

HSCNEWS INTERNATIONAL

THE VIEWS OF HEALTH AND SOCIAL CAMPAIGNERS WORLDWIDE



HEALTH CAMPAIGNERS: CHILDREN AND YOUNG PEOPLE

Plus

Members' News, Events, and Websites on the same theme

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COVER ILLUSTRATION

With thanks to the Mental Health Foundation, and to Henry Nead, aged 10

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Children and young people— the key campaign issues



THIS MONTH'S ISSUE OF *HSCNEWS* LOOKS AT THE ADVOCATES WHO WORK IN ONE OF THE FASTEST-GROWING SEGMENTS OF THE HEALTH CAMPAIGNING MOVEMENT—CHILD HEALTH. THE ISSUE DESCRIBES HOW CHILD-HEALTH ADVOCACY GROUPS HAVE RECENTLY FORMED TO SUPPLEMENT THE ACTIVITIES OF THE MORE LONG-STANDING CHILDREN'S RIGHTS AND WELFARE MOVEMENT. CHILD HEALTH ADVOCATES ADOPT THE SAME RIGHTS-ORIENTED APPROACH ESPOUSED BY THE CHILDREN'S RIGHTS GROUPS, BUT SPECIALISE IN DISEASE, TREATMENTS, AND HEALTHCARE SYSTEMS [PAGES 8-11].

CHILD HEALTH GROUPS ARE MULTIPLYING IN NUMBER. THEY ARE TYPICALLY FOUNDED EITHER BY CHILDREN THEMSELVES, BY PARENTS, BY DISENCHANTED HEALTH PROFESSIONALS, BY PHILANTHROPISTS, OR BY ANY INDIVIDUALS INTERESTED IN CHILD AND FAMILY HEALTH [FOR CASE STUDIES FROM CANADA, SLOVENIA, SPAIN, SWEDEN, THE UK, AND THE US, SEE PAGES 12-17]. THE EXPANSION IS, IN PART, DRIVEN BY A PERCEIVED DETERIORATION IN THE HEALTH OF THE YOUNG WORLDWIDE, AND BY THE FACT THAT POLICYMAKERS ARE STILL ONLY STRUGGLING TO COME TO TERMS WITH THE TREND [FEATURE 2, PAGES 32-33]. MANY CHILD HEALTH ADVOCACY GROUPS ARE FORGING INTERNATIONAL ALLIANCES AND PARTNERSHIPS, SOMETIMES WITH OTHER HEALTHCARE STAKEHOLDERS [PAGES 17-19]. A LIST OF 34 PAN-EUROPEAN AND INTERNATIONAL ADVOCACY GROUPS DEDICATED TO CHILD HEALTH IS ALSO AVAILABLE [FEATURE 1, PAGES 29-31].

ANALYSIS OF *HSCNEWS* DATASETS HAS ALLOWED THE VARIOUS TYPES OF CAMPAIGNS RUN BY THE CHILDREN'S HEALTH MOVEMENT TO BE QUANTIFIED. EXAMPLES ARE PROVIDED [PAGES 19-26, AS WELL AS PAGES 6-7, MEMBER'S NEWS, AND EVENTS]. CASE STUDIES IN THIS ISSUE INCLUDE DESCRIPTIONS OF TWO EXTRAORDINARY EXPERIMENTS THAT AIM TO BRING YOUNG PEOPLE INTO THE POLITICAL AND HEALTHCARE DEBATE. THE FIRST IS THE PORSGRUNN PROJECT—A NORWEGIAN TOWN'S SUCCESSFUL ENDEAVOURS TO INCORPORATE DISAFFECTED YOUTH INTO LOCAL POLITICAL PROCESSES [FEATURE 3, PAGES 34-35]. THE SECOND IS AN EU WEBSITE AIMED AT HELPING SCHOOLCHILDREN UNDERSTAND HOW THE EU'S COMPLEX DECISION-MAKING STRUCTURES FUNCTION [PAGE 47-48; AND WEBSITES].

FINALLY, A GUATEMALAN ORGANISATION, FUNDANIER (A SUPPORT GRUP FOR CHILDREN WITH RENAL DISEASE), SEEKS YOUR INPUT AND COMMENT ON A NEW WEBSITE THEY ARE BUILDING [PAGE 49].

Advocacy in children's health: a profile

Anyone logging onto the 'Child Health' section of the website of the Washington DC-based Children's Defense Fund (CDF) [<http://www.childrensdefense.org/childhealth>] is presented with unsettling statistics about the state of health of babies born in the world's richest country. According to the Fund, a baby who has not yet reached its first birthday dies every 19 minutes in the US. Each day, 390 American babies are born to mothers who have received no (or only late) prenatal care. Some 860 babies a day are born with a low birthweight. One in eight of the country's children is without health insurance.

These statistics place America 16th among industrialised countries in terms of low birth weight, and 23rd in infant mortality. Stark differences in the health—and health coverage—of American children manifest along racial lines. Yet, as a June 2006

“EACH YEAR, EIGHT MILLION CHILDREN ARE EITHER STILLBORN OR DIE WITHIN THE FIRST MONTH OF LIFE. THIS FIGURE NEVER MAKES NEWS.”

Editorial, *the Lancet*,
March 2005.

publication by the CDF points out [*Improving Children's Health: Understanding Children's Health Disparities and Promising Approaches to Address Them*]: “Studies have shown that preventive healthcare, newborn screening, and immunisation not only save lives and improve health, but also save money”. Founded in 1973 as a private, non-profit foundation supported by corporate grants and individual donations, the CDF's mission is to ensure that every child benefits from a healthy start in life.

Thousands of miles away, another health campaigner, the Australian Capital Territories-headquartered Nutrition Australia [<http://www.nutritionaustralia.org.au>] has compiled data that shows Australia's rates of childhood obesity rank among the highest in developed countries. Around one quarter of Australian children are currently regarded as overweight or obese—a huge jump from the 1960s figure of 5%. Australian parents are worried by the trend. In 2004, several hundred of them from across the country joined forces to launch an Internet network, the Parents Jury [<http://www.parentsjury.org>], backed by Melbourne-based

Diabetes Australia (DA)-Victoria, and two Sydney-based bodies, the Cancer Council Australia, and the Australasian Society for the Study of Obesity (ASSO). In November 2005, the Parents Jury launched an online 'Junk-Food-Free Kids-TV kit' to help parents voice concerns about junk-food advertising on children's television. According to the group: "Australian children face more food advertisements per hour than children in any country in the world. Three quarters of these advertisements are for low nutritional-value junk foods that are high in sugar and fat".

During the week of June 10th-17th 2006, the London-based British Lung Foundation (BLF) unveiled its 'Lungs are for Life' campaign, highlighting the fact that many adult lung conditions are first developed by infants (or at an even earlier stage of life). The BLF considers respiratory disease to be the most common of childhood conditions. Each year, 1.5 million visits to UK GPs are made by children experiencing breathing difficulties.

On June 1st 2006, the Dublin-based Children's Rights Alliance Ireland [<http://www.childrensrights.ie>] published a detailed report on children's rights in Ireland, *From Rhetoric to Rights*, which it presented the following week, in Geneva, to the United Nations Committee on the Rights of the Child. The report looked at the Irish government's post-1988 successes and deficiencies in implementing the UN Convention on the Rights of the Child. One of *From Rhetoric's* major criticisms is the inappropriate care and social services available for Irish children with emotional, behavioural, and mental health problems. The Alliance, a league of 80 Irish NGOs working in the area of children's rights and welfare, is developing an online information centre to help notify children and young people of their rights (including rights that aspire to securing the wellbeing and health of the young).

The above examples are just a sample of the types of activities that health advocates around the world are undertaking on behalf of children and young people.



THE SIZE OF THE CHILDREN'S HEALTH MOVEMENT

The size of the children's health movement is hard to quantify. At least half of the groups in the *HSCNews International* database of health advocates (which currently numbers just over 40,000 organisations) declare some interest in children's health issues. If the only groups counted, though, are those that claim the specific goal of addressing children's needs alone, then children's health advocates account for about 12% of the overall health campaigning movement—roughly the same percentage as patient groups specialising in neurological or mental health conditions. [Some of these child health advocates may conduct other activities, but children's health remains a predominant part of their mission.]

DISTINCTIONS BETWEEN CHILD HEALTH AND WELFARE

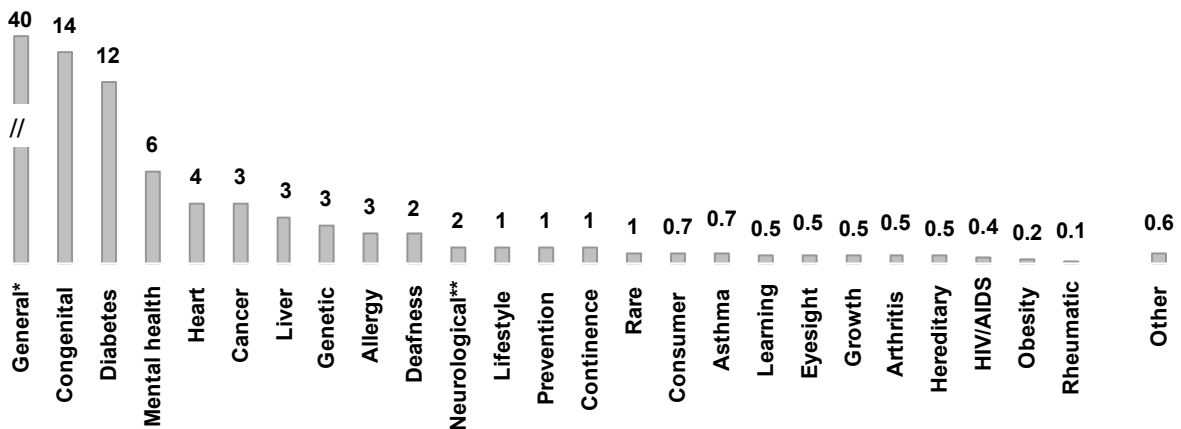
This analysis of the children's health movement draws a distinction between longstanding, high-profile NGOs that tackle the issues of aid development, child welfare, and poverty—such as Oxfam International, Save the Children, and World Vision—and child health advocates. The latter are a relatively new phenomenon. Child health advocates focus on questions related to diseases, healthcare reform, and children's rights to appropriate healthcare—including the right of children and their parents to have a say in that care.

Almost 60% of child health advocates campaign about a disease area or disability. Some 40% of the groups focus solely on chronic disease—namely,

ACTIVITIES UNDERTAKEN BY CHILD HEALTH ADVOCATES

% of total

Number of groups analysed = 4,800



* Includes aid development

** Angelman syndrome and neurofibromatosis

Source: *HSCNews International*, 2006

arthritis, allergies, asthma, cancer, diabetes, heart, liver, and mental health problems. Chronic illness has reached epidemic proportions among children of developed countries. And, despite recent advances against childhood cancers, the disease remains the leading cause of death for people under the age of 19 in the bulk of the richer countries.

Until recently, most patient groups placed their emphasis on people who are already ill—in other words, patients. But the realisation that diabetes (type 2), heart and respiratory disease, and, in some cases, mental health problems, were all significantly preventable has galvanised health advocates into a change of direction—prevention. The focus on children is seen as particularly important, as they have yet to develop these conditions—but could do so, unless intervention occurs.

THE ORIGINS OF CHILD ADVOCACY

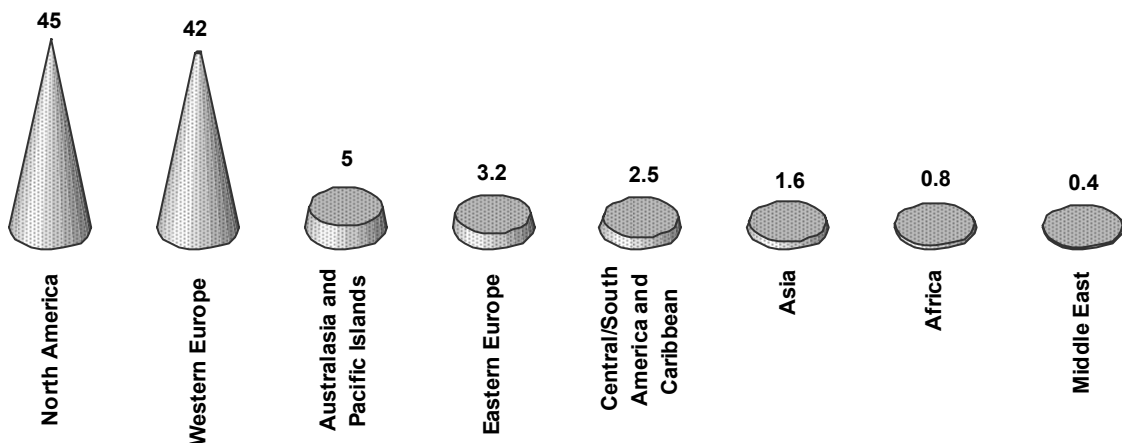
The origins of modern child advocacy can be traced back almost a hundred years to just after the end of the First World War. Save the Children International, probably one of the first major child advocacy groups, was founded in London in 1919 by two sisters with a strong social conscience and a commitment to public service.

The sisters had travelled far during that war, and had become aware of the appalling suffering experienced by some children. The two set themselves an ambitious goal to relieve the plight of children by creating “a powerful international organisation which would extend its ramifications across the globe”. Save the Children has more than fulfilled those ambitions.

COUNTRY HEADQUARTERS OF CHILD HEALTH CAMPAIGNERS

% of total

Number of groups analysed = 4,800



Source: HSCNews International, 2006



Child advocacy groups gradually proliferated, eventually spurred on by the activities of the United Nations Children's Fund (UNICEF), created in 1953. The lead-up to the 1989 signing of the UN Convention on the Rights of the Child saw a number of international organisations established, such as the two Toronto-based groups, Pueblito, and Free the Children. Like Save the Children, these are dedicated to improving the welfare of the young. National and local groups also began to appear.

The political momentum driving the movement did not let up after the 1980s. The 1990 World Summit for Children in New York brought together the largest gathering of world leaders in history to adopt a 'Declaration on the Survival, Protection and Development of Children'. In September 2000, leaders of state signed the UN General Assembly's Millennium Declaration. A reduction in childhood mortality was among the goals set out in the document.

In 2002, the UN General Assembly held a Special Session on Children, devoted purely to young people. The session culminated in the production of a grand plan—'A World Fit for Children' [see box, left], a ten-point set of children's rights. This remarkable proposal led to the creation of the Barcelona-based Global Movement for Children (GMFC), a worldwide alliance of NGOs and individuals dedicated to "building a world fit for children".

Child advocates have largely held true to the original aspirations of the sisters who founded Save the Children, and to the mandate espoused by the UN Convention on the Rights of the Child.

The online encyclopaedia, Wikipedia, notes that child advocates are motivated to protect the interests of children from harm, and to obtain justice for injured children. Child advocacy groups may also seek to ensure that their constituency can access positive influences or services which will benefit children's lives in a major way (including education and childcare).

In the past ten years, child advocates, taking their lead from the WHO [see box, right], have explored additional remits. They are looking, in particular, at the environmental factors that cause childhood illness and death, at HIV/AIDS, and at reproductive and mental health. But their involvement with disease and healthcare probably ends there.

CHILD HEALTH ADVOCATES—IN A CLASS OF THEIR OWN

Still relatively young, the children's health movement is, in effect, a response to a political deficit in one area of child advocacy. Child health advocates concentrate on the details of disease awareness, diagnoses and prevention, treatments and healthcare delivery. They campaign and work at local, national, and international levels, as well as providing support to sections of the population sometimes ignored within healthcare systems—the young and the very young.

Such groups are nonetheless strongly influenced by the priorities of the child advocacy platform. And unsurprisingly, much of the rhetoric within the child health movement is centred around concepts of children's rights, representation, and

WORLD HEALTH ORGANIZATION AND CHILD AND ADOLESCENT HEALTH

In 1998, the WHO established a new department of Child and Adolescent Health (CAH). The CAH department became responsible for interventions concerning child health, and growth and development in young people up to 19 years old. Previously, the WHO's main focus was the reduction of childhood mortality.

In 2002, the WHO published seven priority areas for CAH:

1. Supporting maternal and newborn health.
2. Improving nutrition.
3. Preventing and managing communicable diseases.
4. Preventing and managing injuries.
5. Reducing threats in the physical environment.
6. Improving the reproductive and sexual health of adolescents.
7. Promoting psychosocial development and mental health.

In 2004, the WHO published a major study, the first to look at the impact of the environment on the health of European children [F. Valent, D. Little, G. Tamburini, F. Barbone, *Burden of Disease Attributable to Selected Environmental Factors and Injury Among Children and Adolescents in Europe*, WHO, Geneva, June 2004].

In 2005, a European Strategy for Children's Health was presented at the WHO's regional committee, calling for more effort to combat accident and injury, outdoor and indoor air pollution, unsafe water, and lead contamination.

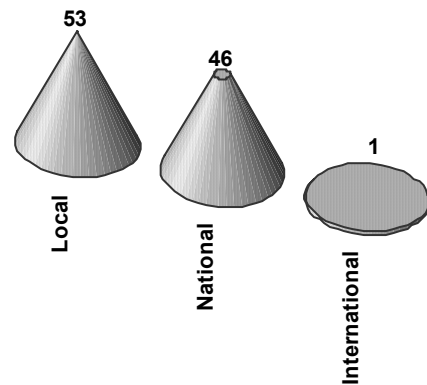
inclusion. Moreover, child health advocates work alongside the international child-advocacy community to endorse the disease-based initiatives of the WHO and others.

Examples of child-health advocacy groups are listed below. Most were formed either by children themselves, by people in regular contact with children, by philanthropists, or by individuals interested in child and family health.

DISENCHANTED HEALTH PROFESSIONALS

- Spanish NGO Respirar [To Breathe] [<http://www.respirar.org>] was founded by paediatrician Carlos Vazquez. Dr Vazquez has drawn together a large number of like-minded healthcare providers to improve the quality of life for asthmatic children and adolescents in the Spanish-speaking countries of the world. The group's website contains information for professionals, as well as for families and the public. The organisation is running campaigns to increase public awareness of the WHO's call for improved asthma control—the 1992 Global Initiative for Asthma (GINA). Respirar also promotes a 'Decalogue on Healthy Schools for Children with Asthma', to support the adoption of appropriate sports activities for asthmatic schoolchildren. Respirar provides support for parents to quit smoking, and espouses a set of rights for children with asthma.
- The New York-based Children's Health Fund [<http://www.childrenshealthfund.org>] was founded in 1987 by paediatrician Irwin Redlener, together with singer-songwriter Paul Simon. Its mission is to provide comprehensive healthcare to America's

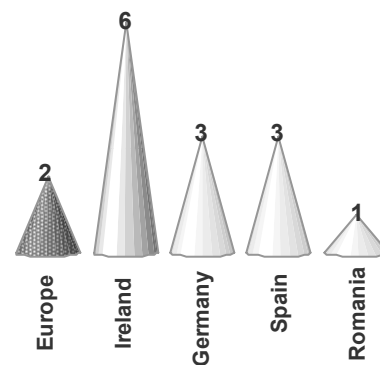
Geographic remit of child health advocacy groups
 % of total
 [Number of groups analysed = 4,800]



Source: HSCNews International, 2006

Burden of asthma in Europe
 (DALYs* per 1000), 2002

DALYs= Disability-Adjusted Life Years



Source: The European Health Report 2005, Copenhagen, WHO Regional Office for Europe, 2005.

most underserved children through the development of innovative primary-care programmes, and by campaigning for universal access to suitable healthcare for all children.

- In 1933, pioneering child health advocate, Dr Elise Ottensen-Jensen, founded the Stockholm-based Riksförbundet för Sexuell Upplysning (RFSU) [<http://www.rfsu.se>], the Swedish Association for Sexuality Education, with a number of other radical physicians and trade-union representatives. The RFSU's original aim was to develop sexual education for schools, counselling centres, and to campaign for the abolition of a ban on information about contraception. The organisation was instrumental in the Swedish government's decisions to allow condoms to be sold in stores with special permits (1952), to approve 'the Pill' as a contraceptive (1964), and to establish the first reproductive clinic for young men (1991). Since 2002, the RFSU has also run an advocacy project that promotes the concept of sexual and reproductive health rights for adolescents (SRHRA), and which has become a model for similar activities in Europe. Between October 19th and November 10th 2006, the RFSU is running a series of training programmes on the subject for people from developing countries.

REPRESENTATIVES OF CHILD-CARE PROFESSIONALS

The London-based YoungMinds [<http://www.youngminds.org.uk>] was born in 1989 out of an existing organisation that, at the time, represented the interests of child and family mental-health professionals.



YOUNGMINDS: REQUIRED REFORMS

1. SUPPORT FOR PARENTS
2. HELP FOR SCHOOLS
3. MENTAL HEALTH SERVICES FOR YOUNG OFFENDERS
4. COMPREHENSIVE SERVICES FOR ADOLESCENTS
5. ACCESSIBLE, CO-ORDINATED, EMERGENCY SERVICES FOR YOUNG PEOPLE
6. GREATER ACCESS TO TRAINING FOR THOSE WHO WORK WITH CHILDREN AND YOUNG PEOPLE
7. CO-ORDINATION ACROSS HEALTH, EDUCATION, AND SOCIAL SERVICES
8. PROVISION OF WELL-STAFFED, SPECIALIST CHILDREN'S MENTAL HEALTH SERVICES
9. INCREASED ACCOUNTABILITY FOR CHILDREN'S MENTAL HEALTH SERVICES
10. AN END TO 'POSTCODE LOTTERY' OF SERVICE PROVISION

YoungMinds continues to speak for what it believes is a unique alliance of individuals, groups, and professional bodies within the fields of health education, social services, and youth justice. The group's mission is to effect change in government policy and service delivery. YoungMinds has drawn up its own ten-point manifesto about the types of reform it would like [see box, previous page].

LONG-TIME SUPPORTERS OF HEALTH CAMPAIGNERS

Larry Kirkman, currently head of the Washington DC-based American University School of Communication, has a long history of helping non-profits develop novel communication strategies to improve relations with their constituencies. In 1995, he spearheaded an effort to raise funding from the AT&T Foundation, and negotiated a

A YOUNG PERSON'S VIEW
BY TABITHA LOUGHLIN

EXTRACTS FROM THE
HIGHLAND USERS GROUP'S
SPRING 2006 NEWSLETTER

"Being young and having mental health problems results in a lot of problems that you very often can't handle, or just don't understand how to handle. Attention-deficit hyperactivity disorder (ADHD) is not recognised in adults, but it does exist. I am living proof of that. A lot of kids pick on me. They throw stones and pennies at me, so I tell the police. But the police can't do anything about it. Unless you can tell them everything—down to the colour of the person's underwear—then there is nothing the police will do about it.

Once, a group of kids took their coats off and put them on backwards, pretending that they were wearing straight jackets. They then proceeded to block

the path, so I couldn't get through—which made me twice as angry. I could feel the tears bursting from my eyes, and hear the horrible noises they were making. All I wanted to do was get past them. So I shoved the two nearest me, so that I could get through. But I was so upset that I shoved them so hard that they fell over. And, because they didn't have their arms in their sleeves, they couldn't get up. Every time the kids come out of the high school, I avoid going out, because I'm frightened of them.

A lot of adults also aren't very nice to young people with mental health problems. Because I'm maturing mentally at a 16 year-old's rate, a lot of people who are older than me say regularly, "Act your age, not your shoe size", or "You are twenty now, not two", and that makes me angry, because I know that I'm acting normally in my terms of normal, not the majority's. I am as normal as a

person can be who has no medication to control them any more.

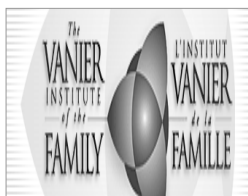
When I first stopped taking my medication, I had no medical support whatsoever. I was on powerful drugs from the age of nine. I've only come off them a year ago, and still hurt physically, even though the doctors said I would be OK in eight weeks.

A lot of people call me an attention-seeker or a hypochondriac. I hate that the most, because my family used to call me that constantly until I moved out. The truth of the matter is that I get aches and pains at night, and there is no one to ask for help. In the morning, because I've been worrying about the aches, I ask someone, and they call me an attention-seeker and a hypochondriac—which makes me enraged."

partnership with the US Ad Council to support a ten-year public-service announcement campaign that elevated children's issues onto the US policy agenda. Connect For Kids (CFK) [<http://www.connectforkids.org>], one of the first web gateways devoted to children's issues (including healthcare and healthcare reform), was created in 1999 out of these efforts. In 2003, CFK became an independent non-profit organisation. Its website now carries news, online chat rooms, book reviews, blogs, information about events, and funding alerts. On the subject of health, the website provides a valuable information resource for the young, and a place to exchange views.

PHILANTHROPISTS

In 1965, Georges Vanier (Governor-General of Canada, 1959-1967) and his wife founded the Vanier Institute of the Family [<http://www.vifamily.ca>], an Ottawa-based organisation that works on behalf of the long-term health of Canadian families. The group conducts research, is involved in public education, and acts as consultant and advocate. Allan MacKay, president of the Institute, is an out-spoken member of the health campaigning community. He used the run-up to the Canadian federal election of January 2006 to comment on government policy, and to offer some publicly-reported suggestions on how best to support the health and well-being of Canadian families and children. In an open letter to the editor of the *Globe and Mail* newspaper, Mr Mackay wrote: "All parents make personal sacrifices in order to invest in the next generation of citizens. Ultimately, we shall all benefit from their contribution. Regrettably, however, the tax system fails to acknowledge that parents have less disposable income than others without dependent children."



CONNECT FOR KIDS (CFK) SETS UP NEW STANDARDS FOR ONLINE COMMUNICATION AMONG THE YOUNG

CHILDREN WITH A MEDICAL CONDITION

Born in Eugene, Oregon, Clare Rosenfeld was diagnosed with type-1 diabetes at the age of seven. Since then, she has become a persuasive campaigner, achieving empathy with other younger people. "Young people", she says, "often lack support and help in

the management of their disease. They are also more likely than adults to be disenfranchised from healthcare politics". Her view is that a special voice is required to represent the needs of children and teenagers.

Ms Rosenfeld became a national youth advocate for the American Diabetes Association (ADA) in 2000-2001 at the age of 14. She helped with ADA fundraising and educational programmes. She lobbied at local, regional, and national level, pressing Congress to spend more on diabetes research, and testifying before the US Food and Drug Administration (FDA).

Leveraging the prestige that came with her appointment, Ms Rosenfeld obtained grassroots support in 2001 to back the passage of legislation obligating the state of Oregon to provide education and supplies on behalf of diabetes self-management.

In 2002, when just 17 years old, she founded the International Diabetes Youth Ambassador (IDYA) programme, which allows young, motivated people to communicate on a virtual network [<http://www.childrenwithdiabetes.com>].

Today, Clare Rosenfeld is working with Martin Silink, president-elect of the International Diabetes Federation (IDF) in a campaign entitled 'Unite for Diabetes' [<http://www.unitefordiabetes.org>]. The campaign, which was launched on June 10th 2006, is seeking government support for a United Nations Resolution on Diabetes on or around World Diabetes Day, November 14th 2007. [For more on Ms Rosenfeld, see *HSCNews International*, issue 11, October 2004, pages 37-40.]

DISENCHANTED PARENTS

María Escudero is the mother of a child born with a congenital cardiopathy. She is founder and President of Madrid-based Menudos Corazones—Fundación de Ayuda a los Niños con Problemas de Corazón [Slight Hearts—Foundation to Aid Children with a Heart Problem], a patient organisation devoted to helping children with a heart condition and promoting their interests [<http://www.menudoscrazones.org>].



Clare Rosenfeld

*Photograph
accreditation:
Jesper Westley and
Novo Nordisk*



As often happens, the organisation was formed following a personal experience of illness. María and her husband were living in London at the time of the birth of their daughter. The two parents were understandably distressed when the child was diagnosed with a congenital cardiopathy. A London-based patient support group, Heartline Association, helped them through this difficult period.

When the family returned to Spain, María tried to get in touch with an equivalent organisation in her home city, Madrid. To her surprise, none existed. After meeting parents with comparable problems, María formed the Association for Children with Cardiopathies in 1998. The group forged links with similar organisations in other parts of Spain, and eventually evolved into Menudos Corazones. [For more on Menudos Corazones, see *HSCNews International*, issue 16, March 2005, pages 29-32.]

GOVERNMENT

The Ljubljana, Slovenia-based Ustanova 'Skupaj' [Foundation Together] was founded in 2002 by the Slovenian



government and another Ljubljana-based NGO, Slovenska Filantropija [Slovene Philanthropy—Association for

the Promotion of Voluntary Work], to address the “harsh implications and difficult transitional processes in many countries of the psychosocial well-being and mental health of children”. The Foundation [<http://www.together-foundation.si>] travels to countries affected by armed conflicts, terrorist acts, and social adversities, with the aim of helping children.

ALLIANCES, PARTNERSHIPS, AND COALITIONS

Child health advocates (as with other areas of the health campaigning movement) have sought a greater presence on the international stage. Intercontinental child health organisations—some of which are not new—are rapidly recruiting member groups. In doing so, they are gaining a greater potency within policymaking.

- Founded in 1994, the Netherlands-based International Confederation of Childhood Cancer Parent Organisations (ICCCPO) [<http://www.icccpo.org>] is one example of a global network of child health groups. The 80-member



ICCCPO enables parents' organisations around the world to share information on how to build better links

between the parents of children with cancer and healthcare professionals.



- Another growing network is the Brussels-based Autism Europe [http://

www.autismeurope.org], which was founded in 1983 as a European network of associations of parents with autism. The group fights for the same rights and privileges for people with autism as are enjoyed by other able citizens.

- In some cases, international groups include all types of healthcare stakeholders. Based in Memphis, Tennessee, the International Children's Heart Foundation (ICHF) [http://www.ichf.org] is a multi-disciplinary group that includes clinicians. The ICHF sends teams of doctors to resource-poor parts of the world to provide children's surgery. The ICHF also helps build local resources, and its surgeons operate in Memphis on children from overseas.



Backed by a large team of volunteers and host families (who care for the children

coming into the US), the organisation finances medical research, and acts as a global advocate to raise awareness of the need for treatment of congenital heart defects.

- The Netherlands-based World Alliance of Organisations (WAO) [http://www.vsop.nl/teksten/WAOfacts.htm] is another example of the trend described above. In this case, patient organisations have spearheaded the move to bring together a cross-disciplinary team to tackle the problems of congenital and genetic conditions in the young. The WAO was founded in 1994 by the March of Dimes [http://www.marchofdimes.com], a US-based



voluntary health agency which works to improve the health of mothers, infants and babies, and

the Vereniging Samenwerkende Ouderen Patiëntenorganisaties (VSOP), the Dutch Genetic Alliance. On June 10th-14th 2007, the WAO is sponsoring the 3rd International Conference on Birth Defects and Disabilities in the Developing World [see page 45].

[See Feature 1, pages 29-31, for further examples of international networks.]

NETWORKING IS OCCURRING AT NATIONAL LEVEL, TOO

- In the US, the Virginia Coalition for Children's Health was formed in 1997 when 100 organisations came together to ensure that Virginia take advantage of the few federal initiatives that provide health insurance programmes for the uninsured children of lower-income working families. The 100 founders included paediatricians, local branches of national child advocates (such as the March of Dimes), local groups focusing on improving healthcare delivery

for their constituency, as well as grassroots advocates for child care, such as Voices for Virginia's Children.

- The UK-based Children's Liver Disease Foundation (CLDF) was established in 1980 by two parents whose son had died of liver disease. Other parents nationwide who had children with a similar medical condition joined as members. Today, CLDF provides support, information, and promotes the need for more medical research into the causes, early diagnosis, and cure of children's liver disease.
- Canada's Success By 6 is a nationwide, community-based

multidisciplinary movement of public and private partnerships dedicated to ensuring that children aged up to six can access programmes that support their healthy growth and development. The project builds community consensus by engaging all local sectors in early-childhood development, and by funding schemes that strengthen services for young children and families. Over 300 communities are involved in Success By 6. Partners include Credit Unions, the Kentucky-based group United Way, and the British Columbia Ministry of Children and Family Development.

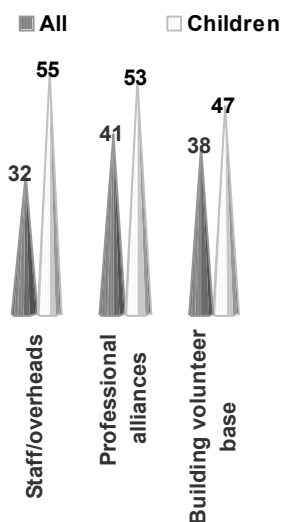
CAMPAIGNING BY CHILDREN'S HEALTH ADVOCATES

Between December 2005 and January 2006, *HSCNews International* surveyed health advocacy organisations around the world about their primary achievements in 2005 and their plans for 2006. The results were summarised in *HSCNews*, issue 25/26, January/February 2006. In all, 179 responses in various specialities were received from across the globe. Of these, however, over one fifth (38) stated that their organisations conducted campaigns in the area of child health. The interests of the 38 groups are listed in the table, right, and largely span the range of interests found in *HSCNews's* total database of child health advocates. Half of the 38 were national groups, over one third local, and the rest international.]

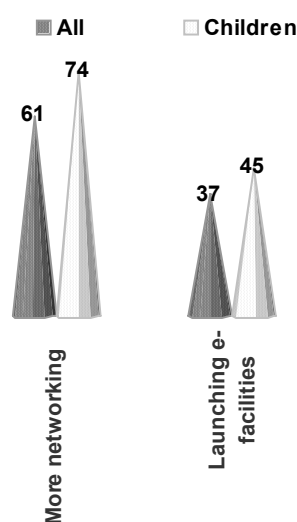
SPECIALITIES OF 38 RESPONDENTS CAMPAIGNING ON CHILDREN'S ISSUES % OF TOTAL	
Arthritis	3
Asthma	8
Injury	5
Cancer	13
Congenital	11
Families, parents, and carers	16
Genetic	8
Healthcare	5
Mental health	11
Newborn	3
Pain	3
Patients' rights	3
Rare	8
Renal	3
Sexual health	3

Source: HSCNews global survey of healthcare campaigners, issue 25/26, January/February 2006

Capacity expansion in 2005: groups campaigning on children's issues, versus all campaigners



Expansion of activities in 2005: groups campaigning on children's issues, versus all campaigners

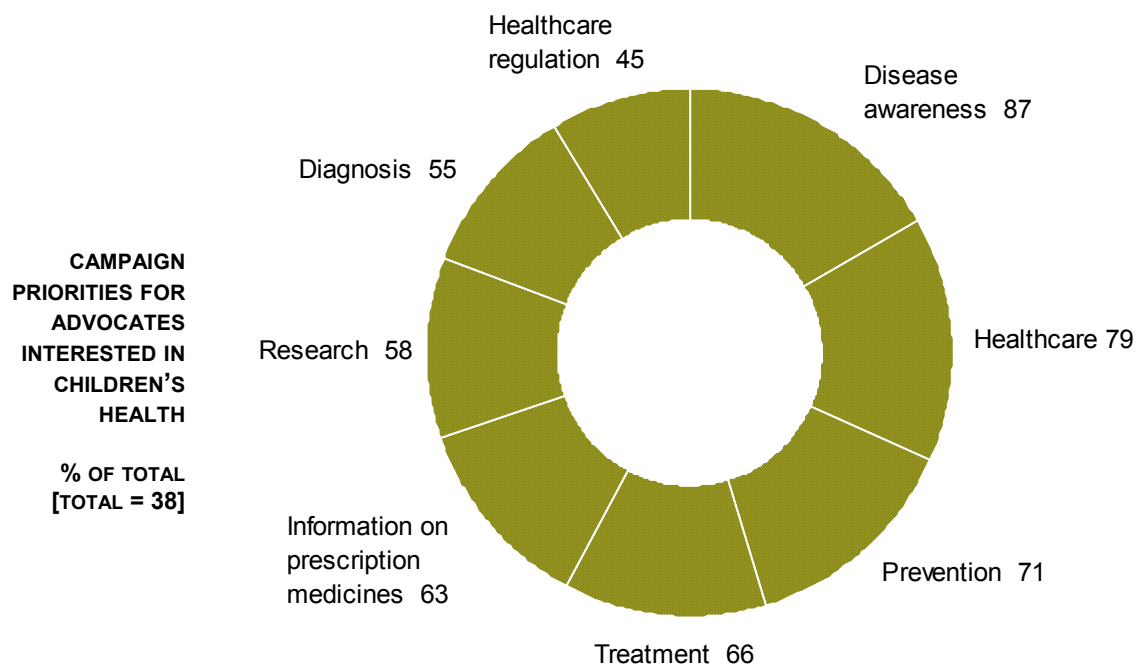


Source: HSCNews global survey of healthcare campaigners, issue 25/26, January/February 2006

We look below at the responses received from these 38 child health advocates, to determine the most significant structural changes taking place within the organisations, and their major campaigning issues.

SCALING UP

About half of the respondents with an interest in children's issues reported to *HSCNews* that the main structural changes taking place within their organisations in 2005 were threefold: an increase in the size of staff and overheads; an upgrading in the numbers of alliances with professional medical organisations; and the building of the volunteer base [for percentages, see graph, above]. Noticeably fewer groups in the survey's total sample of respondents said that they were pushing through the three categories of changes. The groups with an interest in children's issues also undertook more networking (74% versus 61%), and building of e-facilities (45% against 37%) than their peers. The finding underscores the earlier observation in this article that children's health is one of the fastest-growing sectors of the health campaigning movement.



Listed below are the main campaigning areas for groups with an interest in children's issues, as found by the December 2005-January 2006 *HSCNews* survey.

DISEASE AWARENESS

Nearly 90% of the groups with an interest in children's issues indicated—like most health campaigners in the survey—that they would be campaigning on disease awareness. One association of family, carer, and parent groups specified that the diseases in question were those “referring to the changes that can occur in a carer's life through caring, stress, and strain—coronary, cardiac, psychological, and other associated illnesses”.

Some 70% of the groups with an interest in children also stated that they would be conducting their disease-awareness exercises with like-minded peers.

One recent high-profile example of multiple-stakeholder collaboration is a US-based campaign, 'Rx for Child Survival', which is attempting to raise US citizens' awareness of children's health needs in the developing world, and is funded by the Merck Company's Foundation and the Bill and Melinda Gates Foundation. Participating in the Rx campaign are two Washington DC-based organisations, the Core Group, and the US Coalition for Child Survival, plus Westport, Connecticut-based Save the Children US, and Atlanta-based CARE USA. A host of smaller local US groups have also signed up to the initiative. Partner bodies include UNICEF, the Pan American Health Organization (PAHO), the American Academy of Pediatrics, and the Johns Hopkins Bloomberg School of Public Health.

HEALTH PROVISION

Nearly 80% of the survey's health campaigners interested in children's issues stated that they would be campaigning on the subject of healthcare

provision in 2006. Some 55% said that their campaigning would be directed towards securing greater support for carers and families.

The large number of children lacking insurance coverage for care is one particular concern identified by organisations in the US. In August 2005, for instance, the Princeton-based Robert Wood Johnson Foundation, which describes itself as the country's largest foundation making grants to improve healthcare, issued a report—*Going Without: America's Uninsured Children*—on the levels on uninsured children in the US. The report was written to coincide with the Foundation's campaign 'Covering Kids and Families', a national effort to enrol eligible children in public-health coverage programmes [<http://www.coveringkidsandfamilies.org>]. The report argued that as many as 8.4 million children were uninsured for healthcare (of which 2.9 million were Hispanic, and 1.6 million African-American).

The Oakland, Californian-based group Children Now, the Santa Monica, California-based Children's Partnership, and the Washington DC-based Children's Defense Fund (CDF) have teamed up to launch the '100% Campaign' [<http://www.100percentcampaign.org>] in California. The campaign hopes to use advocacy to ensure that the 10% of Californian children (a total of 800,000) who are without health insurance gain some access to care.

PREVENTION

Just over 70% of health campaigners interested in children's issues told the *HSCNews* survey that they would be campaigning on the subject of prevention. (Exceptions were organisations which concentrated on diseases that are currently non-preventable, such as congenital heart disease and cystic fibrosis.)

A new category of child health advocates have lately emerged to promote physical activity, reduce obesity, and encourage appropriate eating habits in the young. These

campaigners are worried by the tendency among today's children (in developed and developing countries alike) to adopt unhealthy lifestyle habits that are widely believed to lead to early onset of type-2 diabetes, coronary heart disease, large bowel cancer, and gall-bladder disease.

Examples of such 'lifestyle/prevention' NGOs include the Chicago-based Consortium to Lower Obesity in Chicago Children (CLOCC), and the Australian Capital Territories-based Early Childhood Australia (ECA).

Prevention groups sometimes form temporary leagues to publicise issues of mutual importance. For example, nine European and US groups attending a Brussels conference on good practice in diet and healthcare issued a consensus statement on May 12th 2006 against the worldwide promotion of junk food to children [see pages 40-41].

Typically, however, the main method by which the groups disseminate

prevention messages is through educational programmes. Thus, as the Guayaquil, Ecuador-based Fundación de Asistencia Sicopedagógica para Niños y Adolescentes que Sufren Retraso Mental (Fasinarm) [<http://www.fasinarm.org>] told the *HSCNews* survey: "Most of our services have objectives which refer to prevention, especially in our work with high-school students". Fasinarm's mission is to improve the quality of life of children and young people with a handicap (particularly those with mental retardation).

Similarly, in the same survey, Buffalo, New York-based Be Active New York State said that it had conducted the local management of a number of initiatives, including: state-wide promotion of the national 'Walk to School' campaign; 'America on the Move' (a state-wide, behaviour-change programme); and a school wellness-policy training workshop that aimed to build community capacity state-wide. The group explained its credo: "We

advocate a more strategic approach to community health improvement—which starts with those who wish to improve health first, learning/ understanding how (and if) their community works, and building on that understanding. We then encourage a strategic approach to fostering change that will support healthy lifestyles. To guide that plan of action, we use the Ottawa Charter principles".

TREATMENT

Nearly two thirds of health campaigners interested in children's issues stated that a campaigning topic in 2006 would be treatment. One example of such a campaign is the 'Dia-a-Dia com Diabetes' project of the Sao Paulo-based Associação de Diabetes Juvenil (ADJ) [<http://www.adj.org.br>]. The project allows ADJ representatives to visit local communities, educating groups of children and adolescents on state-of-the-art medical know-how and the best ways to comply with diabetes treatment.

Subjects include physical activity, the administration of insulin, self-monitoring, foot care, and nutrition.

INFORMATION ON PRESCRIPTION MEDICINES

Around 63% of health campaigners interested in children's issues stated in the *HSCNews* survey that they would be campaigning for access to better information on prescription medicines.

Respondents from mental health groups, however, contended that many children suffering from attention deficit/hyperactivity disorder (ADHD) and depression are over-medicated. These individuals, the groups insisted, are more in need of information that could help them manage their day-to-day lives, than in facts about medication.

Some groups—such as Sussex, England-based Informed Parent [<http://www.informedparent.co.uk>]—argue against the lack of transparency surrounding the medical evidence for and against childhood vaccination.

MEDICAL RESEARCH

Nearly 60% of campaigners interested in children's issues stated in the *HSCNews* December 2005-January 2006 survey that they would be campaigning about medical research.

Although medical technology has helped extend the life of children, campaigners say that the pharmaceutical industry (and non-industry bodies) should work harder to explore new treatments for diseases that afflict the young. Such research is vital—relatively common, but serious, childhood conditions (such as cystic fibrosis and juvenile-onset diabetes) remain incurable.

The view is supported by a November 2004 WHO report, *Priority Medicines for Europe and the World*. The report, written by Warren Kaplan and Richard Laing of the WHO's Department of Essential Drugs and Medicines Policy, noted that patient needs for medicine differ widely according to the age, gender, and genetic profiles of individual

patients. The report emphasised that the pharmaceutical industry, however, finds the cost of developing medicines for consumption by certain categories of population—especially children, older people, and pregnant and breast-feeding women—too prohibitive to be worthwhile.

A March 2005 survey undertaken by *HSCNews* on behalf of Netherlands group Vereniging Samenwerkende Ouderen Patiëntenorganisaties (VSOP) and the Brussels-based European Forum for Good Clinical Practice (EFGCP) [results reported in *HSCNews*, issue 16, March 2005, pages 5-28] asked European health campaigners whether they believed that the pharmaceutical industry conducted sufficient research into improving the quality of medicines for children. Only 5% of the 75 groups participating in the survey said "Yes".

One of that survey's respondents, Latvijas Kaulu Par Mums, the Latvian Rheumatic Organisation for Children

and Youth [<http://www.reimatik.lv/parmums.htm>], told *HSCNews* that pharmaceutical companies were “not good in this area”. Other groups declared that, until the arrival of regulatory intervention, or some form of coercion, the pharmaceutical industry would never develop medicines exclusively for younger people, since the market for such products is not profitable enough.

REGULATION OF CHILDREN'S MEDICINES

Another tangential, but related, matter rousing health campaigners into action is the regulation of children's medicines.

To date America is the only country worldwide that regulates medicines used by children. Yet in its publication “Regulation on Medicinal Products for Paediatric Use” issued by the European Commission on September 29th 2004, more than half of the medicines used to treat European children are untested and unauthorised for paediatric use. The result can be unfortunate side-effects. On June 1st 2006,

however, the European Parliament finally approved a regulation to improve the quality of medicines available to children in the EU (scheduled to be adopted by 2007). But experience from the US shows that such legislation will be difficult to enforce—in part, because of ethical concerns about (and physical difficulties in) testing drugs in children.

The Washington DC-headquartered Elisabeth Glaser Pediatric AIDS Foundation (EGPAF) [<http://www.pedaids.org>] was founded in 1988 by Elisabeth Glaser (wife of actor Paul Glaser) after her HIV-positive daughter died following an inability to access a drug that might have prolonged her life.

The EGPAF today is concerned to see that current research into vaccines for HIV/AIDS incorporate testing of the vaccines in infants and the young—as early as is “medically and ethically appropriate”. To this end, the EGPAF is working to develop guidelines for the inclusion of children in HIV vaccine trials. In addition, the group is supporting the passage of the Children and Family HIV/AIDS

Research and Care Act [S.1051, introduced to the Senate on May 17th, 2005]. The Act would direct the National Institutes of Health (NIH) and the Food and Drug Administration (FDA) to develop plans and guidelines for including children and teenagers in HIV vaccine trials.

“Ultimately”, reflects the EGPAF, “the failure to include these groups in clinical trials could mean significant delays in the availability of a paediatric HIV vaccine, at the cost of countless numbers of lives”.

DIAGNOSIS

Just over half of the respondent campaigners interested in children's issues informed the *HSCNews* December 2005-January 2006 survey that they would be campaigning about diagnosis. Rare-disease groups, in particular, professed themselves vexed with the length of time that children take to be diagnosed with an uncommon condition. A number of groups are therefore stressing that more intensive screening of newborn children could avoid unnecessary deaths.

The Newborn Screening Saves Lives Act (S.2663), introduced into the Senate on April 27th 2006, calls for better education of parents and an end to the US's inequitable access to screening facilities for newborns. The legislation was proposed by Senator Christopher Dodd and drawn up with the help of March of Dimes and the Alexandria, Virginia-based group, National Health Mothers, Healthy Babies Coalition (HMHB) [<http://www.hmhb.org>]. The latter is a membership organisation which draws its participants from all sectors of healthcare, including industry. The legislation has drawn widespread support from US rare-disease organisations.

HEALTHCARE REGULATION

Just under half of the respondent groups interested in children's healthcare indicated to the *HSCNews* survey that they are campaigning about healthcare regulation.

As mentioned earlier in this article, child health campaigners have been influenced by the longer-standing child advocacy movement, which attaches importance to fighting for the children's rights enshrined in the 1989 UN Convention on the Rights of the Child, and for representation of the views of children and the young in all policymaking matters.

In relation to health and healthcare, the Convention advises three types of rights:

(1.) resources and care (such as hospital care, food, warmth, safety, the loving care of parents); (2.) rights to protection from harm (for instance, from neglect and abuse, from fear, pain and loneliness, from excessive

ACTION FOR SICK CHILDREN'S MILLENNIUM CHARTER

1. All children shall have equal access to the best clinical care within a network of collaborating services.
2. Health services for children and young people should be provided separately from adults in child-centred environments, so that the young patients can feel welcome, safe, and secure at all times.
3. Parents should be empowered to participate in decisions about the treatment and care of their children through a process of clear communication and adequate support.
4. Children should be informed and involved to an extent appropriate to their development and understanding.
5. Children should be cared for at home with the support and practical assistance of community children's nursing services (unless they require care that can only be provided in hospital).
6. All staff caring for children shall be trained to understand and respond to children's clinical, emotional, developmental, and cultural needs.
7. Every hospital admitting children should provide free overnight accommodation for parents.
8. Parents should be encouraged to participate in the care of their sick child.
9. Every child in hospital shall have full opportunity for play, recreation, and education.
10. Adolescents will be recognised as having different needs to younger children and adults. health services should recognise the necessity to meet those needs.

[http://
www.actionforsickchildren.org/
aboutmillenium.html](http://www.actionforsickchildren.org/aboutmillenium.html)

medical interventions, and from the denial of necessary treatment); and (3.) rights to self determination (such as dignity, respect, integrity, non-interference, the right to make informed personal decisions).

However ahead of the UN, the European Association for Children in Hospital (EACH) [<http://www.each-for-sick-children.org>], an umbrella organisation for member associations specialising in the welfare of hospitalised children, formulated a charter of rights for hospitalised children. The EACH charter has since been refined and adapted by some of the Association's members, including English group Action for Sick Children, which espouses an individualised Millennium Charter [see box, previous page].

In the meantime, NGOs are exploring models for including children within healthcare decision-making processes. A November 2005 Brussels conference on children's health, organised by the European Public Health Alliance (EPHA), 'Future European: the Rights Start in Life', drew attention to an extraordinary attempt to incorporate children into local political processes. Named after the town in Norway in which it was initiated, the Porsgrunn Project has spread a message of childhood involvement in democracy throughout Scandinavia and beyond [see Feature 3, pages 34-35].

Another model, funded by the Commission, is <http://www.playdecide.org>. Visitors to the site can download a series of 'kits' on six scientific topics: stem cells; genetic tests; nano-technology; neuroscience; HIV/AIDS; and xenotransplantation. The kits can be used in debates and dialogues in science



YOUNG PEOPLE IN PORSGRUNN
HAVE A SAY ABOUT HOW
THEY LIVE

Source of photograph:
<http://www.hit.no>

centres, schools, and in the home. A similar and parallel website project allows children to understand the working processes and bureaucracy of the EU [see pages 47-48].

THE FUTURE

These are early days for the children's health movement. NGOs working in the subject area are still refining their campaigns, consolidating, and forging new alliances. Many of the disease-focused groups are likely to spin off new, separate entities solely concerned with children's issues.

The sector still needs to experience a greater, and more uniform, clarity of vision as to what precisely these groups want from policymakers. Additional consultation with (and presentation to) children and young people has to take place, too, before tomorrow's priorities can be determined.

Nonetheless, with children's health being widely regarded across the world as a subject of crucial significance, child health advocates are set to become one of the most important segments of the health campaigning community—with perhaps prevention and childhood lifestyles accounting for the largest element of that movement.



FEATURE ONE

INTERNATIONAL NETWORKS AND ALLIANCES OF CHILDREN'S HEALTH GROUPS

ADHD GLOBAL NETWORK(AGN)

<http://www.adhd-global.org>

Founded in 2003, an umbrella organisation for attention deficit hyperactivity disorder (ADHD) organisations worldwide. (ADHD is a developmental disorder that occurs in children.)

ASSOCIATION GENEVOISE POUR L'ALIMENTATION INFANTILE

<http://www.gifa.org>

The Geneva Infant Feeding Association (GIFA) is a pan-European group, and member of the International Baby Food Action Network [see below], adhering to similar principles.

AUTISM EUROPE

<http://www.autismeurope.org>

Founded in Belgium in 1983. Fights for the same rights and privileges for people with autism as are enjoyed by able European citizens.

BASICS

<http://www.basics.org/about.shtml>

A US\$100 million [Euros 80 million] government contract to fight needless childhood deaths in the developing world through effective child healthcare interventions.

CHILDREN'S HEART LINK

<http://www.childrensheartlink.org>

Founded in 1969, a Minneapolis-based medical charity dedicated to preventing and treating congenital heart disease. Works in partnership with medical centres worldwide.

CHILD-TO-CHILD TRUST

<http://www.child-to-child.org>

Acts as a central platform for the worldwide movement of healthcare and education workers who wish to involve children in health promotion activities (in and out of school). Located at the Institute of Education, University of London. Works closely with the University's Institute of Child Health.

CONJOINED TWINS INTERNATIONAL

<http://www.conjoinedtwinsint.com>

Founded in 1996, the only known support group for conjoined twins.

CYSTIC FIBROSIS EUROPE e.V

<http://www.cfww.org/cfe.index.asp>

Based in Germany, a federation of national European Cystic Fibrosis (CF) associations, and a subdivision of Cystic Fibrosis Worldwide [see below].

CYSTIC FIBROSIS WORLDWIDE

<http://www.cfww.org/>

An international platform for the exchange of ideas among CF groups worldwide.

EUROPEAN COUNCIL FOR ALCOHOL RESEARCH REHABILITATION AND EDUCATION

(EUROCARE) <http://www.eurocare.org>

An alliance of volunteers and NGOs concerned about the impact of the European Union on alcohol policy in Member States. Became affiliated to the Global Alcohol Policy Alliance in 2003. Founded in 1990 with 9 member organisations; now lists 55 members.

EUROPEAN ASSOCIATION FOR CHILDREN IN HOSPITAL (EACH)

<http://each-for-sick-children.org>

An umbrella organisation for member groups involved in the welfare of children before, during, and after a hospital stay. Member groups include 18 associations from sixteen European countries, and one Japanese group.

EUROPEAN CHILD SAFETY ALLIANCE

<http://www.eurosafe.eu.com/csi/eurosafe2006.nsf/wwwVwContent/12europeanchildsafetyalliance.htm>

An initiative of the European Association for Injury Prevention and Safety Promotion (EuroSafe), a consumer organisation.

EUROPEAN CHILDREN—OUR CONCERN (ECOC)

<http://www.ecoc.be>

A pan-European group. Supports children and young people with learning difficulties.

EUROPEAN NETWORK OF HEALTH-PROMOTING SCHOOLS (ENHPS)

<http://www.euro.who.int/enhps>

A Commission-backed project in collaboration with the World Health Organization and the Council of Europe. Develops approaches to health promotion and education within school curricula.

FAMILY HEALTH INTERNATIONAL (FHI)

<http://www.fhi.org/en/index.htm>

Formed in 1971, the largest and most-established NGO active in international public health. Has a mission to improve family health.

HEALTH NETWORK INTERNATIONAL (HNI)

<http://www.hni-paris.org>

A volunteer, non-profit, English-speaking organisation founded in 1993 for health professionals and members of the public concerned with healthcare subjects. Exchanges information and promotes professional development.

HELEN KELLER INTERNATIONAL (HKI)

<http://www.hki.org>

Aims to prevent the major causes of blindness in developing countries—cataract, infectious diseases (such as trachoma and onchocerciasis), and xerophthalmia (vitamin-A deficiency). Has begun to strengthen school-based strategies for eye health, including education, skill development, and service delivery. Also provides services to the visually handicapped and incurably blind.

INTERNATIONAL CONFEDERATION OF CHILDHOOD CANCER PARENT ORGANISATIONS (ICCCPO)

<http://www.icccpo.org>

Founded in 1994, a Netherlands-based group whose 80 member organisations represent children with cancer. These groups share information on how to build better links between the parents of children with cancer and health professionals.

INTERNATIONAL AICARDI-GOUTIÈRES SYNDROME (IAGSA)

<http://www.aicardi-goutieres.com>

Founded in 2000 at the Division of Child Neuropsychiatry at the University of Pavia, Italy. Allows parents to network. (AGS is a rare inherited trait, occurring in the first year of life, with symptoms of progressive encephalopathy.)

INTERNATIONAL BABYFOOD ACTION NETWORK (IBFAN)

<http://www.ibfan.org>

Public-interest groups working throughout the world to reduce morbidity and mortality in infants and young children.

INTERNATIONAL CHILDREN'S ANOPHTHALMIA NETWORK (ICAN)

<http://www.ioi.com/ican>

Parent-support group for families with a child with anophthalmia or microphthalmia (congenital conditions that affects the eyeballs).

INTERNATIONAL CHILDREN'S HEART FOUNDATION

<http://www.babyhearts.com>

Based in Memphis, Tennessee, spearheaded by specialists, and backed by a team of volunteers. Dedicated to helping children with congenital and acquired heart disease worldwide.

INTERNATIONAL CHILDREN'S HEART PATIENTS' FUND

http://www.pah.com.my/charities/cardiac_kids

Founded in 2000 by the Penang Adventist Hospital, Malaysia. Aims to assist children with heart ailments in neighbouring countries.

INTERNATIONAL KIDS FUND (IKF)

<http://www.internationalkidsfund.org>

A philanthropic programme of the US-based Jackson Memorial Foundation. Committed to helping critically-ill children (mainly in Latin America and the Caribbean) gain access to essential medical treatments otherwise largely-unavailable in their home countries.

INTERNATIONAL FEDERATION FOR SPINA BIFIDA AND HYDROCEPHALUS (IF)

<http://www.ifglobal.org>

Created in 1979 by national organisations of people with the condition and/or their parents. Has grown to embrace national organisations from over 40 countries.

INTERNATIONAL ORGANISATION OF YOUTH WITH RHEUMATISM (IOYR)

<http://www.ioyr.org>

Launched in 1995 in Berlin by 11 different nations. Represents young people with rheumatism. First and foremost a networking group.

INTERNATIONAL RESEARCH AND INFORMATION NETWORK ON CHILDREN'S HEALTH, ENVIRONMENT, AND SAFETY (INCHES)

<http://www.inchesnetwork.net/about.html>

Promotes healthy and supportive environments that protect the foetus and child from environmental and safety hazards.

KIDS RIGHTS

<http://www.kidsrights.info>

Formed in July 2003 as a Dutch Aid Organisation. Funds the projects of local organisations that provide children with basic necessities, including healthcare.

LA LECHE LEAGUE INTERNATIONAL (LLI)

<http://www.lalecheleague.org>

Founded in 1956 to help mothers breastfeed through mother-to-mother support.

MOVE INTERNATIONAL

<http://www.move-international.org>

Dedicated to helping children and adults with severe disabilities to sit, stand, and walk.

PARENT AS TEACHERS

<http://www.parentsasteachers.org>

Provides parents information about child development and parenting support. Headquartered in the US, with outlets in Australia, Canada, China, Germany, Mexico, New Zealand and the UK.

PARTNERSHIP FOR CHILD DEVELOPMENT (PCD)

Formed in 1992, and committed to improving the education, health, and nutrition of school-age children and youth in low-income countries. Based in the Faculty of Medicine, Imperial College, London.

VULNERABLE ROAD USERS ORGANISATIONS IN COOPERATION ACROSS EUROPE (VOICE)

<http://www.etsc.be/Voice.php>

A Europe-wide campaign to protect vulnerable road users, including children. Members are well-established NGOs.

WORLD ALLIANCE OF ORGANIZATIONS FOR PREVENTION AND TREATMENT OF GENETIC AND CONGENITAL CONDITIONS (WAO)

<http://www.world-alliance.org>

Founded in April 1994, an initiative of the US-based children's charity, March of Dimes, and the Dutch Genetic Alliance (VSOP). Aims to prevent, cure, and ameliorate genetic and congenital conditions through scientific endeavour and application.



FEATURE TWO

THE DETERIORATING HEALTH OF THE YOUNG

TOP TEN COUNTRIES FOR UNDER-5 MORTALITY

Country	Life expectancy at birth
Sierra Leone	34
Angola	40
D.R. Congo	41
Liberia	41
Afghanistan	43
Guinea-Bissau	45
Burkina-Faso	46
Niger	46
Somalia	48
Mali	49

Source: UNICEF

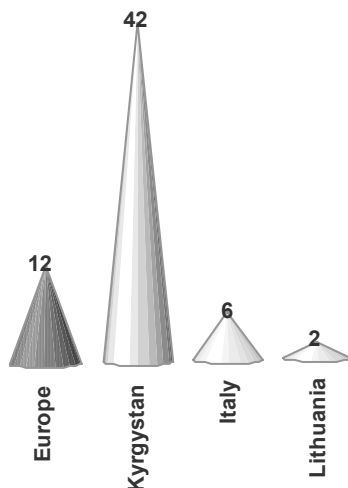
Across the globe, the state of children's health is generally perceived to be deteriorating. Mentioned below are some of the studies that reveal the scale of this alarming trend.

In developing countries

Despite the World Health Organization's concerted efforts to counteract malnourishment and childhood infectious diseases, children in the poorest regions of the world continue to be affected by malnutrition, diarrhoea, measles, respiratory diseases, and more recently HIV/AIDS. The UK Department for International Development (DFID) believes that around 2.2 million out of 11 million childhood deaths per year could be prevented through routine immunisation. Seven out of 10 deaths in under-fives in developing countries are due to respiratory infections, diarrhoea, measles, and malaria. Although developing nations have seen some improvements in child mortality over the past decade, child mortality continues to rise across sub-Saharan Africa. Around 30% of the region's children are undernourished, while 60% of childhood deaths from communicable diseases are compounded by malnutrition.

Burden of neonatal sickness in Europe (DALYs per 1000), 2002

DALYs = Disability-adjusted life years



Source: *The European Health Report 2005*, WHO Regional Office for Europe, Copenhagen, 2005.

In developed countries

Environmental pollutants, inappropriate diet, lack of physical activity, high levels of obesity, increased risk taking (including smoking, unsafe sex, and consumption of illicit drugs and alcohol) have combined to increase the incidence of chronic diseases and mental health problems in all pre-adult age groups.

In the US

The US infant mortality rate began to rise in 2000 after 50 years of decline, and is now higher than in many other industrial

**HEALTH AND HEALTHCARE
FOR CHILDREN
IN THE USA, 2005**

%	Under-18	All ages
Without coverage	9	16
No regular place to go for care	5	13
Fail to obtain needed care	2	5
Health not good	18	33
Asthma episode	5 [0-14 yrs]	4.2
<i>Source: National Health Interview Survey, CDC</i>		

**HEALTH AND HEALTHCARE
FOR CHILDREN
IN THE UK, 2005**

<ul style="list-style-type: none"> 1,300 young men committed suicide in 2005.
<ul style="list-style-type: none"> 5.2 million people in the UK are receiving treatment for asthma: 1.1 million children (1 in 10), and 4.1 million adults (1 in 12).
<ul style="list-style-type: none"> In England and Wales, 17 children per 100,000 develop diabetes each year. In Scotland, the figure is 25 per 100,000. Finland: 43 per 100,000. Japan: 3 per 100,000.
<i>Sources: DoH; Asthma UK</i>

countries (and on a par with Malaysia). Between 2004-2005, the National Center for Health Statistics at the US Centers for Disease Control and Prevention (CDC), the lead federal agency charged with protecting the health and safety of Americans, conducted its regular survey on children's health. The preliminary figures were released in June 2006 [see table, left]. The health of nearly one fifth of the population aged under 18 is described as "not good".

In Australia

On November 24th 2005, the federal Minister for Family and Community Services released the results of the government-funded Australian Early Development Index (AEDI), which looked at the development of 16,700 five year-olds in 25 communities. Measures of health, literacy, numeracy, behaviour, social and physical skills were assessed. The report found that nearly a quarter of Australian children could be developmentally at risk. Professor Frank Oberklaid, Director of the Victoria-based Centre for Community Child Health (CCCH), who launched the AEDI initiative, said "the first five years of life are critical to a child's life-long development, and communities who put effort and resources into those early years will reap long-term benefits."

In the UK

On September 15th 2004, the UK Department of Health released its National Service Framework (NSF) for children, young people and maternity services. Although the NSF was largely pushed through in response to children's deaths following shortcomings and failures within the National Health Service, the government also recognised that higher priority should be given to the healthcare of children.



FEATURE THREE

CHILDREN AND ADULTS AS CITIZENS TOGETHER

The Porsgrunn Project is not a new initiative. But it is a remarkable one, and deserves mention in this issue on campaigning for children's health, as it provides an example of how young people can be included in policymaking.

The background

The Norwegian town of Porsgrunn has maintained a focus on children's activities since the mid-20th century, when a 'Children's Day' was first established and run by voluntary organisations. For many of the town's children, the day became one of the most wonderful of the year. Then, in the 1980s, factory closure pitched the town into a period of unemployment and gloom. The town councillors of the day produced several initiatives to rebuild the town's confidence. Among the projects was an extraordinary attempt to incorporate children into local political processes. Over the next decade and a half, the scheme proved so successful that—as the Porsgrunn Project—it adopted the name of the town itself, and spread a message of childhood involvement in democracy throughout Scandinavia and beyond.

The Porsgrunn Project

The Project involves several arms active since the early 1990s:

- Older children are elected as full councillors to the Porsgrunn town council. At the first such election, in 1995, five young people aged around 18 were elected to the 49-strong body of councillors. At the most recent election, in 2003, three young people were elected. The policy of bringing young people onto the town council has allowed the town's youth and children to be incorporated into Porsgrunn's political and administrative activities.
- Every proposed town policy and new planning exercise has to be favourably matched against a test of child suitability (the 'Child test') by a full-time specialist council officer before authorisation and local implementation.
- Schoolchildren aged 6 to 18 are involved in local issues in Porsgrunn via their school-based Youth Councils. Children compete to sit on the Councils (which one Project worker describes as existing in their own right, "not at the behest of the headmaster"). The Councils, which are chaired and operated by the schoolchildren themselves, pass binding judgements on school matters—and beyond (covering subjects such as local parks, litter, road schemes, and street lighting).
- The town council awards Porsgrunn's children a yearly grant of several thousand Euros. The children have full control over this budget, and decide which town projects need to be allocated money. Porsgrunn's schools set aside time for the children to debate the destinations of these sums. The children's choices are unveiled at an annual town hall meeting, presided over by the children, and attended by the Mayor and councillors. Another Project worker explains the

reasoning behind the award scheme: “One main goal of the city-hall meeting (called ‘local negotiations for children and youth’) is for the children to be able to communicate with the local politicians. The meeting and the money marked for immediate actions motivates the children and youth to participate”.

The thinking behind the Project

The Porsgrunn Project represents a relatively new approach to preventive work for children and youth. The scheme is a practical, long-term manifestation of the belief that emphasis on childhood problems and on striving to protect children should be reduced in favour of attempts to exploit children’s innate abilities and to empower them (and their local communities). A project motto insists that “Children are to be seen as a resource, not a problem”—prompting a Project worker to write: “Children should be regarded as positive contributors to collective life, not as teenage muggers, hooligans, or truants”. Similarly, another such Project maxim states: “Every child is to be listened to, and to experience being heard in everyday life”—meaning, according to the same worker, that the Porsgrunn project does not limit childhood “involvement to the ‘bright’, the ‘capable’, and those who might become life’s ‘chosen few’”. This is a programme of maximum involvement by the maximum number”.

The Project’s main goal is the strengthening of local democracy. Porsgrunn’s children—dubbed ‘fellow citizens’ by the Project—are encouraged to assume responsibility and to engage adults, thereby developing a positive identity, a sense of belonging to society, and forming a habit of regular participation in decision-making processes. The previously-quoted project worker concludes: “The Project has had a huge impact on the self-belief of the children, and on their sense that they are indeed full partners in the political process. It has resulted in more children aiming to become members of Youth Councils, and in a closer understanding of how the town council itself operates. By the time that young people in Porsgrunn leave school, they know how the system works, are not alienated from it, and sense that they can affect its decision-making. Some take the next step, and opt to become councillors themselves”.

Influence beyond Porsgrunn

The Porsgrunn Project fits in well with UNICEF’s ‘Child-Friendly Cities’ initiative [<http://www.childfriendlycities.org>], and has been promoted by the Norwegian government for ten years. The Project has inspired numerous municipalities in Scandinavia to set up their own variants. One example can be found at Kempele, a Finnish rural town of 12,000 inhabitants. Seventeen young people representing their communities meet twice yearly at the town’s ‘mini children’s parliament’ to allocate Euros 5,000 [US\$6,200] to town projects of the representatives’ choice. The Finnish cities of Kokkola and Toijala also have child-participation projects, with children retaining responsibility for dispersal of a small element of city budget, and sitting as advisors to the city council on childhood and youth matters.

<http://www.ungdomsutvalget.no> and <http://www.lillestol.no/english>



Members' News

—**ALKOHOLPOLITIK [SWITZERLAND]**

A method of reducing the national consumption of alcohol among the young

—**EUROPEAN MEN'S HEALTH FORUM [BELGIUM]**

UK government signs up to Vienna Declaration on the Health of Men and Boys in Europe

—**INTERNATIONAL BABY FOOD ACTION NETWORK [UK]**

Nine groups combine to issue a statement against children's junk food

A POLITICAL METHOD OF REDUCING YOUTH ALCOHOL ABUSE

THE GROUP BEHIND THE NEWS

Founded in 2001, the Effretikon, Switzerland-based **Alkoholpolitik** disseminates information on the public-health and economic consequences of alcohol abuse. Although mainly Europe oriented, the site also contains significant amounts of material on the societal effects of alcoholism in the developing world, in North America, and globally.

<http://www.alkoholpolitik.ch>

The problem

Hermann Meyer, Publisher and Editor of the Alkoholpolitik site, sent a letter on June 9th 2006 to the Swiss newspaper, *Winterthurer Zeitung*, summarising some of the problems caused by excessive consumption of alcohol by Switzerland's young: "Young people's consumption of alcohol has risen substantially in the last 10-15 years, while the 'entrance age' at which children begin to drink alcohol has constantly been sinking. The result is alcohol-conditioned criminality, physical and sexual force, traffic accidents (with mostly innocent people as the victims), and difficulties inside families for partners and children". Mr Meyer elaborated on the theme in a June 7th 2006 letter to the Swiss Parliament, in which he asked Parliamentarians to increase taxes on alcoholic drinks as a means of reducing national consumption of alcohol (particularly among

younger people): "We not only have hundreds of thousands of alcohol-handicapped children, their future prospects in life disadvantaged by living in alcohol-damaged families, we also have an alcohol-damaged economy, an alcohol-damaged health service, and alcohol-damaged sport. We are an alcohol-damaged society. And we pay for it, each year, with billions".

Forces exacerbating the problem

The letter to the *Winterthurer Zeitung* drew attention to a selection of the forces that Mr Meyer believes are contributing to the growth in alcoholic consumption, including: "the globalisation of the alcohol industry; its development and marketing of types of drinks designed to win over young people (and, above all, women); the penetration of alcohol sponsorship into sport, which is often conducted in the proximity of the youth; and the myth of alcohol contributing to a sophisticated lifestyle—a contention largely supported by the media. The press, with few exceptions, has put itself on the side of the alcohol industry, and, for years, has prevented material, solution-oriented information and discussion. The press keeps knowledge low among its readership, and encourages traditional attitudes—which remain on a 'beer-table level'. The economy, too, promotes intoxication drinking. Naturally, the bad economic situation in Switzerland, with unemployment and many young people's hopelessness of obtaining places on training schemes, has brought about a feeling of 'no future ahead'—a tendency which only further entices the young into alcohol abuse".

A potential answer: the Alkoholpolitik Project

Mr Meyer pointed out in the letter to Parliament that a 1999 reduction in the cost of liquor in Switzerland resulted in a rise in alcohol consumption, whereas an increase in

the price of so-called 'alcopops' in 2005 caused consumers to drink fewer such products. Sweden's strategy of high prices for alcoholic drinks, he wrote, allows the country to claim half as much alcohol consumption as Switzerland. "Price strategy is not the only possibility of decreasing alcohol problems," emphasised Mr Meyer, "but the opportunity is now current in the Parliament's summer session. The Alkoholpolitik site develops a project idea that could defuse the problem to a large extent. In our country, practically all would win—as would the economy (because health brings prosperity)".

The Alkoholpolitik site's potential solution to excess consumption of alcohol is its Alkoholpolitik Project. The Project proposes an increase in excise duties on alcoholic drinks, with the extra revenue generated not vanishing into government coffers in the usual way. Instead, it would be placed in a social fund—an independent, accountable 'Foundation for Alcohol Politics'—from which money could be distributed as tax refunds to deserving causes that would benefit the public (such as the national old-age pension fund), and to projects that might help curb alcohol consumption. The Alkoholpolitik site sets out a suggested scale of tax increases per product. Stakeholders who would need to be canvassed for their views are listed on the site (for instance, Swiss winegrowers and farmers; health insurances companies; healthcare professionals; political parties; NGOs, etc). The Project floats the idea of publicising the tax increases at a national conference.

Benefits of the Alkoholpolitik Project

The Project would aim to "cover the social cost caused by alcohol in Switzerland; improve public health and the public's quality of life by reducing the damage wrought by alcohol; and boost young people's chances of reducing their alcohol consumption". Other benefits of the Project include: "The fact that more than half of the population would profit from a refund of the taxes should be a strong argument for acceptance. Plus, as soon as consumption of alcohol drops, everybody would get the benefit of reduced social cost. Sporting and cultural events forced to survive without alcohol advertising and sponsorship (and which have some sort of preventative character) could be funded by the Project".

Possible objections to the Alkoholpolitik Project

The Alkoholpolitik site agrees that consumers of moderate amounts of alcohol (over half of the population) could feel discriminated against, with their harmless tipple apparently demonised. However, it also stresses that these people would profit financially from the Project's tax refund, and by a reduction in personal healthcare costs (insurance, health insurance, and income taxes), while "their quality of life will rise as the roads become safer, and alcohol-related divorces, accidents, and crimes of violence are reduced".

The Alkoholpolitik site notes that the Project could be accused of bringing hardship to the poor without exerting any real deterrent effect upon the rich. "This", replies the site, "although correct for risk drinkers, is a wanted effect—consumption should go down. If the risk consumption of rich people is not reduced, that is regrettable, but the group comprises only about 5% of taxpayers, and is therefore not too important. Also, the rich mostly pay their own hospital costs themselves in private hospitals".

UK GOVERNMENT ENDORSES A DECLARATION ON MALE HEALTH

THE GROUP BEHIND THE NEWS

The Brussels-based European Men's Health Forum (EMHF) was set up in 2002 by the UK-based Men's Health Forum (MHF) to promote male health across Europe. The EMHF's executive committee represents the group's diverse European and national member organisations that maintain an interest in male health.

<http://www.emhf.org>

The 'Vienna Declaration on the health of men and boys in Europe' is a public call by the European Men's Health Forum (EMHF) for action on the subject of male-oriented healthcare provision in Europe. The Declaration is also an invitation for other organisations, bodies, and individuals to endorse the document's provisions.

The Declaration has already been supported by some prestigious institutions, including the European Patients' Forum (EPF), the European Medical Association (EMA), the European Union of General Practitioners (UEMO), and the American Medical Association (AMA). But perhaps the most significant endorsee so far is a government

department—England's Department of Health, which offered the Declaration official approval in May 2006. In a letter published on the EMHF website, the UK's Minister of State for Public Health wrote: "The Department of Health welcomes and supports the principles and aims of the Vienna Declaration. ... The Department recognises the importance of addressing health (and health inequalities) issues relevant to males across Europe. ... And the Department is committed to encouraging and supporting European initiatives to improve the health and well-being of males across Europe".

Vienna Declaration: http://www.emhf.org/resource_images/Viennadeclaration.pdf

MAJOR POINTS OF THE 'VIENNA DECLARATION ON THE HEALTH OF MEN AND BOYS IN EUROPE'

The Vienna Declaration was signed in Vienna in October 2005 by attendees at the European Men's Health Forum's first conference.

The Declaration makes three observations on the current situation for male health across the continent:

- ▶ Male use of healthcare information and services is surprisingly meagre throughout Europe.
- ▶ Europe's available healthcare and healthcare information does not always meet the needs of men and boys.

- ▶ Male health as a subject receives little research and investment.

The Declaration then requests that politicians in Europe do more for male health, including:

- ▶ Recognise male health to be a distinct and important issue.
- ▶ Help forge a deeper understanding of male attitudes to health.
- ▶ Invest in a 'male-sensitive' approach to the provision of healthcare.
- ▶ And "initiate work on health for boys and young men in school and community settings".

EU AND US GROUPS COMBINE AGAINST JUNK FOOD

THE GROUP BEHIND THE NEWS

Founded in 1979, the **International Baby Food Action Network (IBFAN)** is a truly global single-issue organisation with regional bases in most continents. IBFAN aims to improve the health and well-being of babies and young children, their mothers, and their families through the protection, promotion and support of breastfeeding and optimal infant feeding practices.

<http://www.ibfan.org>

A May 2006 joint EU/US government-level conference on good practice in diet and health generated a relatively unusual occurrence: a number of European and US groups came together to issue a consensus statement.

The EU/US Conference, 'Good Practices: Action on Diet, Physical Activity and Health', European Commission, Brussels, May 11th-12th 2006 was attended by high-ranking government officials, including Alex Azar, US Deputy Secretary for Health and Human Services, and Markos Kyprianou, EU Commissioner for Health and Consumer Protection. In the course of exchanging ideas on best practice in obesity prevention, conference attendees debated several ideas: tackling the condition's causes through public-

private partnerships; influencing young people's lifestyles and choice of foods; and considering whether further research on obesity prevention is necessary.

The conference inspired nine attending patient and consumer organisations—five European and four from the US—to combine to issue their own consensus call for changes in the marketing of food to children [for signatories, see next page]. The consensus statement emphasised four actions that governments could take to reduce popular reliance on junk food:

- National public-health authorities should create targets for reductions in the levels of fat, sugar, and salt in junk foods.
- Promotion of junk food to children (whether on TV, the Internet, or other emerging media, such as cell phones) should cease.
- Companies that manufacture foods of low nutritional value should end all marketing or other commercial activities in schools, and should also stop producing so-called 'educational materials'.
- Finally, governments should become aware of the dangers of working in partnership with the food industry, and thereby possibly allowing the food industry to gain influence over policymaking.

The nine organisations were united in their belief that governments must take the lead in the fight to cut children's consumption of junk food: "This is a time of public health crisis, and significant, sustainable action must be taken, commensurate with the severity of the problem. No public health epidemic has ever been resolved by individual responsibility alone. This one, too, will require government leadership".

Consensus statement: <http://www.babymilkaction.org/press/press12may06.html>

**SIGNATORIES TO THE MAY 2006
'CONSENSUS STATEMENT FROM US AND EU
CITIZENS' GROUPS ON THE MARKETING OF
FOODS TO CHILDREN'**

US

- ▶ Berkeley Media Studies Group (BMSG), Berkeley, California.
<http://www.bmsg.org>
- ▶ Centre for Science in the Public Interest (CSPI), Washington DC.
<http://www.cspinet.org>
- ▶ Consumers Union (CU), New York and Washington DC.
<http://www.consumersunion.org>
- ▶ Prevention Institute, Oakland, California.
<http://www.preventioninstitute.org>

Europe

- ▶ European Association for the Study of Obesity (EASO), London.
<http://www.easoobesity.org>
- ▶ European Heart Network (EHN), Brussels.
<http://www.ehnheart.org>
- ▶ International Association for the Study of Obesity (IASO), London.
<http://www.iaso.org>
- ▶ International Baby Food Action Network (IBFAN).
- ▶ International Obesity Task Force (IOTF), London.
<http://www.ietf.org>

Events

—**EUROCHILD**

**Non-Formal and Informal Learning Conference—
Key Aspects for Social Inclusion of Children
and Young People**

—**INTERNATIONAL FORUM FOR CHILD WELFARE**

WorldForum2006: Future Directions in Child Welfare

—**THIRD INTERNATIONAL CONFERENCE ON BIRTH
DEFECTS AND DISABILITIES IN THE DEVELOPING
WORLD**

Eurochild

presents a conference

Non-Formal and Informal Learning: ' Key Aspects for Social Inclusion of Children and Young People '

Tuesday November 14th to Wednesday November 15th 2006

Logenhaus,
12-13 Emser Strasse, D-10719 Berlin, Germany

This conference on non-formal and informal learning will compare national policy developments that affect three key subject areas: the fight against child poverty and social exclusion; cooperation in the field of youth policy; and implementation of the European Youth Pact.

The conference will highlight best practice on how to tackle social exclusion (and, in particular, ensure equal access to education).
The conference will exchange experience of policy approaches across the EU on how educational systems fight social exclusion by offering accessible, balanced learning contexts and participation opportunities.

Conference languages: English and German

Registration details will be forthcoming

For more information:

Jana Hainsworth, Secretary General, Eurochild
email: secretarygeneral@eurochild.org

Conference Partner

Berlin-based **Arbeitsgemeinschaft für Kinder- und Jugendhilfe (AGJ)**
[Child and Youth Welfare Association]

Eurochild AISBL

Promoting the welfare and rights of children and young people

A network of 35 member European organisations and people working to improve the quality of life of children and young people.

Eurochild is mainly funded by the European Commission (DG Employment and Social Affairs) and through membership fees.

53, Rue de la Concorde, 1050 Bruxelles, Belgium

Tel: +32-2-511-70-83 fax: +32-2-511-72-89

email: contact@eurochild.org

<http://www.eurochild.org>

The International Forum for Child Welfare (IFCW)

presents

WorldForum 2006

Seventeenth Annual Summit of NGO Child Welfare Leaders:

' Future Directions in Child Welfare '

Sunday November 19th to Wednesday November 22nd 2006

Fairmont Hotel Vancouver,
900 West Georgia St, Vancouver, British Columbia, Canada

This international conference will explore and share knowledge, information and data on promising practices and innovative approaches to prevention and responses to child abuse and neglect.

New trends and developments in child welfare practice, research and networking will be emphasised. The presentations will highlight practical and innovative solutions, cutting-edge research, and evidence-based practice.

Presenters of discussion papers and delegates from all parts of the globe will participate in this important event.

The involvement of youth as co-presenters is encouraged.

Registration fees include:

IFCW members \$450 students \$350

For more details:

email: worldforum2006@gov.bc.ca Tel: 1-866-660-9704 (North America only)

<http://www.worldforum2006.ca>

WorldForum 2006 is sponsored by the British Columbia Ministry of Children and Family Development, the International Forum for Child Welfare (IFCW), Alberta Children's Services, and the Child Welfare League of Canada (CWLC)

The International Forum for Child Welfare (IFCW)

A Costa Rica-based international NGO chartered in Switzerland, the IFCW was founded in 1989 "to strengthen national NGO child-welfare organisations worldwide through capacity building, and to collaborate on new initiatives on behalf of the world's most valuable resource—children."

The IFCW is funded through annual membership fees, cost contributions from members, foundation grants, and event fees.

<http://www.ifcw.org/mission.html>

The Third International Conference on Birth Defects and Disabilities in the Developing World

Sunday June 17th to Friday June 22nd 2007

Rio de Janeiro, Brazil

This conference hopes to raise the issue of the impact of birth defects and congenital abnormalities on people in the developing world. Up to 8 million children die annually as a result of birth defects. Most of the deaths take place in resource-poor countries, and many are preventable.

The conference will focus on:

- Medical prevention and care
- Establishing international networks for research and service
- Capacity building
- Public education for effective prevention and care of birth defects and disabilities

Individual programme topics will include:

- Networks of parents' associations
- Lifelong care and management of people with a disability
- Best practices in Latin America
- Newborn screening in the developing world
- Public health involvement
- Public health actions—cost-effectiveness
- Networks of genetic services
- The influence of alcohol, tobacco, and drugs
- Selected clinical cases

Registration details will be forthcoming

For more information, contact the Conference organisers:

JZ Congressos (attn: Monica Cevidanes)
Rua Guilhermina Guinle, 272 / 2º andar, Botafogo, Rio de Janeiro, Brazil

Tel: (55) (21) 2266-9150 fax: (55) (21) 2266-9175

email: genetic_conference@jz.com.br

<http://www.jz.com.br/congressos/2007/3rdconference/en/index.php>

Conference supporters

Brazilian Society of Clinical Genetics (SBGC)
Estudio Colaborativo Latino Americano de Malformaciones Congénitas (ECLAMC)
Escola Latino Americana de Genética Humana e Médica (ELAGH)

Main Sponsor

March of Dimes Birth Defects Foundation

Websites

—**DECIDE FOR EUROPE [EUROPE]**

A website that helps schoolchildren understand the European Union through role play

—**FUNDANIER [GUATEMALA]**

The foundation for Children with Renal Disease
....requests comment on a new website it is building

HELPING CHILDREN UNDERSTAND THE EUROPEAN UNION

The problem: a distant, seemingly irrelevant European bureaucracy

Comprehending the apparently complex structures and opaque political processes of the European Union can be challenging to most people. For children, the task is even more daunting. Generations of children have lacked the opportunity to learn how the bureaucracy of the European Union actually functions, and have grown up uninterested in the principles or practice of European governance.

A potential answer: the Decide for Europe website

In 2005, the European Commission funded the creation of a website that attempts to solve the problem of intellectual disenfranchisement from the European Union by explaining European government to teachers and schoolchildren. Called 'Decide for Europe', the website contains perhaps the simplest and clearest description of Europe's administration available anywhere. The site's downloadable documents make organisations and procedures of Byzantine complexity leap into sharp focus and assume relevance to real people's lives. Suggested role-play scenarios allow classes of schoolchildren to spend an hour or so pretending that they are chief decision-makers and functionaries within august European governing bodies—creating, debating and refining legislation of importance to the children themselves. The results of their endeavours can be uploaded onto the Decide for Europe site, occupying a slot alongside the output of hundreds of schools from every EU country. At the end of the exercise, the workings of the European Union will never again seem alien or convoluted to the participating 'bureaucrats', 'civil servants', 'ministers', and 'politicians'.

How the site works

After reading the site's brief explanations of the three major European Union institutions—the European Commission, the European Parliament, and the Council of Ministers—schoolchildren participating in Decide for Europe's role-play activities choose a subject or subjects worthy of receiving legislative attention. The site suggests some 30 potential topics (including children's rights, health, and space discovery). The children print off worksheets to record their 'decisions'. The site recommends that a classroom of children then conducts a sequence of four tasks:

- Sequence 1. The whole class acts as the various Commissioners and civil servants of the European Commission, drafting a piece of proposed European legislation that they believe would benefit Europe's citizens.
- Sequence 2. The class then splits into two. Half of the class acts as the politicians of the European Parliament, and amends the 'Commission's' proposal.

Simultaneously, the other half of the class acts as national ministers in the Council of the European Union, adding their own amendments to the Commission's proposal.

- Sequence 3. The 'Council' then discusses and votes upon the 'Parliament's' amendments, while the 'Parliament' discusses and votes upon the 'Council's' amendments.
- Sequence 4. The class returns together to write the final decision document, and upload it to the Decide for Europe website.

Follow-up activities for participating schoolchildren

To help the participating pupils build upon their experience of managing the reins of European government, the Decide for Europe site advises them to choose from a succession of supplementary ventures, including:

- Documenting the process of European governance by photographing (or videoing) the role play, writing a report about it, sketching out a comic book on it, or putting together a collage, and exhibiting the results at school.
- Further deepening understanding of issues discussed in the role play by inviting a politician, a lawyer, or other experts to school to discuss the proposed 'legislation'.
- Arranging and running a special open day at school, at which the 'legislation' is presented for the comments of parents and members of the local community.

<http://decide4europe.eun.org>

CONTRIBUTIONS TO THE 'DECIDE FOR EUROPE' SITE BY SCHOOLCHILDREN FROM ACROSS THE EUROPEAN CONTINENT

A sample of the written work and drawings sent into the Decide for Europe website by Europe's schoolchildren can be found on the site's 'Gallery' page.

One example on the subject of children's rights was written in English by Romanian schoolchildren: "Our concern for making public and respecting the children's rights is continuous. We think that even if great things have been done in this field, we should not give up. Many other things can be done in other areas, such as education. The right to education is one of the most important, and we believe that things can be improved here. We should get the skills and knowledge for facing life".

FUNDANIER (Fundación Para el Niño Enfermo Renal Guatemala—the Foundation for Children with Renal Disease) was formed in 2003 by a group of Guatemalan parents of children with renal disease. The group is concerned that children with the condition are poorly served by the country's healthcare system

FUNDANIER SEEKS SUPPORT IN BUILDING ITS WEBSITE

Fundanier—the Foundation for Children with Renal Disease—is a Guatemalan group that is currently building a website for its constituency. Fundanier has asked members of Health and Social Campaigners' Network International and subscribers to *HSCNews* if they would be kind enough to comment on this new site, <http://www.fundanier.org>

The Fundanier site—which is still largely under construction—is highly visual, with multimedia features.

PLEASE SEND YOUR COMMENTS (WHICH CAN BE IN ENGLISH OR SPANISH) TO *HSCNews* AT: info@patient-view.com

We will pass on all comments and suggestions to Fundanier.

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