

Dear Member,

Herewith the third of our new monthly *HSCNEWS Bulletins*. Each *Bulletin* provides details about the latest activities of the 2,500 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-August to end-September 2006. All items are selected on the basis that they should be of interest to health campaigners worldwide.

Thank you for sending us your news and updates—please keep them coming. We are now sending out the bulletins to a select number of journalists worldwide who have requested to receive this news.

Kind regards,  
Louise Oatham  
Manager  
*HSCNews Bulletins*

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*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**

AGE / AGEING; AIDS; ALS; ALZHEIMER'S / ALZHEIMER; ARTHRITIS; AUTOIMMUNE; BIRTH DEFECTS; CANCER; CARERS; CERVICAL CANCER; CHILDREN; COMPLIMENTARY ALTERNATIVE MEDICINE; COMMUNITY CARE; CYSTIC FIBROSIS; DEAF; DEMENTIA; DIABETES; DISABLED / DISABILITY; HEALTHCARE; HEART; HIV/AIDS; HOSPICE; HUMAN PAPILLOMA VIRUS; HUMAN RIGHTS; INFORMATION; INTELLECTUAL DISABILITY; LONGEVITY; MENTAL HEALTH; MENTAL ILLNESS; MULTIPLE SCLEROSIS, OVARIAN CANCER; PAIN; PALLIATIVE-CARE; PEOPLE INVOLVED IN CLINICAL RESEARCH; PSORIASIS; TRIGEMINAL NEURALGIA; VASCULITIS; WORLD HEALTH ORGANIZATION.

**COUNTRIES AND REGIONS**

ARGENTINA; AUSTRALIA; CANADA; ENGLAND; EUROPE; GERMANY; HUNGARY; INTERNATIONAL; IRELAND; LATVIA; LUXEMBOURG; NEW ZEALAND; ROMANIA; UK; USA; WALES.

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**MEMBERS' NEWS**

**SEPTEMBER 1, 2006, LUXEMBOURG**

Luxembourg-based **ALZHEIMER EUROPE (AE)** issued a position paper on its response to the European Commission's November 2005 European Transparency Initiative. Among subjects included in the Commission Initiative are strict criteria for the transparency and legitimacy of NGOs. AE's paper insists that the organisation supports the Transparency Initiative, and that AE itself already fulfils the proposed Commission criteria. The paper adds that AE has helped establish criteria (including representation, mission, values, governance, consultation and communication, and financial transparency) for the European Medicines Agency's interactions with patient groups.

[<http://www.alzheimer-europe.org>]

**SEPTEMBER 5, 2006, IRELAND**

Dublin-based **IRISH CANCER SOCIETY (ICS)** issued a press release on its attitude to the

forthcoming introduction of vaccines to protect against the human papilloma virus (a major risk factor in the development of cervical cancer). The Society applauds the availability of the vaccines as "an historic breakthrough for women's health", but cautions women who might be vaccinated not to neglect having regular smear tests. The Society points out that not all cancers will be prevented by the vaccine, and it says that the length of time the vaccines offer protection remains unknown. [<http://www.cancer.ie>]

**SEPTEMBER 8, 2006, ARGENTINA**

The Buenos Aires-based **ASOCIACIÓN DE LUCHA CONTRA LA ENFERMEDAD FIBROQUÍSTICA DEL PANCREAS (FIPAN)** [Argentine Cystic Fibrosis (CF) Association] celebrated National Cystic Fibrosis day on September 8th 2006. The Day marks the anniversary of the publication of the CF gene in 1989. In Argentina, 300-400 CF children are born every year, but only 5% are diagnosed. **FIPAN** is campaigning for greater disease awareness about CF symptoms—which should help towards better diagnosis and treatment. [[www.fipan.org.ar](http://www.fipan.org.ar)]

**SEPTEMBER 20, 2006, UK/ENGLAND**

Connecting for health (cfh) is the National Health Service organisation responsible for delivering England's 'National Programme for IT' (NPfIT). CfH plans to connect 30,000 GPs in England to almost 300 hospitals over the next 10 years, giving patients better access to their personal healthcare information. CfH has now created a '**VOLUNTARY-SECTOR NATIONAL ADVISORY GROUP**' to ensure that the needs of different healthcare service users can be incorporated into the NPfIT. The group, which met for the first time on Wednesday September 20th 2006, has 23 members, and includes representatives from the **ROYAL NATIONAL INSTITUTE FOR THE DEAF (RNID)**, **MENCAP**, **TERRENCE HIGGINS TRUST (THT)**, **AGE CONCERN**, AND THE **CARERS FEDERATION**. These organisations will help to publicise among their members the changes brought about by the NPfIT. [<http://www.connectingforhealth.nhs.uk/news/news210906>]

**SEPTEMBER 22, 2006, NEW ZEALAND**

Wellington-headquartered **AGE CONCERN NEW ZEALAND** issued a news item highlighting the potential for the financial abuse of older people. Financial abuse, noted the organisation, involves the misuse of funds or other resources of older people by individuals they trust. "Of the elder abuse reported to Age Concern New Zealand, 42% involved financial abuse. Most abusers are family members (67% of cases)—usually sons or daughters," reported the Age Concern article. Age Concern offered guidelines to help people be aware of the signs of elder financial abuse: "Indicators include older people who appear worse-off financially than they should be; older people who appear surprised at the balance of their bank account; and older people who appear to be fearful at discussing their finances, especially if accompanied by others who speak for them." [<http://www.ageconcern.org.nz/?/article&id=0000000120>]

**SEPTEMBER 22, 2006, UK/ENGLAND**

The London-based **ENGLISH COMMUNITY CARE ASSOCIATION (ECCA)**, the leading representative body for independent care homes in England, issued a press release responding to a Department of Health consultation on the subject of a forthcoming national framework for National Health Service (NHS) continuing care, and NHS-funded nursing care in England. The release expressed regret "that the opportunity has not been taken for a root and branch reform of the current policy, and for reform of the wider framework of healthcare and social-care funding for people with long-term care needs." The ECCA maintains "that there are still too many layers to the assessment framework—including a yet-to-be-unveiled screening tool that will cost the NHS considerable sums of money. In ECCA's view, this money could be better spent on funding continuing care and nursing care".

[<http://www.ecca.org.uk>]

**SEPTEMBER 30, 2006, UK**

London-based **ARTHRITIS CARE**, the UK's largest voluntary organisation working for and with people with arthritis, has just completed an extensive consultation exercise among patients with arthritis and people connected to someone with arthritis. Arthritis Care believes that the results of the exercise will help frame its future strategy.

[<http://www.arthritiscare.org.uk/AboutUs/Puttingpeoplewitharthritisfirst>]

**SEPTEMBER 2006, USA**

Helen Dearman, Founder and Executive Director of the Houston, Texas-based **NATIONAL CHRONIC PAIN SOCIETY (NCPS)**, hosts *PainTamers: Living with Chronic Pain*, a weekly radio programme on the subject of pain control. Aired on the VoiceAmerica network every Thursday at 5pm EST, Pain Tamers is also accessible online at the NCPS website. Two of September's programmes were dedicated to trigeminal neuralgia (TN). Guests on the show (TN specialists or people with TN) gave up-to-date information on treatment and self-help options.

[<http://ncps-cpr.org>]

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[<http://ncps-cpr.org>]

**SEPTEMBER 2006, CANADA**

The Toronto-based **NATIONAL OVARIAN CANCER ASSOCIATION (NOCA)** has had a successful year. In June 2006, the organisation launched a public-awareness campaign, 'Turn Up the Volume', encouraging women and doctors to be aware of the subtle symptoms that might indicate ovarian cancer. 'Turn Up' included public-service announcements on Canadian radio and TV. Then, the group's 5th annual walk, held on September 15th 2006 in 12 cities across the country, raised \$1m. Now NOCA is publicising a movement to have the Federal House of Commons pass a bill proclaiming September as annual 'Ovarian Cancer Month' in Canada. NOCA is one of three founding members of the Canadian Gynecologic Cancer Group (CG2), an entity set up to run the campaign. The CG2 site [<http://www.cg2.ca>] contains a form that members of the public can use to petition their MP on behalf of 'Ovarian Cancer Month'.

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

**SEPTEMBER 2006, ROMANIA**

In early September, Cezar Irimia, co-chair of the Brasov, Romania-based **ASOCIATIA BOLNAVILOR DE CANCER** [Federation of Cancer Patient Associations], sent an email appeal to major academic, medical, patient, and political organisations within Europe. The request asked for help in fighting the Romanian government's decision to drop the field of medical oncology from its list of medical specialties—at a time when the EU is fighting for recognition of this specialism to supplement the fields of surgery and radiotherapy in treating cancer. On September 11th 2006, the Lugano, Switzerland-based medical professional organisation, the European Society of Medical Oncology (ESMO), wrote to Dr Eugen Nicolaescu, Romania's Minister of Health, urging him to review the decision, which could otherwise result in Romania falling behind other European countries in the field of cancer care.

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

**SEPTEMBER 2006, USA**

The Alexandria, Virginia-based **AMERICAN DIABETES ASSOCIATION (ADA)** has listed on its website the various coalitions and collaborative campaigns with which it is involved. The list is diverse and continuing to expand. Heading the inventory is the ADA's longstanding and important cooperation with two other senior US patient organisations, the American Cancer Society (ACS), and the American Heart Association (AHA), on the 'Everyday Choices for a Healthier Life' campaign. The ADA is also a national partner in a four-part primetime television series entitled *Remaking American Medicine*, intended for broadcast on US TV channel PBS during October 2006. Among numerous other collaborative efforts, the ADA is promoting the 'Let's Just Play Go Healthy Challenge', an annual campaign to encourage children to lead healthy lives, mounted by the US cartoon TV channel Nickelodeon. This year's Challenge will be aired on Saturday September 30th 2006.

[<http://www.diabetes.org/coalitions-and-collaborations.jsp>]

## **CAMPAIGNS**

**AUGUST 2006, UK**

The Cannock, Staffordshire-based **BDF (BIRTH DEFECTS FOUNDATION) NEWLIFE** has launched a campaign called 'It's Not Too Much To Ask'. Operating as an online petition, the campaign hopes to highlight what BDF Newlife describes as the UK's poor provision of equipment and grants for sick and disabled children. The organisation also requests members of the public or healthcare professionals to provide it with their stories or experiences of disabled children being denied basic aids. BDF Newlife itself is a grant-issuing charity that offers funds for items of equipment such as standing frames, support chairs, wheelchairs, and car seats.

[<http://www.bdfnewlife.co.uk>]

**SEPTEMBER 22, 2006, UK**

London-based **BRITISH HEART FOUNDATION (BHF)** initiated the second phase of its 'Food4Thought' campaign by releasing shocking images of children drinking from bottles of cheap cooking oil, accompanied by the slogan "Some crisps contain 33% cooking oil. What goes into crisps goes into you—don't try this at home". A BHF press release pursued the message with a set of worrying statistics about the poor nutritional habits of British children, including: half of the UK's children are 'drinking' almost five litres of cooking oil every year as a result of their packet-of-crisps-a-day habit; almost one in five children are eating two packets of crisps or more a day, and therefore consuming at least nine litres of cooking oil a year; the UK as a nation eats enough crisps to fill an Olympic-sized swimming pool every 14 hours. The BHF indicated that it would be sending teaching resources on the subject to 2,500 of the country's schools.

[<http://www.bhf.org.uk>]

## **PUBLICATIONS**

**SEPTEMBER 2006, ROMANIA**

Bucharest-based **ROMANIAN ANGEL APPEAL (RAA)** sent a letter of complaint to a UK newspaper, the *Sunday Express*, about an article written by the paper on the subject of Romanian children with AIDS coming to Britain. "You described the awful discrimination they confront", noted the RAA letter, "and then you increased it". The RAA provides family, community, and infrastructural support to young Romanians in need (including those with HIV/AIDS).

[<http://www.raa.ro/newView.do?id=158&lang=en>]

## FUNDING

### **SEPTEMBER 2006, USA**

Since 1999, the Calabasas Hills, California-headquartered **ALS ASSOCIATION** has mounted an annual nationwide signature event to raise money, the 'Walk to *D'Feet ALS*'. Over 150 walks of three miles or more are held during August and September, with anyone, in any part of the country, eligible to participate. The 2006 'Walk to *D'Feet ALS*' is being publicised by two new half-minute-long public service announcements (PSAs). The PSAs ask the public to participate in the 'Walk to *D'Feet ALS*', and feature a 24-year-old American who has developed ALS. Both PSAs have been delivered to national television and cable networks, and have begun airing on the Independent Film Channel and the Discovery Health Channel. [<http://www.alsa.org>]

### **DECEMBER 2006, UK**

The London-based **CONSUMERS FOR ETHICS RESEARCH (CERES)** is scheduled to be wound up at the end of 2006. This volunteer-staffed group was founded in 1989 to help people involved in clinical research make informed decisions—which it did through its website and information leaflets. The decision to cease operating follows a clinical trials disaster in London in March 2006, when six healthy young male volunteers nearly died during the course of a clinical trial. The volunteers had been injected with an experimental anti-inflammatory drug. The incident convinced the trustees of CERES that a viable and "independent organisation is needed to represent the interests of subjects who face considerable risk in taking part in medical research". The efforts of CERES to raise sufficient independent financing to establish such a body fell short of target, and the organisation's officers made the decision to fold CERES. [<http://www.ceres.org.uk>]

## RESEARCH

### **SEPTEMBER 2006, AUSTRALIA**

The September issue of *Activist*, an email update from Melbourne-based **SANE AUSTRALIA** referred to research that the organisation published in June 2006: Sane's 2-page *Research Bulletin 3: Employment and Mental Illness*. The *Bulletin* is based on studies conducted by Sane during March-April 2006 among a sample of 284 people with a mental illness. The survey, which concentrated on exploring respondents' experiences of employment, found that an absence of suitable, flexible part-time employment forms a major barrier for people with a mental illness who wish to work. On the other hand, respondents identified an understanding, supportive employer (and workplace situation) as the most significant positive influence on retaining a job. [[http://www.sane.org/images/stories/information/research/0606\\_info\\_rb3.pdf](http://www.sane.org/images/stories/information/research/0606_info_rb3.pdf)]

### **SEPTEMBER 7, 2006, IRELAND**

The Dublin-based **IRISH CANCER SOCIETY (ICS)** announced the results of a June 2006 telephone poll that the Society had conducted among 500 Irish women aged 20-60. One of the survey's main results, in a country with no nationwide cervical screening programme, was that 1-in-5 Irish women have never had a smear test. Another worrying finding was that only 10% of the respondent women were aware that "not having regular smear tests might contribute to them getting cervical cancer". [<http://www.cancer.ie/news/news.php?newsID=133>]

### **SEPTEMBER 21, 2006, IRELAND**

The Dublin-based **ALZHEIMER SOCIETY OF IRELAND** published a report, *Perceptions of*

*Stigma in Dementia: an Exploratory Study* to coincide with World Alzheimer's Day. Written in collaboration with Trinity College Dublin, the report is a first look at the subject of dementia stigma in Ireland. The document, which indicated that prejudice and discrimination against people with dementia is widespread in the country, argues for the establishment of education-and-awareness programmes for the public, for healthcare professionals, and for providers.  
[<http://www.alzheimer.ie>]

**SEPTEMBER 21, 2006, EUROPE**

Similarly, the Luxembourg-based umbrella organisation **ALZHEIMER EUROPE (AE)** also published a report, *Who Cares? The State of Dementia Care in Europe*, to coincide with World Alzheimer's Day. Based on a survey of 1,100 carers in five European countries and conducted at the end of 2005-beginning of 2006, the study produced some disturbing findings about the situation of Alzheimer's carers, including: half of respondent carers spent at least 10 hours a day looking after their loved one; only two out of five carers were informed about the existence of an Alzheimer's patient support group; half wanted more information on drug treatments; and more than half did not have access to services such as home care, day care, or residential/nursing-home care. When the latter services were available, emphasised the report, many carers had to pay for the cost of access themselves.  
[<http://www.alzheimer-europe.org/?lm3=6C831951B6DF>]

## **NEW WEBSITES**

The Riga-based **SUSTENTO (LATVIAN UMBRELLA BODY FOR DISABILITY ORGANISATIONS)** has launched its new website. The site is mainly in the Latvian language, but English-language pages explaining the group's aims and objectives are available.  
[<http://www.sustento.lv/section/show/12> and <http://www.sustento.lv/resource/show/56>]

The Budapest, Hungary-based **OPEN SOCIETY MENTAL HEALTH INITIATIVE (MHI)** has launched its website. The MHI (a programme of the New York-based Open Society Institute) wishes to end inappropriate institutionalisation of people with a mental disability. The website concentrates on identifying best practices in community-oriented care. Publications on community care and advocacy are available for download. One of the site's main features is a Resource Directory that supplies facts about mental health, intellectual disability, and the human rights issues of people with a mental health problem. The Directory is an information exchange aimed at civil-society groups, stakeholders, and policy-makers. The site also holds a wealth of the latest news in its areas of specialisation, lists relevant events, and contains links to other sites.  
[<http://www.osmhi.org>]

## **EVENTS**

**SATURDAY, OCTOBER 7, 2006**

**WORLD HOSPICE AND PALLIATIVE CARE DAY, INTERNATIONAL**

The theme for the 2nd annual World Hospice Day is 'Access to Care for All', emphasising that anyone who needs high-quality end-of-life care should be able to access it. The Day (which, last year, was marked by 1,100 events around the world) intends to allow people to speak out about palliative-care issues, raise public awareness, and generate funds for hospice and palliative-care services. Participation in the Day is for everybody interested in the subject.  
[<http://www.worldday.org>]

**FRIDAY, OCTOBER 13-SUNDAY, OCTOBER 15, 2006**

3rd INTERNATIONAL CONFERENCE ON HEALTHY AGEING AND LONGEVITY, **AUSTRALIA**

The Sydney-based **INTERNATIONAL RESEARCH CENTRE FOR HEALTHY AGEING AND LONGEVITY (IRCHAL)** has sited its third annual conference in Melbourne, Australia. Sponsored by the World Health Organization, the event will allow interested members of patient organisations and patient groups to meet the world's foremost researchers into ageing. The very latest thinking on the subject of healthy ageing is scheduled to be explored by a multidisciplinary array of speakers.

[<http://www.longevity-international.com>]

**SUNDAY, OCTOBER 29, 2006**

WORLD PSORIASIS DAY, **INTERNATIONAL**

Forty national psoriasis patient organisations from around the world have put together the 3rd annual World Psoriasis Day (WPD). The Day is intended to raise awareness of the condition and to encourage healthcare authorities to offer greater access to high-quality psoriasis treatments for the 3% of the world's population that has the disease. The Day's official website contains a worldwide online petition asking the World Health Organization to elevate psoriasis to the category of a serious disease.

[<http://www.worldpsoriasisday.com>]

**SATURDAY, NOVEMBER 11, 2006**

CONFERENCE: NATURAL MEDICINES IN THE EUROPEAN CONTEXT, **GERMANY**

The **ASSOCIATION OF NATIONAL MEDICINES IN EUROPE** is hosting a conference on November 11th 2006, at the Meridien Parkhotel, Frankfurt, Germany. The conference is about the situation of natural medicines in Europe. Under discussion will be the economic savings that complementary/alternative medicines (CAMs) can bring to national healthcare systems. In attendance will be NGOs, consumer organisations, and policy-makers. The European Public Health Alliance (EPHA) is sponsoring the event. Further information is available at ...

[<http://www.eph.org/IMG/doc/Flyer-E-Ruckseite.1.doc>]

**TUESDAY, NOVEMBER 21, 2006**

CONFERENCE: SHARING THE WELSH EXPERIENCE—DELIVERING EFFECTIVE PATIENT INFORMATION, **UK/WALES**

On Tuesday November 21st 2006, the phone-in healthcare information service NHS Direct Wales is collaborating with the Manchester, England-headquartered **PATIENT INFORMATION FORUM (PIF)** to mount a joint conference, Sharing the Welsh Experience, at the Thistle Hotel, Cardiff. As part of a drive for greater 'joint working' across Wales, the conference will enable healthcare and social care professionals to meet to share experiences and discuss issues affecting the provision of healthcare information in Wales. Challenges to delivering more patient-focused services are due to be examined. Speakers will include Brian Gibbons, Minister for Health, Welsh Assembly Government. Further information is available at ...

[<http://www.healthcare-events.co.uk/tabid/63/Default.aspx/?conferenceId=68>]

**FRIDAY, MAY 11-SATURDAY, MAY 12, 2007**

10th NATIONAL INFORMATION CONGRESS FOR VASCULITIS PATIENTS AND THEIR DOCTORS, **GERMANY**

The Working Committee of the Bad Bramstedt-based **VASKULITIS PATIENTEN SELBSTHILFEGRUPPE (VPS) [VASCULITIS PATIENT SELF-HELP GROUP]** is pleased to announce its 10th National Information Congress for Vasculitis Patients and their Doctors will be held at the non-profit-making Rheumaklinik Hospital, Bad Bramstedt, Friday May 11th–Saturday 12th 2007. Anyone interested in vasculitis, a still relatively little-heard-of autoimmune disease, is welcome to attend. The Congress working language will be German. VSP cooperates with Kiel-based Deutsche Rheuma-Liga Schleswig-Holstein.

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

## **APPOINTMENTS**

### **INTERNATIONAL PROGRAMME OFFICER, MULTIPLE SCLEROSIS INTERNATIONAL FEDERATION (MSIF), UK**

The London-based (MSIF) has recently appointed Zoe Burr as its new international programme officer and member of the organisation's Secretariat. Her duties will be liaising with people with MS, with the 'Persons with MS International Committee', with the International Medical and Scientific Board (IMSB), and managing MSIF's info@msif.org mailbox. Ms Burr comes from the mental health charity, Rethink, where she was events, campaigns and communications officer.

[[http://www.msif.org/en/news\\_press/news/new\\_member\\_of\\_st.html](http://www.msif.org/en/news_press/news/new_member_of_st.html)]

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