan national HIV/AIDS organisation. Draws a small or tiny proportion of income from pharma.

Provide speakers for groups' meetings

"Recruit major researchers and or physicians to provide educational presentations at no cost to our organisations."

American Samoa local Alzheimer's disease organisation. Does not draw any income from pharma.

Provide speakers for groups' meetings (Continued)

"Perhaps provide speakers to talk to our support group from time to time."

Mike Hemsley, member of a New Zealand local mental health organisation. Does not draw any income from pharma.

"Provide us speakers for our meetings."

Thomas W. Nuckols, Ph.D., member of USTOO Texoma Prostate Cancer Support Group, a US local cancer organisation. Does not draw any income from pharma.

"Assist in obtaining speakers for support group meetings."

Canadian local cancer organisation. Draws a significant proportion of income from pharma.

"Secure in-kind speakers for treatment updates, hosting roundtable community-based discussions."

Tom Kujawski, VP for Development, National Association of People With AIDS (NAPWA), US. Draws a moderate proportion of income from pharma.

"Visiting speakers."

US national organisation. Draws a significant proportion of income from pharma.

"We appreciate collaboration from the companies in developing meeting topics and speakers."

US national genetic disorders organisation. Draws a significant proportion of income from pharma.

"Take part in seminars and meetings arranged by our organisation—whether for members, politicians, or people in general."

Swedish local organisation specialising in ostomy. Does not draw any income from pharma.

"Have pharmacists available to consult with our members at our meeting site, where the member might feel more 'secure' in seeking extended information."

Canadian local branch of a national prostate cancer organisation. The local branch does not draw any income from pharma.

"When patient educational meetings are attended by pharma personnel who cannot adhere to privacy policies, patients can perceive the meeting and our organisation as being sales-driven, and can question whether our commitment is to the patients, or to pharma."

US national genetic disorders organisation. Draws a significant proportion of income from pharma.

Help groups run their own conferences/annual meetings

"Help to organise the annual [meeting] of our Society."

'Arvan' Multiple Sclerosis Society, an Estonian national multiple sclerosis organisation. Does not draw any income from pharma.

"Of course, support for a Congress (even a single-day Congress) we have been planning. We have never had this support, even though we have been working since 2001, and have a network of branches in seven cities. Pharma could support one of our events."

Member of Voz Pro Salud Mental DF, a Mexican national organisation specialising in mental health. Draws a small or tiny proportion of income from pharma.

"Provide sponsorship for our activities, such as conferences and production of leaflets."

UK national organisation specialising in pelvic joint pain related to pregnancy. Does not draw any income from pharma.

"Organisational support, such as making facilities available for conferences/meetings (like Bank of Montreal does)."

Member of the ALS Society of British Columbia, a provincial unit of the ALS Society of Canada (a national motor neurone disease organisation). Draws a small or tiny proportion of income from pharma.

Help set up relevant conferences/annual meetings

"Work together on issues such as developing conferences for patients and professionals."

UK national organisation specialising in ultra-orphan cancers. Draws a significant proportion of income from pharma.

Help groups attend other conferences/annual meetings

"Assist with the costs of attending meetings."

Australian local blood disorders organisation. Does not draw any income from pharma.

"Yes, including us in the congresses of psychiatrists and neurologists. Doctors need to know the needs of families and patients."

Graciela B. Cámara Cáceres, President of Ingenium Morelos AC, a Mexican national mental health organisation. Draws a significant proportion of income from pharma.

"Ask us to share a stand at an exhibition (or similar)."

Thorkild Bach, member of a local branch of Osteoporose Foreningen, a Danish national organisation specialising in osteoporosis. Draws a small or tiny proportion of income from pharma.

Sponsor relevant conferences/annual meetings

"Sponsor conferences for professionals and the public."

Dr Pedro A. Ricart, member of a Dominican Republic national organisation. Does not draw any income from pharma.

"Monetary support of patient information conferences."

US local organisation. Draws a small or tiny proportion of income from pharma.

"They can underwrite the cost of providing regional conferences with the focus on a particular disease."

US local organisation. Does not draw any income from pharma.

"Sponsor congresses in which Voz Pro Salud can participate."

Member of Voz Pro Salud Mental DF, a Mexican national organisation specialising in mental health. Draws a small or tiny proportion of income from pharma.

"By possibly sponsoring part of significant conference fees for healthcare professionals who are other than medical personnel."

Irish national cancer organisation. Does not draw any income from pharma.

"Yes ... sponsor conventions."

US national blood disorders organisation.

Other

"By founding activities not directly connected to their specific medication."

Danish Society of Obesity, a Danish national obesity organisation. Does not draw any income from pharma.

Supporting patient groups' campaign activities

Support patient groups' lobbying activities

"Help us to do advocacy with our government to improve mental health in Mexico."

Graciela B. Cámara Cáceres, President of Ingenium Morelos AC, a Mexican national mental health organisation. Draws a significant proportion of income from pharma.

"Assistance in performing public-awareness campaigns, including awareness of risks and medications in general."

SAFE – Stroke Alliance for Europe, UK-headquartered European-level stroke organisation. Draws a significant proportion of income from pharma.

"Support awareness campaigns."

FibroAction, a UK national organisation specialising in fibromyalgia. Draws a moderate proportion of income from pharma.

"Support media campaigns. More resources for campaigns."

Member of Voz Pro Salud Mental DF, a Mexican national organisation specialising in mental health. Draws a small or tiny proportion of income from pharma.

"Increase publicity for awareness campaigns."

Beka Serdars, RN, MS, NP, member of Care4Dystonia, a US-based global dystonia organisation. Draws a small or tiny proportion of income from pharma.

"I work with people living with an invisible disability, brain injury. Awareness of the consequences of brain injury is a huge need. A programme to educate the public, medical personnel, and caregivers is both much needed and very expensive. Sponsorship of efforts in this field would be a tremendous service."

Canadian national brain injury organisation. Does not draw any income from pharma.

"Provide more support for patient education programmes, as they did in the past. Now they support only healthcare professionals—which is wonderful, but there's a need for both. Eliminate their end-user marketing strategies, and allow independent organisations to educate honestly the public and patients."

US local organisation. Draws a moderate proportion of income from pharma.

"Run joint programmes of education."

Irish national diabetes organisation. Draws a moderate proportion of income from pharma.

"We have not worked with all of the companies. But those from which we have received funds have also given good partnership in the projects they have supported."

Swedish national depression organisation. Draws a small or tiny proportion of income from pharma.

"Yes. We would like them to help us develop our project—which is courses to families and workshops for patients."

Ingenium Morelos AC, a Mexican national mental health organisation. Draws a small or tiny proportion of income from pharma.

Support campaigns for greater access to medicines and other healthcare services

"Pharma companies join together with consumer groups in campaigns for federal and provincial policy change related to access to and coverage/payment of medications."

Canadian Arthritis Patient Alliance, a Canadian national arthritis organisation. Draws a significant proportion of income from pharma.

"Exchange ideas about improving the obtainability of the remedies. Influence politicians for approval and reimbursement of remedies."

Swedish cancer organisation. Does not draw any income from pharma.

"Lobby government to approve funding for drugs and devices that support the quality of life of people living with a spinal cord injury."

Canadian Paraplegic Association, Ontario, a Canadian provincial branch of a national spinal injury organisation. Draws a small or tiny proportion of income from pharma.

Support campaigns for greater access to medicines and other healthcare services (Continued)

"They can work much harder on getting medicines to patients with rare disorders, so that the latter don't have to fight for years to try to get certain medicines."

US-based global primary immunodeficiency organisation. Does not draw any income from pharma.

"They could use their lobbying powers to advance the goals of intervention and treatment for all people with an illness."

NAMI Forensic Network MN, a US national mental health organisation. Does not draw any income from pharma.

"Improving patient access to drugs as soon as national approval for marketing has been obtained."

Vancouver Advanced Prostate Cancer Support Group, a Canadian local prostate cancer organisation. Does not draw any income from pharma.

"Give us programmes that would help people get the drugs they need even when they can't afford to pay the normal fees. Give us the information needed to make these programmes accessible to a wide range of people who don't have much time to pursue little-known programmes. Please help the people who need the treatments. You have got the treatments that will help them."

US organisation.

Help with campaigns about accessing drugs for supplementary indications

"When a drug developed for one problem is discovered to help another, it is very difficult to get the drug covered for the secondary use. Powerful drug companies could focus on helping gain easier patient access, vital to many patients."

Canadian local organisation. Draws a small or tiny proportion of income from pharma.

"We'd like help promoting the off-label use of drugs that benefit people with brain injury."

Brain Injury Association of America, a US national brain injury organisation. Does not draw any income from pharma.

"Lupus 'borrows' medications from other diseases. We have approximately 40 drugs being developed, but we require approval from Canada Health for them to be prescribed to patients. Diagnosed patients are increasing at unprecedented numbers. We need help in public-awareness campaigns and earlier diagnoses to ensure that those needing medications receive them."

Canadian local autoimmune disease organisation. Does not draw any income from pharma.

Publicise patient groups' campaigning activities

"Make the public aware of patient education materials."

US national organisation. Draws a small or tiny proportion of income from pharma.

"They could (and one does) perform informational campaigns in the media (newspaper and TV)."

Thorkild Bach, member of a local branch of Osteoporose Foreningen, a Danish national organisation specialising in osteoporosis. Draws a small or tiny proportion of income from pharma.

"If a company is not able to help find a cure or a stabiliser, it can help in awareness of disability diversity within the work- or school-place."

National Nieman Pick Disease Foundation, a US national metabolic and degenerative neuromuscular organisation. Draws a small or tiny proportion of income from pharma.

"Campaign against the media's impression that patient organisations are the speaking tube of, and dependent upon, pharmaceutical companies. It's not possible to work without financial security, but also not without pharma collaboration. Hopefully, the answers are helpful."

German national cancer and blood diseases organisation. Draws a small or tiny proportion of income from pharma.

"Help us with the media, to inform the general public that mental illness exists, and to fight stigma."

Graciela B. Cámara Cáceres, President of Ingenium Morelos AC, a Mexican national mental health organisation. Draws a significant proportion of income from pharma.

Publicise patient groups' campaigning activities (Continued)

"Make the public aware of patient education materials."

US national organisation. Draws a small or tiny proportion of income from pharma.

"We desperately need someone to help us promote ourselves in the media, etc. Some sort of media/promotional support is just as important to us as funds for research. With the proper support, we could raise a lot of our own research funds."

Muscular Dystrophy Association of Western Australia, an Australian state-wide organisation specialising in genetic muscle disease. Draws a moderate proportion of income from pharma.

"They could give us support in the media."

Member of Voz Pro Salud Mental DF, a Mexican national organisation specialising in mental health. Draws a small or tiny proportion of income from pharma.

"Promote ovarian cancer awareness by making public-service announcements (not by using young actresses, but with real women and/or survivors of ovarian cancer), adverts in magazines, TV, radio, the Internet, posters, and literature in medical offices."

US national ovarian cancer organisation. Does not draw any income from pharma.

"Help with gaining media attention for our awareness campaigns."

Jeannie May, member of Living Sphere (Herpes Support and Awareness), an Australian national herpes organisation. Draws a small or tiny proportion of income from pharma.

"Increase their commitment to campaign on blindness in general."

National Council for the Blind of Ireland. Draws a small or tiny proportion of income from pharma.

"Create awareness on warning signs and early detection."

Anonymous South African national organisation. Draws a small or tiny proportion of income from pharma.

"Work politically for both the patient and the company, not only for the company."

Danish Society of Obesity, a Danish national obesity organisation. Does not draw any income from pharma.

"Mention us in their brochures and other advertisements and on the Internet (on their homesites)."

Thorkild Bach, member of a local branch of Osteoporose Foreningen, a Danish national organisation specialising in osteoporosis. Draws a small or tiny proportion of income from pharma.

"Advertising."

US national organisation. Does not draw any income from pharma.

"We would like to see pharmaceutical companies act as a tool to advertise our operation."

'Enosh'—Israeli Mental Health Association. Draws a small or tiny proportion of income from pharma.

Help with accessing branded drugs

"Yes, tell the pharmacists that when a doctor prescribes a certain medication, they should not give us substitute medication. Generic medication has not been through the same testing as the real medications, and almost always have bad side effects that worsens our health problems. Please help us get the medication that is really helpful to us. Thank you."

Canadian national scleroderma organisation. Does not draw any income from pharma.

Offering goods and services

Producing and printing informational publications

"Sponsorship in goods. For instance, printing leaflets with information for patients and the public."
Romanian national cancer organisation. Draws a significant proportion of income from pharma.

"Secure in-kind contributions (printing or other resources) for programmes, etc."
Tom Kujawski, VP for Development, the National Association of People With AIDS (NAPWA), draws a moderate proportion of income from pharma.

"Help publishing patient materials."
Cicatrical Alopecia Research Foundation, a US national organisation specialising in permanent hair loss. Draws a moderate proportion of income from pharma.

"Help us printing our magazines for our membership."
Thorkild Bach, member of a local branch of Osteoporose Foreningen, a Danish national organisation specialising in osteoporosis. Draws a small or tiny proportion of income from pharma.

"Help with material such as brochures, videos, materials for the 'Family-to-Family' National Alliance on Mental Illness (NAMI) course. Support our new course for patients in cities such as Mexico City (we haven't got the support to make it possible). Help us to have a better relationship with psychiatrists."
Member of Voz Pro Salud Mental DF, a Mexican national organisation specialising in mental health. Draws a small or tiny proportion of income from pharma.

"Help with producing educational materials which are expensive for us to create."
Canadian national asbestos-related organisation. Draws a small or tiny proportion of income from pharma.

Distribute the groups' (or other relevant) informational material to the medical profession

"Circulate our information to the relevant practitioners."
Diane Carlton, Chair of Endometriosis SHE Trust (UK), a national organisation specialising in gynaecological health issues. Does not draw any income from pharma.

"Work in joint partnership to help take our patient-led information into clinics. We cannot afford distribution services."
UK national organisation specialising in continence. Draws a significant proportion of income from pharma.

"Use sales reps to provide information to the doctors' offices."
US national organisation. Draws a small or tiny proportion of income from pharma.

"Yes, there are several ways. 1.) Share our information on how healthcare providers can treat their fat/large patients with dignity and respect. 2.) Encourage their clients (that is, the healthcare providers) to have armless chairs in their waiting rooms, bigger gowns, bigger blood pressure cups, etc. 3.) Consider sharing information about the Health at Every Size, which advocates a healthy lifestyle independent of weight loss."
National Association to Advance Fat Acceptance, a US national civil rights and advocacy organisation. Does not draw any income from pharma.

Supply office materials

"Yes, it could provide folders for meetings, plastic label holders and labels, and meeting notepads. We certainly could use an office shredder to aid strict confidentiality (and it must not be too noisy). Currently, our small office fridge has broken, and we need a new one quite urgently. We have 6 office computers and printers, which constantly require expensive supplies of ink cartridges. Any help would of course be most welcome, and publicised in our *Marfan In Touch* magazine, distributed worldwide twice a year, should the donor wish. We would be extremely grateful for any help offered."
Diane Rust, Chairman of the Marfan Association, a UK national organisation specialising in Marfan syndrome. Does not draw any income from pharma.

"Give us access to greater quantities of material (some are limited), since we are regularly out of documentation. Find a more rapid and simple way for us to reach them when ordering."
Association PANDA Lanaudière Nord, a Canadian local ADHD/ADD organisation. Does not draw any income from pharma.

Supply office materials (Continued)

"Companies could support NGOs with office support."
Irish local disability organisation.

Supply other goods: general

"Offer promotional items for use and distribution."
Australian local blood disorders organisation. Does not draw any income from pharma.

"Donate prizes to fund raisers."
The Lupus Society of Manitoba, a Canadian provincial autoimmune disease organisation. Does not draw any income from pharma.

"Work with consumer groups to develop mechanisms to deal with the often-horrific side effects of medications. Provide the following: 1.) funding that would enable consumers to access the health and other care needed to counter the iatrogenic diseases resulting from medication side effects; 2.) gym membership; 3.) access to nutritionists and dieticians; and 4.) access to decent food."
Gwen Scotman, member of an Australian national mental health organisation. Draws a small or tiny proportion of income from pharma.

Supply other goods: testing equipment

"We are trying to have Holter monitor testing available to all patients with a congenital heart defect, whether their insurance will cover it or not. Arrhythmias are the leading cause of death for people with a congenital heart defect (especially when the arrhythmias are undetected)."
Kids With Heart—National Association for Children's Heart Disorders Inc., a US national congenital heart organisation. Does not draw any income from pharma.

"Help with measuring blood glucose and with the materials for measurement."
Danish national organisation. Draws a small or tiny proportion of income from pharma.

Supply other services: access to medications without the involvement of the medical or pharmacy professions

"Direct access to medications for people if it is an emergency, and the person cannot go through the regular channels that provide access to pain medication."
Colorado Cross-Disability Coalition, a US local disability organisation. Draws a small or tiny proportion of income from pharma.

Supply other services: care staff

"There is always a shortage of respite care, home-help services, and personal-assistance services for people with MS in our country. Providing some of these services would be helpful."
Irish national multiple sclerosis organisation. Draws a small or tiny proportion of income from pharma.

Supply other services: telephone helplines

"Better pathways for accessing information. For example, fund a generic drug helpline for consumers about side effects, mixing medicines, dosage queries, etc."
Anonymous Australian local carer/parent organisation Does not draw any income from pharma.

Supply other services: specialist staff

"They already are very helpful. They supply advice, volunteer personnel, and materials, and are much appreciated."

Edwin L. Wilson, member of a US local organisation specialising in blood disorders. Draws a moderate proportion of income from pharma.

"Give us access to professionals and professional services at their disposal—publishing, advertising, creative, media relations, clipping services, etc."

Asthma Society of Canada, a Canadian national asthma organisation. Draws a moderate proportion of income from pharma.

"Provide services in kind, for instance, use of PR and lobbying offices, with costs covered by them."

SAFE – Stroke Alliance for Europe, UK-headquartered European-level stroke organisation. Draws a significant proportion of income from pharma.

Supply other services: websites

"Link patient group websites on main pharma company websites as 'educational partners' or other. Provide access to (or pro-bono) market/marketing research about consumers in the disease groups. Provide expert brand and marketing advice. Provide executives to serve on the organisation's Board of Directors."

US-based global bereavement organisation. Draws a moderate proportion of income from pharma.

"Allow us to access corporate discounts in purchases (pooling resources), and assist in infrastructure support—for instance, website technical support."

National Association For Continence, US. Draws a moderate proportion of income from pharma.

"Provide links to our online information. Provide online advertising for us on an equal basis, without expecting us to promote their products."

Beka Serdars, RN, MS, NP, member of Care4Dystonia, a US-based global dystonia organisation. Draws a small or tiny proportion of income from pharma.

"Awareness, promotion of our meetings, and our website (<http://www.amyloidosisupport.com>)."

Amyloidosis Support Groups Inc., a US national amyloidosis organisation.

More and better informational material

Information for patient groups (especially information about drugs)

"Small readable articles (which are true) for our own publications and magazines would be helpful."

German local kidney donor organisation. Draws a small or tiny proportion of income from pharma.

"Yes, with publications, newsletters, etc."

Dr Nira Dangoor, Chair of the Israeli Support Group for Families of HD, an Israeli national Huntington's disease organisation. Does not draw any income from pharma.

"They could offer to help us with educational materials about mental health and mental-illness management (such as what Eli Lilly does on physical health issues). Mental health patients die 25 years younger, on average, than their peers with normal mental health. This is an outrage to our family members, and to our patient members."

US local branch of a national mental health organisation. Draws a moderate proportion of income from pharma.

"We have many clients with mental illnesses. Knowing the appropriate drugs, dosages, and their likely side effects would always help, even for those who are not directly in charge of the nursing of the clients."

Australian national mental health organisation specialising in telephone counselling. Does not draw any income from pharma.

"Information about the product (written in layman's language) is important for patient groups. Comparison information between drugs would also be helpful."

Canadian local Alzheimer's disease organisation.

"Exchange information about their products and the usage."

Swedish cancer organisation. Does not draw any income from pharma.

"Information. Would be nice to have things such as both prescription and over-the-counter (OTC) *Physicians' Desk Reference* (PDR)s to be provided by drug companies. Plus less 'fluff and puffery' in their literature, and more direct information on the efficacy and safety of the drugs."

Rev Dr John Benjamin Tatum, DD, PhD, Chief Executive Officer of CADMEI, a US national disability organisation. Does not draw any income from pharma.

"Yes. Share relevant late-breaking HIV and hepatitis information, and treatment updates."

Tom Kujawski, VP for Development, National Association of People With AIDS (NAPWA), US. Draws a moderate proportion of income from pharma.

"Yes. Provide us with data sheets, information booklets, pamphlets, story books, etc., explaining their medicine, and investing more in that domain."

Association PANDA Lanaudière Nord, a Canadian local ADHD/ADD organisation. Does not draw any income from pharma.

"Provide current and accurate information to us."

Canadian local mental health organisation. Does not draw any income from pharma.

"Send us updated information. At one time, we did receive pamphlets, brochures, tapes, etc."

Seizure and Brain Injury Centre, Canadian local brain injury and epilepsy organisation. Does not draw any income from pharma.

"Keep us up to date on new directions or future ideas. Newsletters on health matters that impact our organisation."

Canadian local organisation. Does not draw any income from pharma.

"To improve our learning resources."

Member of an Italian national organisation specialising in pulmonary disease. Draws a small or tiny proportion of income from pharma.

Reimbursement information for patient groups

"Provide more and better information about reimbursement and access in a federated country."

Canadian national multiple sclerosis organisation. Draws a small or tiny proportion of income from pharma.

"Advise patient groups how their members can get assistance with costs of medications."

The Lupus Society of Manitoba, a Canadian local autoimmune disease organisation. Does not draw any income from pharma.

Information for patient groups on the results of clinical trials

"The main way that pharma can help us achieve our goals is to provide the information we seek about various products—especially clinical trial results, and their submissions for government approval or subsidy."
Cancer Voices NSW, an Australian state-based cancer organisation. Does not draw any income from pharma.

"Provide the fullest-possible information about clinical trials in entries on <http://www.clinicaltrials.gov>. Provide the results of clinical trials to the public in a timely and consistent fashion."
US national organisation specialising in ethics in human research. Does not draw any income from pharma.

"Supply the trials results in an easy-to-read form."
Romanian national cancer organisation. Draws a significant proportion of income from pharma.

"Provide information on ongoing testing, and any updates on approved medications."
US local organisation. Does not draw any income from pharma.

Information for patient groups on research topics

"Yes. Make available their internal findings on generic drugs. A lot of our patients suffer relapses due to being changed onto the cheapest generic product on the market. Many generic products are OK, but it's a minefield from which the affluent companies ought to help steer patients."
Member of the Danish Depression Association, a Danish national organisation specialising in depression and bipolar disorder. Does not draw any income from pharma.

"Keep us up to date with research papers that are relevant to our client population."
Canadian local Alzheimer's organisation. Draws a small or tiny proportion of income from pharma.

"Give us more reference about scientific studies on ADHD."
Associazione Italiana Disturbi da Deficit dell'Attenzione e Iperattività e patologie correlate (AIDAI) – Toscana, Italian local branch of a national ADHD/ADD organisation. Does not draw any income from pharma.

"[Pass on] awareness of research/development of new drugs that will benefit our members."
Australian national organisation. Does not draw any income from pharma.

Information on prevention

"Provide more information about the prevention of illnesses by consuming less alcohol."
Netherlands national alcohol addiction organisation. Does not draw any income from pharma.

Information for patient groups to pass on to patients

"Send us the leaflets, so that we can give out the information."
Canadian local ADHD/ADD organisation. Does not draw any income from pharma.

"Send us information on what the drug will do, and precautions. Then we can inform our members, as they trust us. But we need to know, so that we can advise them."
Learning Disabilities Association of Oregon, state-wide affiliate of US national organisation specialising in learning difficulties (including autism and dyslexia). Draws a small or tiny proportion of income from pharma.

"More information from the registry could be given to our organisation, in order to educate patients about the course of the disease, treatment paths, and drug interaction."
US national genetic disorders organisation. Draws a significant proportion of income from pharma.

"1.) Educational support in the form of pre-packaged trainings for staff and patients. 2.) Easy-to-understand translations of research data. 3.) Internet-accessible tools (like rating scales, questionnaires). And 4.) patient-friendly language for teaching tools."
Canadian national mental health organisation. Does not draw any income from pharma.

Information for patient groups to pass on to patients (Continued)

"Many of the people we represent are poor/working-poor families uninvolved with government programmes, and without access to information on pharmaceuticals. Many cannot afford the cost of medication for themselves, or family members. We are able to do some outreach to them, and if good, needed information was available for us to distribute in a cost-effective way, it would help."

The Black Children's Institute of Tennessee / US local advocacy organisation specialising in the welfare of Afro-American children Does not draw any income from pharma.

"I think that the pharmaceutical industry needs to become more involved with the smaller non-profit organisations that work with seniors and with people with a disability. By this, I mean they need to contact and work with these groups to assist them in offering informed choices to their clients regarding medications (whether cross-counter or prescription) Also, since my group deals with seniors, and, being a small charity organisation, it would be seen as good PR for large pharmaceutical companies to help us support the clients who use their products on a daily basis. We are all looking out for the best interests of our clients. Being kept abreast of new medications and new ideas would go a long way towards helping us to meet our goals."

Jackie Cajolais, BA, Psy, Gnt, member of Sackville Seniors Advisory Council, a Canadian local health promotion organisation with an emphasis on older people. Does not draw any income from pharma.

Information for patients

"All information that will help our members have a good life."

Hallgeir Grødeland, member of a Norwegian national diabetes organisation.

"Provide more information for patients. For example, leaflets with basic information, and leaflets with more detailed information."

Peggy Scholdei, member of an Irish local diabetes organisation. Does not draw any income from pharma.

"Provide real consumer/patient information."

Australian local mental health organisation. Does not draw any income from pharma.

"Provide reader-friendly patient-education pamphlets about their product and/or the disease/condition it's indicated for."

Canadian local HIV/AIDS organisation. Draws a small or tiny proportion of income from pharma.

"Provide a better range of information to patients, written in a way that can be easily understood, and including the negative effects, plus suggestions for alternative treatment choices."

New Zealand local mental health organisation. Does not draw any income from pharma.

"They can offer more reading material to patients."

US-based global primary immunodeficiency organisation. Does not draw any income from pharma.

"Patient information brochures that cover the correct use of medicines."

Australian national cancer organisation. Does not draw any income from pharma.

"By referring breastfeeding moms to an independent source of breastfeeding and drug information (such as *Dr Hale's Medications and Mother's Milk*), rather than issuing a blanket 'Do not breastfeed' statement."

US national breastfeeding organisation. Does not draw any income from pharma.

"Educational materials in easy-to-understand language for those who may not be educated."

US national organisation. Draws a moderate proportion of income from pharma.

"Educational materials for patients—up-to-date scientific materials that are disease-related."

US national organisation. Draws a small or tiny proportion of income from pharma.

"Provide non-branded information—patient resources."

US local organisation. Draws a moderate proportion of income from pharma.

"Yes. They can help educate our members to better understand their disease and its treatment. They can help educate patients on how to become advocates for their own healthcare."

US local organisation. Does not draw any income from pharma.

Information to medical professionals

"More information to medical professionals about the other (that is, not primary) effects of the company's medications. There are some surprising and interesting 'side effects' that could be utilised for benefit.
Australian CVS Association / Australian national gastrointestinal disorder organisation. Does not draw any income from pharma.

"By referring the healthcare providers of breastfeeding moms to an independent source of breastfeeding and drug information (such as *Dr Hale's Medications and Mother's Milk*), rather than issuing a blanket 'Do not breastfeed' statement."
US national breastfeeding organisation. Does not draw any income from pharma.

Information (unspecified recipients)

"By offering up-to-date information on new drugs."
Canadian local mental health organisation. Draws a small or tiny proportion of income from pharma.

"Offer information about treatment and the medicines for the diseases they deal with."
Norwegian national organisation. Draws a moderate proportion of income from pharma.

"Provide educational materials on pharmaceuticals."
US local organisation. Does not draw any income from pharma.

"Provide detailed information on new products."
Living Bipolar, a New Zealand national mental health organisation. Does not draw any income from pharma.

"Provide more information about the drugs and their side effects."
Canadian national organisation. Does not draw any income from pharma.

"A flow of information on up-coming new treatments for prostate cancer. More in-depth information on the treatments (medication) for prostate cancer."
Informed Prostate Cancer Support Group Inc, a US national prostate cancer organisation. Does not draw any income from pharma.

"Just information on health and wellbeing."
Chris Vernon, member of a New Zealand local organisation. Does not draw any income from pharma.

"Pamphlets on the following: avoiding pressure points; ideas to limit bladder infections from catheters; avoiding osteoporosis; diminishing tension; dealing with depression; and avoiding weight increase due to inactivity."
National Council for Persons with Physical Disabilities in South Africa (NCPDPSA), and the QuadPara Association of South Africa (QASA); South African national disability organisations. Draw a small or tiny proportion of income from pharma.

"Educational material."
Jordan Hemophilia Society. Draws a small or tiny proportion of income from pharma.

"More and more regular information."
Herz-Gesprächsgruppe [Cardiovascular Conversation Group] Rhein-Sieg-Kreis, German local heart organisation. Does not draw any income from pharma.

"Provide information."
Swedish national organisation. Does not draw any income from pharma.

"Information."
Swedish national aphasia organisation. Does not draw any income from pharma.

Information (other)

"Better published grant websites."
Wendy Poage, President of the Prostate Cancer Education Council, a US national prostate cancer organisation. Draws a moderate proportion of income from pharma.

Information for people with a disability: deafness (including the training of pharmacy staff)

“ 1.) Pharmaceutical companies can offer more deaf-friendly services by having their websites accessible for users of BSL (British Sign Language). Sign language is these people's first or preferred language. This would mean that deaf people would have full access to information and services relating to health issues—information that hearing people take for granted every day. 2.) Producing leaflets in plain English would make for a huge change for the local deaf community. 3.) Pharmacy staff could be trained in deaf awareness. It would go a long way in helping deaf customers if pharmacies have at least one or two staff members who can use BSL. This would allow deaf customers to know that they could go to a local pharmacist for advice, and will be able to communicate in their first language, and be understood. The British Deaf Association would be able to offer our services to carry out an audit access. This would be beneficial for local chemists in improving their services to the local deaf community.”

UK national organisation specialising in deafness. Does not draw any income from pharma.

“Provide information in formats accessible to consumers who are deaf (or who have deaf family members).”

Roger Williams, member of a US national organisation. Does not draw any income from pharma.

Information for people with a disability: blindness

“Yes, put their product information in Braille, or on tape.”

Virginia Association of the Blind, a US state-wide eyesight organisation. Does not draw any income from pharma.

Companies mentioned as providing good information

“Pfizer and Novartis have provided literature that is very helpful to our clients.”

Canadian local Alzheimer's disease organisation. Does not draw any income from pharma.

Promoting patient and public involvement

Involve/understand patients more

"Involve patients in the development of educational activities for GPs and other health professionals. Involve patients in surveys, and give some of the results to patient organisations."
Danish Society of Obesity, a Danish national obesity organisation. Does not draw any income from pharma.

"Sponsor patient advisory boards."
Stephen Corman, Secretary of the National Alliance of State Prostate Cancer Coalitions, a US national prostate cancer organisation. Draws a significant proportion of income from pharma.

"One-to-one consultation with consumers."
Terry Thommeny, Manager of an Australian global mental health organisation. Does not draw any income from pharma.

"Do many more surveys to identify the individual needs of patients."
US local hepatitis-C organisation. Does not draw any income from pharma.

"Be patient driven, not \$-driven."
HIVKids, a US local HIV/AIDS organisation. Does not draw any income from pharma.

"Be supportive of patients' needs."
Australian local organisation.

"Yes, support of the patient."
Multiple Sclerosis Foundation, a US national multiple sclerosis organisation. Draws a small or tiny proportion of income from pharma.

"Assist more in developing knowledge around patient behaviour (such as adherence, quality of life, stress and illness, denial, etc)."
Ne'eman Association of Stroke Survivors, an Israeli national stroke organisation. Draws a significant proportion of income from pharma.

"Without consumer participation, pharma's product development and improvement can only go so far. The efficacy, user-friendliness, access, cost, and understanding of medicines is imperative to consumer loyalty (regardless of the fact that some medicines are a captured market). An interest in consumer needs and concerns rates very highly on consumer priority lists."
Louisa Di Pietro, Community Educator of the Thalassaemia Australia Inc (formerly the Thalassaemia Society of Victoria Inc.), an Australian national organisation specialising in blood disorders (including haemophilia and thalassaemia). Draws a moderate proportion of income from pharma.

Help doctors and groups form closer ties

"Develop a closer relationship between physicians and support groups."
Canadian local cancer organisation. Draws a significant proportion of income from pharma.

Help groups recruit new members

"Help us get more members for our organisation."
Deutscher Diabetikerbund e.V., a German national diabetes organisation. Does not draw any income from pharma.

Introducing strategic changes in outlook

Consider overlooked disease areas

"Not be overly specific in the conditions for which they supply treatments. A bigger-picture view would be welcome. Progress is being made with a couple of the companies, but there is clearly a reluctance to get involved in an area if they don't have a specific treatment—despite the fact that awareness on the overall issue would benefit them in the long run."

National Council for the Blind of Ireland. Draws a small or tiny proportion of income from pharma.

"Discuss options for markets still not well covered by medication (rare diseases, severe illness, neglected diseases, etc)."

Grupo de Enlace, Investigación y Soporte - Enfermedades Raras (GEISER Foundation), an Argentinean national rare disease organisation. Draws a small or tiny proportion of income from pharma.

Help poorer countries access medicines

"1.) They could grant patent and data-reference rights, and know-how licenses, to the UNITAID Patent Pool. 2.) They could stop pressurising the United States Trade Representative (USTR) to enforce the Agreement on Trade-Related Aspects of Intellectual-Property Rights (TRIPS)-plus intellectual property rights. And 3.) they could do increased R&D on paediatric formulations appropriate for poor and tropical countries."

Health Global Access Project, a US-based global HIV/AIDS organisation. Does not draw any income from pharma.

Encourage non-pharmaceutical approaches

"Teach people other ways to treat their condition besides taking pharmaceuticals."

Orange County NORML, a US local branch of a national medicinal cannabis organisation.

"Encourage patients to see recovery as a desired goal, and not perpetual drug dependence."

GROW, an Australian national mental health organisation. Does not draw any income from pharma.

"I think pharma should stop exploiting people's fears and vulnerabilities in order to create markets for themselves, and to get drugs listed by the government Pharmaceutical Benefits Scheme (PBS)."

Chronic Illness Alliance, an Australian national chronic illness organisation. Does not draw any income from pharma.

"Yes, by accepting that other treatments or products could produce better results for patients, rather than spreading doubt about them. The drug companies, and, indeed, the medical profession, can get things wrong. I'm living proof. I have lived to tell my story."

Paul Nealon, member of an Irish national diabetes and haemochromatosis organisation. Draws a significant proportion of income from pharma.

Strategic changes in particular disease areas

"I would like to see them less visible in the mental health sector."

Suzy Stevens, member of a New Zealand local mental health organisation. Does not draw any income from pharma.

"Stop trying to eradicate fatness and fat people."

US national organisation. Does not draw any income from pharma.

"Pharmaceutical companies that publicly and proudly renounce development and/or sales of all forms of weight-loss drugs would accomplish both a hugely positive health outcome, as well as a human rights victory. The manufacture and sale of weight-loss drugs directly threatens the health and lives of people of all sizes, while contributing significantly to the continuing popularity of weight-based prejudice and discrimination. If major institutions like drug makers stopped promoting fat hatred, it would contribute significantly to reducing, and possibly ending, this wasteful, needless, crushingly burdensome form of social bias."

Marilyn Wann, US. Does not draw any income from pharma.

Strategic changes in particular disease areas (Continued)

"Stop pushing artificial breastmilk in any form to anyone (including to adults in any form) everywhere in the world. In fact, actually request that formula be removed from free sale, and made a restricted, prescription-only product. That could go half a step toward promoting the idea that pharma isn't solely interested in making money at any cost."

Member of a Canadian national branch of a global breastfeeding organisation. Does not draw any income from pharma.

Lower the prices of medications

"They need to work harder at reducing their prices for medications."

Dr Gordon Bopp, President of the Washington affiliate of a US national mental health organisation. Draws a small or tiny proportion of income from pharma.

"Address the cost of medications."

US local hepatitis-C organisation. Does not draw any income from pharma.

"They can sell the drugs for the patients at a very special price."

Argentinean local tuberous sclerosis organisation. Does not draw any income from pharma.

"In order for patients to get the best treatment, it is vital that pharma companies look at their pricing structures, and stop being so greedy with regards to income for some products."

UK national organisation specialising in cancer. Draws a small or tiny proportion of income from pharma.

"Keep their prices low."

Swedish local organisation specialising in ostomy. Does not draw any income from pharma.

"Make products available in a less expensive manner."

Irish local organisation. Does not draw any income from pharma.

"Yes, by lowering the cost of their drugs, to make them accessible to everyone who needs them (not just the people who can afford them). Make preventative drugs cheaper, making them available to the people who need them the most. Prevention is better than cure."

Anthony J. Rose, member of an Irish sexual diseases organisation. Does not draw any income from pharma.

"Take the long-term view, and reduce the cost of life-saving medication to an accessible level—instead of attempting to buy the impartiality of medical charities by making them largely dependant on pharmaceutical company funding."

Borderline, a UK national mental health organisation specialising in personality disorder. Does not, on principle, draw any income from pharma.

"Subsidise medication for people on hormone therapy."

Canadian local branch of a national prostate cancer organisation. The local branch does not draw any income from pharma.

"Lower the costs of 'orphan' disease medication."

Australian CVS Association, an Australian national gastrointestinal disorder organisation. Does not draw any income from pharma.

"Offer discounts on pharmaceuticals for our organisation's members."

Moises Moreno, member of Voz Pro Salud Mental DF, a Mexican national organisation specialising in mental health. Draws a small or tiny proportion of income from pharma.

"Make tests for early detection more affordable, or subsidise tests for patients without medical aid."

South African national organisation. Draws a small or tiny proportion of income from pharma.

Other

"Cut down on direct-to-consumer ads."

US national asthma and allergy organisation. Draws a significant proportion of income from pharma.

Organisations happy to be named in this report as survey respondents

Organisations are named exactly as written by the appropriate survey respondent.
For some of the organisations listed below, their representatives answered in a personal capacity.

A

A Breath for Life Charity
Acción Solidaria
ACOR carcinoid cancer internet support group
Advocacy Initiative Network of Maine
aifa associazione di genitori
Alice Johnston British Deaf Association
Allan Jørgensen, Bedre Psykiatri, Greve-Solrød
Allergy New Zealand
Alpha-1 Foundation
ALS Society of BC ALS Society of Canada
American Iatrogenic Association
American Tinnitus Association
America's Baby Cancer Foundation
Amyloidosis Support Groups Inc.
ARDSI, Madras Chapter, India.
ASDAH
ASIF Khan, president HDCCS of Pakistan
Associazione AttivaMente
Associazione Italiana Disturbi da Deficit dell'Attenzione e Iperattività e patologie correlate (AIDA)
- Toscana
Asthma and Allergy Foundation of America
Asthma Foundation of Queensland
Asthma Society of Canada
Astma allergi Halmstad
Australian Bipolar Schizoaffective Network
Australian CVS Association

B

BCF Emelie Bohuslän
Borderline UK Ltd
Brain Injury Association of America
Breast Cancer Action Montreal
Bundesverband Prostatakrebs Selbsthilfe e. V. (BPS)
Gunter Feick, chair of BPS

C

Canadian Arthritis Patient Alliance
Canadian Celiac Association
Canadian Mental Health Association for the Kootenays
Canadian Mental Health Association, Halton Branch
Canadian Paraplegic Association Ontario
Cancer Voices NSW
Care Solutions
Care4Dystonia, Inc - Beka Serdars, RN, MS, NP
Cathy Palmer, Blepharospasm Support Group
Cerebral Palsy Association in Alberta
Charity foundation "Kolodetz"
Children Liver Association for Support Services
CLASS -Tennessee
Chronic Illness Alliance

Cicatricial Alopecia Research Foundation
Colorado Cross-Disability Coalition
Commonwealth Respite and
Carelink Centre Mid North Coast
Congenital adrenal hyperplasia NZ
Council on Size & Weight Discrimination
Croydon Stroke Support Group Victoria
CTAC
Cystic Fibrosis Association of New Zealand

D

Danish Society of Obesity
Deborah, MS-Society
Defeat Diabetes Foundation
Deutscher Diabetikerbund e.V.
Diabetes Australia
Diane Carlton, Chair, Endometriosis SHE Trust (UK)
Dr Nira Dangoor, Chair, Israeli Support Group
for Families of HD
Dr. Ulrich Bollmann, President of the
Diabetes Association of the Canton of Zug
Dystonia Medical Research Foundation Canada
Dzmitry Filipau, LaSky Trusting Each Other
(HIV/AIDS Prevention Network for MSM in Russia)

E

enosh - The Israeli Mental Health Association

F

FEmISA
Föreningen Autism i Uppsala Län
Friends for Mental Health

G

Geiser Foundation
GROW
Grupo Otimismo de Apoio ao Portador de Hepatite

H

Halton Aphasia Center
Health Action International Asia-Pacific
Health Global Access Project
Helping Spirit Lodge Society
Herz-Gesprächsgruppe Rhein-Sieg-Kreis
HIVkids

I

Illinois Action for Healthy Kids
Impact India Foundation
Informed Prostate Cancer Support Group Inc.
Ingenium Morelos AC President: Graciela B.
Cámara Cáceres

Organisations happy to be named in this report

Intl Dyslexia Association
Irish Diabetic federation

J

Jackie Cajolais, BA,Psy,Gnt
Sackville Seniors Advisory Council
Jan Norwood Cowichan Valley Arthritis Society
JDRF -Juvenile Diabetes Research Foundation Israel
Jeannie May Living Sphere
(Herpes Support and Awareness)
Jim Byrne Diabetes Fed. of Ireland
Jordan Hemophilia Society
Josanna Savoie; Vancouver/Richmond Mental Health

K

Kapok Clubhouse
Kidney Health Australia
Kids With Heart
National Assn for Children's Heart Disorders, Inc.
Kim Kubilus Director of Member Services
National Tay-Sachs & Allied Diseases
Association, Inc. (NTSAD)

L

Learning Disabilities of Association of America Oregon
LHC-Västra Götaland
Life Support Monaghan
Lindsey Middlemiss, FibroAction
Living Bipolar
Louisa Di Pietro Community Educator
Thalassaemia Australia Inc
(Formerly Thalassaemia Society of Victoria Inc.)
Lupus Ontario

M

Manitoba Schizophrenia Society
Marilyn Wann, FATISO? author, weight diversity trainer
Mood Disorders Association of Ontario
MS forbundet i Sogn og Fjordane
Multiple Sclerosis Foundation
Multiple Sclerosis Society
Muscular Dystrophy Association of Western Australia

N

NAMI Forensic Network/MN
National Association for Advance Fat Acceptance
National Association For Continence
National Association of People With AIDS
National Council for the Blind of Ireland
National Down Syndrome Congress
National Kidney Foundation of Malaysia

National Nieman Pick Disease Foundation
NCPDPA & QASA
NDF-Jæren
Neami LTD
Neeman Association of Stroke Survivors, Israel
New Zealand Tuberous Sclerosis Support
North Carolina Families United, Inc.
NY NAAFA

O

OC NORML
Omaiset mielenterveystyön tukena,
Uudenmaan yhdistys ry. - Anhörigas stöd för
mentalvården, Nylands region rf.
Ontario Parents Advocating for Children
with Cancer (OPACC)
Organic Acidemia Association
Ostomy Association of Melbourne
Out With Cancer, Inc.

P

Panda Lanaudiere Nord
Patients Rights Advocacy Waikato Incorporated
Personligt ombud Falköping/Vara
PFLAG Canada - Ontario
Pregnant with Cancer Network
Prince Edward Island Cerebral Palsy Association Inc.
Profo Helgeland
PROFO. Norway
Promoting Wellbeing in North Canterbury
Prostate Cancer Education Council
Wendy Poage President

R

Rev Dr John Benjamin Tatum DD PhD
Chief Executive Officer - CADMEI
RSMH Tryggheten i Borås

S

SAFE - Stroke Alliance for Europe
(reg. in Belgium, secretariat in London)
Safe Water and AIDS Project
Sarcoma Alliance
Sarcoma Foundation of America
Schizophrenia Fellowship of NSW Inc
Scleroderma Society of Canada
Seizure & Brain Injury Centre
Sickle Cell Disease Association of America, Inc.,
Northwest Louisiana Chapter
Sickle Cell Disease Association of America,
Oklahoma Chapter

Organisations happy to be named in this report

Skedsmo og omegn parkinsonforening
St. Senans Hospital
Stephen Corman Secretary,
National Alliance of State
Prostate Cancer Coalitions
Stichting voedselallergie
Support Organization for Trisomy 18, 13
and Related Disorders

I

The Allergy & Asthma Institute, Pakistan
The Black Children's Institute of Tennessee
The Dutch Stroke Association
"Samen Veder" Dr. J.G.A.J. Slagers, MSc
The Japanese Society of the Patients and Families
with Mucopolysaccharidoses
(The Japanese MPS Society)
The Lupus Society of Manitoba
The name of my Organisation that I am trying to
get started is Angel's Light.
The Prostate Net
The VHL Family Alliance
Thorkild Bach, Osteoporoseforeningen, Afdeling
Nordjylland, Denmark
Thyroid Patient Advocacy-UK

U

USTOO Texoma Prostate Cancer Support Group; T
Thomas W. Nuckols, Ph. D.

V

Vancouver Advanced Prostate Cancer Support Group
Vancouver Richmond Mental Health Network
Vancouver/Richmond Mental Health Network
Virginia Association of the Blind
Voz Pro Salud Mental-Mexico
Voz Pro Salud Mental DF Moises Moreno

W

Walkers in Darkness
www.DiabetesMonitor.com

Z

Zorgbelang Gelderland

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—THEIR HOPES, THEIR FEARS, AND THEIR PLANS FOR THE FUTURE

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