

WORLD HEADACHE ALLIANCE:

STRENGTHENING PATIENT ORGANIZATIONS GLOBALLY - SPOG

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BACKGROUND

Headache disorders are real, common and exist everywhere in the world, and affect both sexes and all age groups. They are burdensome and often disabling. People with headache disorders experience reductions in work capacity and activities of daily life.

Unfortunately, headache disorders remain widely misunderstood and mistreated, often leading to increasingly disabling consequences. Barriers to effective treatment arise at all levels: a pattern of under-consultation by headache sufferers, under-recognition and under-treatment by medical practitioners, and mistreatment or misuse of analgesics and other medication resulting in further complications (Lipton *et al*, 2002; O'Brien *et al*, 1994; Lipton and Stewart, 1997; Stewart and Lipton, 1993; Edmeads *et al*, 1999; Castillo *et al*, 1999; Srikiatkachorn and Phathurachinda, 1997). As well, constraints, both perceived and real, exist within families, work places and society at large based on lack of understanding, stigmas and myths that surround headache disorders and their proper treatment.

Despite all of this, these disorders are remediable. Importantly, with appropriate intervention and treatment, the burden of headache is reducible.

In 2000, the World Health Organization (WHO) published *Headache Disorders and Public Health: Education and Management Implications* in which it recognized that

“Headache disorders generate a substantial disability burden and, therefore, should be classified amongst major public health disorders... there is a specific lack of public and professional awareness of the epidemiology of headache disorders and their impact on individual sufferers, their carers, family and colleagues, and on society” (WHO, 2000).

The recommendations from this publication included the need to develop global and regional education programmes to increase public awareness of the prevalence and impact of headache disorders. Collaboration with Non-governmental Organizations (NGOs) was highlighted as a means to adopt sufferer-focused and sufferer-driven approaches and address specific cultural issues. This collaboration bespeaks the need to involve patient organizations.

The World Headache Alliance (WHA) is committed to reducing the burden of headache world-wide. Working together with partner organizations, WHA strives to bring the genuine needs of people affected by headache disorders, their families and community, wherever in the world they live, to the attention of their governments; presenting the moral case and the persuasive economic argument for seeking to mitigate the burdens attributable to headache disorders; and, thereby, to achieve its aim to relieve these burdens worldwide.

WHA'S EXPERIENCE AND ACTIVITIES

WHA was formed in 1997 to alleviate the suffering of those with headache disorders around the world, in part by working with member organizations. In the intervening time until now, WHA has conducted a host of activities including two global conventions, the establishment of World Headache Awareness Month, the development and maintenance of a state-of-the-art website, and the provision of training workshops and material supports for government relations initiatives and media training.

WHA's international capacity-building planning initiative

With the generous support of the Pfizer Foundation, WHA undertook an evaluation of the practices, experiences and needs of awareness programmes and governmental-relations exercises of non-medical headache organizations. WHA produced a comprehensive working paper on the efficacy of its previous global headache awareness projects (WHA, 2001). An International Expert Panel, comprised of leaders from national lay headache organizations, prominent physicians and researchers from the headache community, was convened to evaluate the effectiveness of these programmes and the current state of headache awareness campaigns in various regions of the world.

A number of important messages emerged from this review. First, in many regions, headache disorders are not recognized as being either real or burdensome. The primary cause of this problem was believed to be the myths and misinformation communicated at all levels. Providing evidence-based factual information to counter these myths was identified as a key strategy that would improve the effectiveness of awareness initiatives in all regions.

Second, while some lay organizations had been quite successful in raising public awareness of the burden of headache in their countries and obtaining government support for headache sufferers, this was not generally the case. In many areas, government lobbying activities were in their infancy; in others, there was no activity at all, or recognition of headache as a health-care priority.

Third, while a substantial body existed of epidemiological data on prevalence of migraine in Western Europe and North America, studies on the prevalence of other headache disorders were lacking and no data at all existed for many areas of the world.

The Expert Panel recommended a full plan for WHA, in conjunction with its partner member organizations and other key stakeholders, to raise awareness of the burden of headache disorders by rolling out the core message within coordinated global capacity-building strategies (table 1).

Table 1: Best practices in raising headache awareness. Consensus recommendations of an expert panel convened June 8-9 2001 by the World Headache Alliance

1. **WHAT?** Headache disorders are:
 - real
 - common
 - occur everywhere in all age groups
 - burdensome
 - remediable (reducible by intervention)

2. **WHO?** This core message needs to be communicated to:
 - World Health Organization
 - governments
 - general public
 - businesses
 - health care providers
 - medical educators

3. **HOW?** **Step one, years 1 and 2: Raise awareness of the core message:**
 - Publish highlights from this meeting, including these recommendations, in a medical journal, either as a full article or as a letter to the editor; also, post them on the website and in newsletters/journals of the World Headache Alliance (WHA), WHA member organizations, and the International Headache Society (IHS); look to popular magazines and media as additional avenues to raise awareness of these recommendations
 - Collect all currently available data to support the core message
 - Publish a primary document, based on this evidence; obtain WHA board endorsement; translate, distribute and promote this document
 - Meet with stakeholders (IHS, European Headache Federation (EHF), WHO) to obtain their buy-in both for the message and for the need for them to communicate this message to their members; reactivate the WHO expert panel to work on filling evidence gaps to support the claims (see *On an ongoing basis* below)
 - Continue to raise awareness via the WHA website and member organizations
 - Use the WHA 2003 global convention to reinforce this message

Step two, years 3-5: Build global capacity:

 - Get the core message to the widest possible audience, the “WHO?” list (above)
 - Consult with and hire a public relations/communications company to create and implement a multi-tiered worldwide communications strategy, targeted to the specific needs of different global audiences

On an ongoing basis: Gather additional data to fill in the gaps where evidence to support the core message is lacking:

- Work in partnership with key stakeholders (WHO, IHS, EHF) with a goal to strengthening the evidence base. This includes:
 - 1) collecting additional data on international prevalence
 - 2) establishing proof of the cost-effectiveness of intervention
 - 3) establishing proof that intervention diminishes disability
 - 4) collecting comparative data on the relative merits of different drug treatments

Challenges

Utilizing the benefit of the thorough evaluation of past global campaigns and initiatives through this planning grant, WHA identified a number of challenges.

Whilst, as noted, collection of information to quantify the disability and burden of headache disorders has begun, it is predominantly restricted to the study of migraine in western societies. This leaves a substantial challenge to ensure all regions of the world are represented in the analysis. Those areas for which data are lacking must be identified, and then the gaps must be filled.

Bringing sound, representative data together is only the first step. Sharing this information requires articulation in useable appropriate forms and translation into a number of key languages. The accuracy and validity of the message and the subsequent translation especially for the non-medical audience must be ensured. After working with accredited professional translation services, WHA will enlist the support of member organizations where appropriate to check translation.

Finally and most importantly, one of the greatest challenges will be to support and encourage the efforts of the lay organizations. WHA's partner organizations face tremendous resource challenges. Over 90% have fewer than five staff and most are run on a completely voluntary basis (WHA, 2001). Providing follow-up, data collection and support will be essential to strengthening these organizations and to building their repertoire of skills to develop self-sustaining programmes.

Strengthening Patient Organizations Globally

In 2001, WHO published the *World Health Report* which outlined the *Global Burden of Disease* (GBD) (WHO, 2001). The GBD defined "burden" to include economic and emotional difficulties that sufferers and their families experience as well as the lost opportunities – the adjustments and compromises that prevent other family members from achieving their full potential in work, social relationships and leisure (Gallagher and Mechanic, 1996). While these human aspects of migraine have historically been more difficult to assess and quantify, they are nevertheless vital to understanding fully the implications of headache disorders.

Using the GBD methodology, WHO identified migraine among the top twenty leading causes of disability in the world. In fact, the report noted that migraine is estimated to account for 2.0% of years of life lost due to a disability in women of all ages. In both sexes of all ages, migraine is responsible for 1.4% of total years of life lost due to a disability. WHO's recognition of migraine as disorder of global importance is a major step forward in relieving the burden of headache world-wide.

Based on WHO's data, this work seeks to fulfil the first of the recommendations. Full discussion of the *World Health Report* forms the next section of this publication, portraying the collected evidence and distilling its implications into evidence-based supportable claims of the burden of headache.

Following this, WHA seeks to develop and promote a consistent core message to raise awareness and deliver programme components necessary to empower lay headache organizations around the world to target the primary stakeholders as the first audience. It is expected that the scope of this project will be global and appropriate for use in countries around the world.

Along with the WHO data, other studies in the US have long reported medical consultation rates of 50% or less (Lipton et al, 2002): that is, only 50% or fewer of those affected by headache disorders are in contact with medical care. In other parts of the world, medical consultation rates are even lower. Research studying prevalence and consultation patterns supports the belief that many sufferers from headache fail to achieve satisfactory reduction in their burden because, in part, of "complacent perceptions of headache disorders as minor, trivial and undeserving of treatment" (WHO, 2000).

Lay organizations play an important role in raising awareness. Knowledgeable about headache disorders, they are particularly well-placed to transfer the core message that headache is real, ubiquitous, common, burdensome and treatable. Regionally based, WHA's member organizations understand first-hand the cultural supports and barriers in their communities and the context of health-care-delivery and government systems, employment issues and perceived public stigmas.

OUR GOAL

WHA's overriding goal is to reduce the burden of headache disorders worldwide.

WHA works to achieve this in cooperation with our member organizations. By providing clear articulation of the core message that headache is real, ubiquitous, common, burdensome and treatable, WHA hopes to assist non-medical organizations effectively to address the burden of headache. WHA is well-placed to make use of the opportunity to present relevant topical information and the skill-training required to use this information to best effect. Once empowered with the skills and supports required, lay organizations will be charged with taking the message forward in the ways that will have best impact in their areas.

Utilizing region-specific research as well as the global perspective, WHA's training will familiarize member organizations with the information and techniques to frame responses conducive to raising awareness, to build articulate, accessible messages and to plan for successful dialogue with governments, thereby promoting access to quality health care and education worldwide.

While the key goal is to reduce headache burden globally, in order for each lay organization to work with WHA to establish a culturally-relevant initiative, the third section of this publication provides a template for review of a health-care system. By learning about the differences and similarities, representatives can formulate arguments and responses for consideration by health officials and their communities. For some, this may form the basis for an intensive campaign to lobby for legislative reform. Preparation of drafts appropriate for submission to

their government contacts may include recognition of the disabling nature of headache disorders and of the need for employment and other supports; for others, this may encompass a public awareness campaign addressing the prevalence and debunking the myths surrounding headache disorders; still others may be focused on educating primary health-care providers or lobbying for a greater allocation of resources to improve research and treatment options in their regions. Participants will identify the task most applicable to their goals at the outset to produce tangible efforts with assessable results.

WHA anticipates this Strengthening Patient Organizations Globally project will provide core strategies that will define transferable best practice structure on many levels: governmental affairs, key message development, media outreach, public awareness campaigns, targeted health literacy campaigns and program initiatives. In addition to providing valuable information for future global campaigns on headache disorders, WHA is confident that this structure will be transferable among headache groups with varying degree of capabilities as well as adaptable across disease lines, wherever patient voice is working to increase awareness and decrease burden of disease.

FUTURE PLANS

Continued dissemination of materials will become integrated into WHA's service delivery, specifically highlighted at the International Headache Congress (IHC2003) in Rome, Italy.

On an ongoing basis, WHA will remain committed to working with others to gather additional data to fill in the gaps where evidence to support the core message is lacking. This includes collecting further data on international prevalence, collecting comparative data on the relative merits of different treatments and establishing proof that appropriate interventions can cost-effectively diminish disability.

WHA looks forward to a major roll-out of the continued benefits from *Strengthening Patient Organizations Globally* project at the IHC2005 in Japan.

By articulating and communicating the core message that headache is real, ubiquitous, common, burdensome and treatable, WHA hopes to assist lay organizations effectively to lift headache's burden of misperception and under-treatment and promote access to quality health care and education world-wide.

APPENDIX 1**Member Patient Organizations**

WHA is proud to work in conjunction with 38 patient organizations from 26 countries:

ARGENTINA	ALCODOC ALUCER AAPCC CEFACLUB Hospital De Clinicas
AUSTRALIA	Brain Foundation Migraine and Severe Headache Support Group
BELGIUM	Ligue Belge contre les céphalées /Belgian League Against Headache
BRAZIL	Brazilian Headache Society
CANADA	Help For Headaches Fondation Québécoise de la Migraine et des Céphalées
COLOMBIA	ANEDOC ACODOC
DENMARK	Hovedpineforeningen
FINLAND	Suomen Migreeniyhdistys-Migranforeningen I Finland Ry
FRANCE	Club Migraine Et Céphalées
GERMANY	Bundesverband Deutsche Schmerzilfe e.V. MigraeneLign e.V. Deutschland
ICELAND	Mígremsamtökin
IRELAND	Migraine Association Of Ireland
ITALY	Associazione Italiana Cefalalgici Alleanza Cefalalgici (AICe Group - Cirna Foundation) Lega Italiana Cefalalgici -ONLUS
JAPAN	Japan Chronic Headache Organization
MALAYSIA	Headache Society Of Malaysia
NETHERLANDS	Nederlandse Vereniging van Hoofdpijnpatiënten (NVVMP)
NEW ZEALAND	NZ Migraine Sufferers Support Group
NORWAY	Norges Migreneforbund
PUERTO RICO	Fundación Puertorriqueña De Dolor De Cabeza
SWEDEN	Svenska Migränförbundet
SWITZERLAND	Swiss Migraine Trust Foundation/Migraine Action
TURKEY	Turkish League Against Headache
UK	Migraine Action Association The Migraine Trust International Headache Society
USA	ACHE (American Council For Headache Education) M.A.G.N.U.M.

VENEZUELA

Clinica De Cefaleas- Meridas HULA

YUGOSLAVIA

Yugoslav Migraine Association

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