

Dear HSCNetwork Member,

Herewith *HSCNews Bulletin* number 6, December 2006.

Each *Bulletin* provides details about the latest activities of the 4,000 members of the Health and Social Campaigners' Network International, and gives information about health campaigners' new appointments, campaigns, events, funding, publications, research, and websites. The items in this *Bulletin* cover the period end-November to end-December 2006. All items are selected on the basis that they should be of interest to health campaigners worldwide.

The *Bulletin* is also despatched to a select number of journalists worldwide who have requested to receive a copy.

Thank you for sending us all your news. Please keep on doing so.

Kind regards,
Louise Oatham
Manager
HSCNews Bulletins

Below, you will find a set of key subject matter mentioned in this Bulletin. If you search for any of these words in the email, you will find the item(s) of news related to that subject matter. Also listed are the countries and regions covered in the Bulletin, which can also be found by searching in the same way.

KEY WORDS

AMYOTROPHIC LATERAL SCLEROSIS; ANXIETY; BOWEL CANCER; CARER; CHILDREN; COLORECTAL CANCER; DEPRESSION; DIABETES; DIETARY SUPPLEMENTS; DISABILITY; ENDOMETRIOSIS; EUROPEAN COMMISSION; GLOBAL HEALTH; HIV/AIDS; HUMAN RIGHTS; LONG-YERM CONDITIONS; MEDICAL RECORDS; MENTAL HEALTH; MOTOR NEURON DISEASE; NEURODEGENERATIVE; NHS REDRESS ACT; NON-PRESCRIPTION DRUGS; NUTRITION; OBESITY; ORPHAN DRUGS; OVARIAN CANCER; PATIENT SAFETY; PHILANTHROPY; PHYSICAL MOVEMENT; RARE DISEASE; PSYCHOTHERAPY; TEENSCREEN; UNITED NATIONS; UNUSED DRUGS.

COUNTRIES AND REGIONS

AUSTRALIA; BANGLADESH; BELGIUM; BRAZIL; CANADA; CHILE; DENMARK; EUROPE; FINLAND; FRANCE; GERMANY; GLOBAL; INDIA; IRELAND; NETHERLANDS; NEW ZEALAND; NORWAY; POLAND; PORTUGAL; SPAIN; UK; USA.

MEMBERS' NEWS

DECEMBER 20 2006, BANGLADESH, BELGIUM AND USA

The New York-based United Nations (UN) General Assembly passed a landmark Resolution recognising the threat posed by the worldwide diabetes epidemic. This is the first time that the UN has officially identified a chronic disease as a global danger. The UN resolution, which was sponsored by the People's Republic of Bangladesh, also upholds every future November 14th as a UN Day in which countries are called upon to develop national policies for the prevention, treatment, and care of diabetes, in line with the sustainable development of national healthcare systems. The decision to pinpoint diabetes as a disease of such importance comes after significant campaigning by an alliance of key diabetes campaigning groups. The component groups joined forces in March 2006 to form the Brussels-based **UNITE FOR DIABETES** campaign, led by the **INTERNATIONAL DIABETES FEDERATION (IDF)**. As part of **UNITE FOR DIABETES**, 25 young people with diabetes were selected as Youth Ambassadors, to advocate for the passage of the UN resolution.

[<http://www.unitefordiabetes.org>]

DECEMBER 19 2006, BELGIUM, FINLAND, POLAND, AND PORTUGAL

The European Commission announced that it had received 237 responses to its public consultation on its Green Paper, *Improving the Mental Health of the Population: Towards a Strategy on Mental Health for the EU*, published October 14th 2005. Some 20 of the 237 responses were from health campaigning organisations, and a further 37 were from individual citizens. Responding health campaigning groups emphasised the importance of several aspects to any trans-national mental health strategy, including: human rights and social inclusion; improving the equity of healthcare systems; and the need for greater financial investment in mental health services. Respondent groups included:

- The Brussels-based **GAMIAN-EUROPE (GLOBAL ALLIANCE FOR MENTAL ILLNESS ADVOCACY NETWORKS—EUROPE)**, which noted: "Structural and legal frameworks must be given priority within the strategy, in order to ensure that the human rights of people with mental health problems (and those of their family/carers) are protected".
- The Helsinki, Finland-based **SUOMEN FOUNTAIN HOUSE**, which stated: "We consider it vital to draw more attention to the tremendous importance of participation in education, work, social communities, and society to the well-being of people suffering from mental illnesses—just as it is for the rest of the population. We would like to see more emphasis on the importance of rehabilitation in the Green Paper. Particular attention should also be drawn to the impact of community and peer-group empowerment in rehabilitation".
- Torun, Poland-based **POL-FAMILIA** [Association of Families and Caregivers of Persons with Mental Health Disorders and Institute of Patients' Rights and Health Education], which stressed: "We regret to state that the quality of life of persons with mental disorders in our country is far below the standards of other EU countries. The basic problems include: lack of specialised care centres; no reimbursement of (and therefore no access to) the most effective therapies using second-generation atypical drugs; and a lack of systemic and legislative solutions to enable people with a mental health problem to function actively in society".
- Coimbra, Portugal-based **VIME-VIVER MELHOR (VIME)**, which stipulated: "The first and most important step to take towards integrating mental health into global health policy would be significantly increasing investment by the Ministry of Health in the mental health sector".
[http://ec.europa.eu/health/ph_determinants/life_style/mental/green_paper/mentalgp_report.pdf
<http://www.gamian-europe-history.org>
<http://www.fh-klubitalot.fi/FH-index.htm>]

DECEMBER 13 2006, BELGIUM AND USA

After five years of intensive negotiations (including campaigns conducted by the Brussels-based **EUROPEAN DISABILITY FORUM [EDF]**), a new international human-rights treaty was adopted by the United Nations. The treaty aims to provide protection to people with a disability, and to safeguard their basic human rights. According to Yannis Vardakastanis, President of the **EDF**, the *UN Convention on the Rights of Persons with Disabilities* "will be vital in our long fight against the daily discrimination of disabled people. It sends a strong message to the world that disability is—first and foremost—a human-rights' issue".

[<http://www.edf-feph.org/en/news/press.htm#280806>
<http://www.un.org/disabilities/convention/>]

DECEMBER 7 2006, IRELAND

Speaking at a conference for healthcare professionals, the Dublin-based **IRISH CANCER SOCIETY** welcomed the Irish government's proposal for a national colorectal-cancer screening programme of people in the age range 50-74. The programme was first officially announced in June 2006 as a major part of the government's National Strategy for Cancer. Figures from the Irish National Cancer Registry suggest that Ireland has the highest incidence of bowel cancer in any European country. However, observed the **IRISH CANCER SOCIETY**, the government has, thus far, offered no timeline for the roll-out of its programme.

[<http://www.cancer.ie>]

DECEMBER 7 2006, BELGIUM

Claude Sterckx, President of the **LIGUE DES USAGERS DES SERVICES DE SANTÉ (LUSS)** [League of Health-Service Users] opened debate at the Brussels-based *First Belgian Workshop on Orphan Drugs*. The Workshop aimed to assess the quality of healthcare services for Belgian patients with a rare disease and in need of orphan drugs. The Workshop, which also compared the Belgian situation with that in neighbouring France and the Netherlands, hoped to identify areas of need. Dr Sterckx emphasised the importance of the role that patients' organisations have to play in fostering research, and in improving healthcare services. Unfortunately, he added, the 146 Belgian patients' organisations operating in the field of rare diseases are not yet sufficiently coordinated to constitute a powerful voice. The Workshop concluded that access to marketed orphan drugs has been delayed in Belgium beyond any acceptable time frame, and pointed out that the situation required corrective action.

[http://en.eurogentest.org/documents2/1161596000942_Final_program.pdf
<http://www.luss.be>]

DECEMBER 4 2006, AUSTRALIA, CANADA, GERMANY, NETHERLANDS, NEW ZEALAND, UK, AND USA

The New York-based **COMMONWEALTH FUND**, the World Health Organization (WHO) Collaborating Centre on Patient Safety (Solutions), and the WHO's World Alliance for Patient Safety announced a seven-country collaborative project [] to improve the implementation of five standardised patient safety solutions [otherwise known as 'High 5s'] that aspire to prevent avoidable catastrophic events in hospitals. The Action on Patient Safety project will be conducted in Australia, Canada, Germany, the Netherlands, New Zealand, the UK, and the USA, and coordinated by the WHO Collaborating Centre. The 'High 5s' are:

- Prevention of errors occurring during the hand over among professionals of patient care.
- Prevention of surgical errors linked to wrong site/wrong procedure/wrong person.
- Prevention of medication errors (particularly the continuity aspect).
- Prevention of high-concentration drug errors.
- Promotion of effective hand-hygiene practices.

[<http://www.cmf.org>
http://www.jointcommission.org/NewsRoom/NewsReleases/nr_120406.htm]

NOVEMBER 29 2006, AUSTRIA AND BELGIUM

The Brussels-based **EUROPEAN MEN'S HEALTH FORUM (EMHF)** has adopted the three main recommendations made at the group's 'Challenges for the Management of Long-Term Conditions' Workshop, held on October 5th 2006 at the Bad Hofgastein, Austria-based European Health Forum Gastein (EHFG). The recommendations are:

- European governments and the European Commission must prioritise the management of long-term medical conditions.
- Greater investment into, and evaluation of, innovative management systems for long-term medical conditions is needed (one example is telephone outreach systems).
- When seeking to recognise patients' needs, health information and patient-enablement programmes must take account of social-economic grouping, ethnicity, and gender.

(The EHFG Workshop was organised in partnership with Schering AG and CAS Services Ltd, and chaired by Miroslav Mikolášik, Slovakian Member of the European Parliament who sits on the Committee on Regional Development, and the Committee on the Environment, Public Health and Food Safety.)

[http://www.emhf.org/resource_images/gasteinnov06ES.pdf]

NOVEMBER 22 2006, UK

After years of personal campaigning, UK citizen **JOSEPHINE Ocloo** managed to gain a Parliamentary procedure known as an Early-Day Motion (EDM), supported by 18 Members of Parliament (MPs). The EDM called for parliamentary debate on the death from acute heart failure on December 1996 of Ms Ocloo's daughter, Krista. The EDM stated its regret "that ten years on, no inquiry has been set up to establish independently the facts concerning Krista's death". The Motion applauded the ongoing attempts of Ms Ocloo to win justice on behalf of her daughter, and supported her call for an independent inquiry. The EDM also cautioned that the

NHS Redress Act 2006, which aims to give patients and their relatives speedier access to justice and compensation when mistakes are made, was a “fundamentally-flawed” document. [<http://edmi.parliament.uk/EDMi/EDMDetails.aspx?EDMID=31834&SESSION=885>
<http://www.thekristaocloocampaign.com/index.php>]

CAMPAIGNS

DECEMBER 16 2006, UK

Following continued public pressure from health campaigners, Lord Warner, the UK’s Health Minister, offered reassurances at a press conference that patients would have the right to veto the forthcoming digitisation of their medical records. UK patients’ medical notes are due to be uploaded on the new government-funded electronic database (NHS Spine). Noteworthy UK campaigning groups specialising in the subject of electronic medical records include the eight-year-old Cambridge-based **FOUNDATION FOR INFORMATION POLICY RESEARCH (FIPR)**, the four-year-old London-based **NO2ID.NET**, and the High Wycombe-based **THEBIGOPTOUT.ORG** (the latter founded as recently as November 29th 2006). During a radio programme’s head-to-head discussion between Lord Warner and Ross Anderson, chair of **FIPR** and Professor of Security Engineering at the Computer Laboratory of the University of Cambridge, Professor Anderson argued that any opt-out process for patients may be more difficult to arrange than the government envisages. Professor Anderson also maintained that the medical confidentiality of patients would be at risk on the NHS Spine, as millions of NHS employees and central government bureaucrats will have access to personal medical records. These staff members will even have availability to patients’ demographic details, including name, address, NHS number, GP details, telephone number (even ex-directory numbers), and cellphone numbers. [<http://www.nhsconfidentiality.org>]
<http://www.fipr.org>
<http://www.no2id.net>]

DECEMBER 9 2006, USA

The US House and Senate both passed the so-called Dietary Supplement and Non-Prescription Drug Consumer Protection Act (the ‘AER Bill’) [S3546]. The Bill places significantly-increased demands on over-the-counter manufacturers to report serious events associated with non-prescription drugs and dietary supplements. Prior to the Bill’s passage, libertarian groups such as the Arlington, Virginia-based **AMERICAN ASSOCIATION FOR HEALTH FREEDOM** had raised alarm bells about it. They believed the legislation to be overly bureaucratic, and ultimately likely to lead to higher prices for non-prescription drugs and dietary supplements—both of which function as a key source of medication and food supplements for millions of people. Groups had insisted that the dangers linked with the products did not warrant such legislative action. Taking an opposing view, James Turner, Chairman of **CITIZENS FOR HEALTH**, a Minneapolis-headquartered, national, nonprofit, consumer-oriented, advocacy group working to broaden healthcare choices, stated: “This is a very important piece of legislation that advances consumer interests within a safe, credible, dietary-supplement marketplace”. [http://ga4.org/campaign/AER_bill]

DECEMBER 4-5 2006, GERMANY

The Berlin-based **PLATFORM ERNAHRUNG UND BEWEGUNG E.V. (PEB)** [Nutrition and Movement Platform] ran a workshop in Jena on the theme of nutrition and physical involvement. The workshop aimed to determine possible interventions to promote physical movement and to reduce the incidence of overweight and obesity (particularly among the poor). In Germany, 10-15% of children and youths are estimated to be overweight, and 4-8% classed as obese. **PEB** is a unique alliance of stakeholders with a mission to reduce the incidence of overweight in German children through preventive measures at national and local levels. **PEB** believes that it is Europe’s biggest initiative on nutrition and physical activity. Stakeholders include parents, government, industrial manufacturers, scientists, insurers, and trade unions. Since being founded in 2004, **PEB** has initiated 10 major campaigns—exceptional in the fact that they directly address children through community projects. **PEB**’s December 2006 workshop

concluded by calling for urgent cooperative action among all the "social forces which shape the environment of children and young people".

[<http://www.ernaehrung-und-bewegung.de>]

DECEMBER 1 2006, AUSTRALIA

On International AIDS Day, the **NATIONAL ABORIGINAL COMMUNITY-CONTROLLED HEALTH ORGANISATION (NACCHO)**, headquartered in Braddon in the Australian Capital Territory, warned of an impending AIDS epidemic among people of Aboriginal descent if federal agencies fail to intervene. The **NACCHO's** warning, which was publicised by the Australian Broadcasting Corporation's online news service, specified that Western Australia in particular is witnessing a rapid rise in HIV/AIDS cases as a result of inadequate educational efforts on AIDS. Henry Councillor, Chair of **NACCHO**, said that his group would like to see more funding awarded to preventive programmes.

[<http://www.abc.net.au/news/newsitems/200612/s1801658.htm>

<http://www.naccho.org.au/Module.html>]

NOVEMBER 29 2006, USA

TeenScreen has been surrounded by controversy since first being developed in 1999 by the Columbia University of New York. TeenScreen, a ten-minute questionnaire, assesses teenagers in school (allegedly on a voluntary basis) about their state of mind, aiming to determine whether they are suicide risks. The TeenScreen programme, which received the backing of President Bush's New Freedom Commission (NFC) on Mental Health in July 2003, has divided health campaigners into two camps. The Arlington, Virginia-based **NATIONAL ALLIANCE OF MENTAL ILLNESS (NAMI)** supports the programme on the basis that many children with mental health conditions remain undiagnosed, and suicide constitutes the third-leading cause of death among individuals aged 15-24. On the other side of the fence stand parent support groups, consumer groups, and human rights' campaigners (including the prestigious civil liberties organisation, the **RUTHERFORD INSTITUTE**, headquartered in Charlottesville, Virginia). The latter category of campaigners believe that the TeenScreen scheme bypasses parental wishes, provides inaccurate diagnoses, and leads to unnecessary medication among the young. In 2006, groups opposing TeenScreen launched an online petition, which has been sent to state and local lawmakers. Arguments over the merits of the TeenScreen programme are now set to escalate. From late November 2006, the US government plans to embark on a large-scale publicity campaign directed at young people. The campaign seeks to diffuse the stigma associated with mental illness. Already, opponents of TeenScreen have stated that the government's campaign will only increase the adverse effects resulting from Teenscreen, since many more teenagers will end up taking drugs.

[http://il.nami.org/children's_news.htm

<http://www.rutherford.org>

<http://www.petitiononline.com/TScreen/petition.html>

<http://www.stopstigma.samhsa.gov/action/GenericPowerPoint.ppt>

http://www.samhsa.gov/SAMHSA_News/VolumeXIV_6/article4.htm]

PUBLICATIONS

DECEMBER 2006, USA

The Orono-based **MAINE BENZODIAZEPINE STUDY GROUP (MBSG)** placed in the public domain a number of presentations made at its Third Annual Unused Drug Return International Conference, held in Portland, Oregon, October 23rd-24th 2006. The presentations emphasised the waste and danger involved in the disposal of unused prescription medicines. The **MBSG** was founded in 2002 by a small group of doctors who were becoming concerned about possible over-prescription of tranquilisers in Maine. The **MBSG** now enjoys the support of government agencies in addition to healthcare professionals. Among its various campaigns, the **MBSG** has been calling for US legislative action to ensure the proper disposal of unneeded pharmaceuticals—and, in particular, for patients to be allowed to return unwanted, controlled-substance prescription medicines to a pharmacy (a practice currently prohibited under US law). According to Dr Stevan Gressitt, one of **MBSG's** founders, clinical researchers estimate

that patient-compliance rates are only 60% for most medicines, falling to as low as 10-20% for certain medicines. The Washington-based **NATIONAL HEALTH CARE PURCHASING INSTITUTE**, an initiative of the Princeton, New Jersey-based **ROBERT WOOD JOHNSON FOUNDATION**, states that non-compliance contributes to 125,00 deaths per year. Dr Gressitt argues that pharmaceutical companies are meanwhile spending six times more to gain a new customer than to retain an existing one. He proposes a three-fold movement forward: firstly, the formation of a variety of local consumer 'take-back' models; secondly, the development of a national programme for reverse distribution of medicines, based on existing infrastructure; and thirdly, a registry of unused or expired medicines, as advocated by the Bellaire, Texas-based **COMMUNITY OF**

COMPETENCE.

[<http://www.mainebenzo.org/2006conference>
<http://www.communityofcompetence.com>]

NOVEMBER 13 2006, BELGIUM

The **EUROPEAN PARTNERSHIP FOR GLOBAL HEALTH (EPGH)**, a virtual network of the members of the Brussels-based **EUROPEAN FOUNDATION CENTRE (EFC)**—which, in turn, is a pan-European organisation representing the interests of diverse foundations and corporate funders of NGOs—published *European Perspectives on Global Health: A Policy Glossary*. Produced by a group of experts from Europe, Africa, and the Americas, the glossary examines pan-European strategies for global health. The **EPGH** partnership is basing its 2007 work programme on the glossary. Activities include:

- Establishing a structured dialogue with the European Commission.
- Organising a 'Eurobriefing' on global health at the beginning of 2007.
- Supporting the development of collaborative initiatives in the global health agenda.

[Editor's note: the **EPGH** is distinct from the newly-launched **EUROPEAN NETWORK FOR GLOBAL HEALTH (ENGH)**, which was formed on November 3rd 2006 to improve standards of healthcare in the southern part of the globe.]

[http://www.efc.be/ftp/public/ic/Health/EFC_EPGH_GlobalHealthGlossary.pdf]

FUNDING AND FINANCING

DECEMBER 19 2006, USA

The White River Junction, Vermont-based **GLOBAL HEALTH COUNCIL** joined forces with ChangingThePresent.org, which lists thousands of worthy causes from among hundreds of leading nonprofit-making organisations. Donors can, for instance, offer money to protect the existence of an acre of rainforest, or fund an hour of a cancer researcher's time.

[<http://www.changingthepresent.org/welcome/nonprofits/show/75>]

DECEMBER 2006, IRELAND

Dublin-based **INCLUSION IRELAND** raised a number of concerns about the government's planned 2007 budget for health-related disability and mental-health services. Much of the government spend is dedicated to the erection of new residential and respite places. **INCLUSION IRELAND** believes that funding should be released on the basis of individual need, rather than being focused on what it believes is unnecessary infrastructure.

[<http://www.inclusionireland.ie>]

NOVEMBER 2006-NOVEMBER 2007, UK

UK government initiative **ASK ABOUT MEDICINES** is working in partnership with pharmaceutical company Merck Sharp and Dohme to provide at least 20 **ASK** grants worth up to £1,000 [US\$2,000; Euros 1,484] to help UK-based NGOs with ongoing activities. Applications for grants may be made prior to the first week of November 2007 (grant application forms available on weblink below).

[http://www.askaboutmedicines.org/Homepage/ASK_Grants/default.aspx]

NOVEMBER 30 2006, BRAZIL, CHILE, FRANCE, INDIA, NORWAY AND UK

Former US President Bill Clinton announced that his **CLINTON FOUNDATION HIV/AIDS INITIATIVE (CHAI)** had achieved a 45% price reduction in paediatric antiretroviral therapies (ART) by negotiating agreements with local generic pharmaceutical manufacturers Cipla and Ranbaxy. The venture is to be financially supported by the newly-formed UNITAID, the international drug purchase facility established in September 2006 by Brazil, Chile, France, Norway and the UK. UNITAID is to provide CHAI with US\$35m [Euros 27m] in 2007 to buy medicines and diagnostics. UNITAID operates an innovative form of funding: it benefits from small levies raised on airline passengers. On July 1st 2006, France adopted a new law legalising such levies.

[<http://www.unitaid.eu>

<http://www.clintonfoundation.org/cf-pgm-hs-ai-home.htm>]

NOVEMBER 30 2006, UK

Dr Ian Banks, President of the **EUROPEAN MEN'S HEALTH FORUM (EMHF)**, wrote an article on the Resources/Editorials section of the EMHF website denouncing the recent trend in the media to denigrate the efforts of patient organisations on account of their relationships with pharmaceutical companies. Dr Banks noted in the editorial: "Of course, voluntary groups who accept funding from any source—including government—experience potential dangers. Safeguards and checks will do much to prevent abuse. But the danger is that the baby will be thrown out with the bathwater. Deprived of such funding, much of the cutting-edge work conducted by voluntary organisations could not be performed—not least because governments are notoriously reluctant to fund the voluntary sector unless a political advantage accrues to them. Lessons to be learned include the need for multiple-funding partners—preferably from the diverse areas of industry, government, and public donation. Transparency on both sides is a vital necessity, not just a bolt-on extra. Clear, published aims of the partnership, plus information on the levels of financing—posted on the appropriate websites and in Annual Reports—are no longer 'just good ideas' ". Dr Banks called on readers to contribute to the debate.

[http://www.emhf.org/index.cfm/item_id/429/CFID=8900275&CFTOKEN=89355579]

RESEARCH

DECEMBER 12 2006, AUSTRALIA

Melbourne-based **SANE AUSTRALIA** released the results of research conducted with the backing of Pfizer Australia. The **SANE AUSTRALIA** study found that half of all Australians living with a chronic illness have considered seeking help for depression and anxiety. Coincidentally, in November 2006, **SANE AUSTRALIA** had expressed support for a government decision—coming after years of campaigning on the subject by **SANE AUSTRALIA** and many other groups—to allow patients to access psychotherapy under the national-government-financed Medicare scheme. Barbara Hocking, Executive Director of **SANE AUSTRALIA**, noted: "For many years, callers to the SANE Helpline have complained that the psychological treatment they desperately need is only available in the private healthcare system (which they cannot afford). People with a range of mental-health problems will finally be able to get psychological help—with the cost mostly covered by Medicare".

[<http://www.healthreport.com.au/Reports/32.pdf>

http://www.sane.org/Information/Information/Psychotherapy_on_Medicare.htm]

DECEMBER 11 2006, UK

London-based **CANCER RESEARCH UK** released the results of a UK-wide survey of the public on the dangers posed by 69 chemicals found in cigarette smoke. Survey findings indicate that the majority of the British public are completely unaware of the poisons in cigarette smoke. **CANCER RESEARCH UK**, one of the largest medical research charities worldwide, has launched a media campaign entitled 'Smoke is Poison', to alert the public to the dangers of cigarette-borne chemicals.

[<http://info.cancerresearchuk.org/news/pressreleases/2006/december/259299>

<http://info.cancerresearchuk.org/healthyliving/smokeispoison/poisonoussmoke>]

NOVEMBER 20 2006, UK

The London-based **BRITISH HEART FOUNDATION (BHF)** revealed that a staggering 40% of people would not make an emergency call if they suspected they were having a heart attack. The results were released following a November 2006 YouGov survey of 2,523 UK adults. Professor Peter Weissberg, BHF Medical Director, commented: "These statistics portray a very worrying—and perhaps very British—reluctance to telephone the emergency services, even in the most serious of emergencies. Maybe it is our natural reserve and stoicism. But it is an attitude that is costing lives".

[<http://www.bhf.org.uk/news/index.asp?secondlevel=241&thirdlevel=1913&artID=8493>]

FEATURED WEBSITES AND WEBPAGES

The Sundry, Massachusetts-based <http://www.lotsahelpinghands.com> [<http://www.alsa.lotsahelpinghands.com>] is a newly-launched website supported by the Calabasas Hills, Californian-based **ALS ASSOCIATION**. Amyotrophic lateral sclerosis (ALS) is a progressive neurodegenerative disease attacking nerve cells in the brain and strikes those aged between 40-70 years of age. The website provides the carers of people with ALS with answers to practical questions, and allows them to talk to each other.

A Novo Nordisk-sponsored website, <http://diabetesexchange.org> hopes to serve as a central clearinghouse for innovations in diabetes care, prevention, and management (mostly in the US). Major contributors to the site include the Alexandria, Virginia-based **AMERICAN DIABETES ASSOCIATION (ADA)**, and the New York-based **JUVENILE DIABETES RESEARCH FOUNDATION (JRDF)**.

Following diagnosis with motor-neuron disease (MND) by a 27-year-old UK citizen, John Bell, the Northampton, UK-based **MND ASSOCIATION** has been hosting webpages in which Mr Bell describes his deteriorating health, and explains his methods of coping with the condition. <http://www.johnsjourney.org> has attracted over 750,000 visitors from across the world. Mr Bell, who has received many communications of sympathy and support, has lately become too ill to be photographed on the website.

EVENTS

TUESDAY MARCH 11-FRIDAY MARCH 14 2008

10th WORLD CONGRESS OF ENDOMETRIOSIS, AUSTRALIA

The Melbourne-based conference is being organised under the auspices of a London-based professional group, the World Endometriosis Society, but with significant input from patient organisations. The conference will act as a forum for the exchange of knowledge on the latest discoveries on the condition. Included will be presentations on endometriosis epidemiology, clinical trials, new diagnostic tools, and drugs. The conference will also offer facts and trends on the management of the disease, and practical solutions to its main symptoms of pain and infertility. The event will emphasise the London-based **WORLD ENDOMETRIOSIS RESEARCH FOUNDATION** (launched on October 22nd 2006) as the first global organisation with an "aim to foster research into endometriosis, and improve knowledge and treatments of this enigmatic disease". Increased patient involvement in endometriosis research is signified by the appointment of Lone Hummelshoj as Chief Executive Officer of the new Foundation. Ms Hummelshoj co-founded the Aasted, Varde, Denmark-based **ENDOMETRIOSE FORENINGEN** [the Danish Endometriosis Society].

[<http://www.endometriosis.ca>
<http://www.wce2008.com/invitation.htm>
<http://www.endometriosisfoundation.org>
<http://www.endo.dk>]

FRIDAY JUNE 1-SUNDAY JUNE 3 2007

FOUNDATIONS FOR EUROPE: THE NEW CHALLENGES FOR GLOBAL PHILANTHROPY, SPAIN

The Brussels-based **EUROPEAN FOUNDATION CENTRE (EFC)**—a pan-European organisation representing the interests of diverse foundations and corporate funders of NGOs—is to hold its next Annual General Assembly in Madrid. The conference intends to look at the roles and responsibilities of philanthropists in the context of the turbulent global backdrop to global warming, increased global poverty, and other subjects currently in the political spotlight worldwide. Sections of the conference will be allocated to the following specific themes: global health; HIV/AIDS; incorporating a gender perspective in donations; and public-private partnerships.

[<http://www.efc.be/aqa/AGA2007>]

THURSDAY MAY 31-SATURDAY JUNE 2 2007

MENTAL HEALTH EUROPE 2007 CONFERENCE, AUSTRIA

Entitled 'No Health Without Mental Health: From Slogan to Reality', Brussels-based **MENTAL HEALTH EUROPE (MHE)**'s 2007 conference will be co-organised by Linz-based **PRO-MENTE AUSTRIA** and **PRO MENTE VIENNA**, and held in Vienna's House of Industry. The conference will focus on the outcome of the consultation process to the European Commission's Green Paper, *Improving the Mental Health of the Population* [Editor: see above], and will discuss potential strategy for the next years. As part of the proceedings, MHE will hold a 'capacity-building' seminar primarily directed at mental-health patient organisations located in the new EU Ascendant Nations. This seminar will hope to provide assistance and training for groups that wish to conduct the following activities: fighting social exclusion; making information about social exclusion available at European and national levels; and promoting dialogue and the exchange of ideas between organisations attending the MHE conference.

[<http://www.mhe-sme.org>

<http://www.promenteaustria.at>]

TUESDAY APRIL 24-WEDNESDAY APRIL 25 2007

1st CANADIAN CONFERENCE ON RARE DISORDERS AND ORPHAN PRODUCTS POLICY

Hosted by the Toronto-based **CANADIAN ORGANIZATION FOR RARE DISORDERS (CORD)**, the Canadian Genetics Disease Network (CGDN), and BIOTECanada, the conference will be located at the Crown Plaza Hotel, Ottawa. This new event is scheduled to consider a wide range of topics that offer 'made-in-Canada' solutions to R&D and access to orphan products for rare diseases. The conference organisers insist that Canada, unlike many other countries, has no 'orphan-products' policy that specifically supports development and access to drugs, and diagnosis and treatment for rare diseases.

[http://www.raredisorders.ca/index.php/site/media/files/hold_the_date_apr_24_25]

APPOINTMENTS AND PEOPLE

EXECUTIVE DIRECTOR, NATIONAL OVARIAN CANCER ASSOCIATION (NOCA), CANADA

Elisabeth Ross, the Executive Director of Toronto-based **NOCA**, was named by the Women's Executive Network (WXN) as a 'Champion' among Canada's 2006 top-100 most-powerful women. The award by the Top-100 jury recognised Ms Ross' work in her nine years as an agent of change for the Canadian ovarian-cancer community. Acting as an advocate for ovarian-cancer support and awareness, Ms Ross has led notable initiatives on the disease (including 'Turn UP the Volume!'), all delivering awareness and resources on the subject to the farthest reaches of Canada.

[<http://www.ovariancanada.org>]

CHIEF EXECUTIVE OFFICER, MULTIPLE SCLEROSIS INTERNATIONAL FEDERATION (MSIF), UK

Christine Purdy retired in early December 2006 following seven years as the CEO of **MSIF**. Ms Purdy's place is to be taken by Peer Baneke.

[http://www.msif.org/en/news_press/news/chief_executive.html]

END OF *HSCNews Bulletin 6*, December 2006