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## World Headache Alliance: raising headache awareness worldwide

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**Abstract** The World Headache Alliance (WHA) works to reduce the burden of headache worldwide. Headache disorders are real, common and affect people of all ages, everywhere in the world. To reduce the burden resulting from untreated or mistreated headache disorders, WHA has developed initiatives to raise awareness. By increasing capacity of lay support groups to raise awareness and speak with their governments, WHA hopes to provide a conduit that will encourage sufferers to seek and have access to appropriate treatment. In its five-year history, WHA has provided a global stage for headache awareness

through: establishment of World Headache Awareness Month (WHAM), global conventions with training and support for governmental relations, media training and scientific review, a state-of-the-art Web site with strong Internet presence and sound, informative content, presentation of the Elizabeth Garrett Anderson Award, and speakers, posters and special lectures at professional congresses. Review of successes and lessons learned will steer WHA's initiatives for future success.

**Key words** Headache · Migraine · Burden · Disability · Patient · Awareness

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### Introduction

Headache disorders are real, common, disabling and burdensome, affecting people of all ages, everywhere in the world. The World Headache Alliance (WHA) is an international umbrella organization of lay or "patient-based" groups with 37 member organizations in 26 countries that provide assistance to people affected by the burden of headache in the area in which they live. Working with these organizations, and in cooperation with the International Headache Society (IHS), World Health Organization (WHO) and other non-governmental organizations, WHA raises awareness of the true nature of headache disorders and the resulting disability and burden realized by sufferers, their families, workplaces and communities. WHA exists to reduce the burden of headache worldwide.

Studies in the United States [1] have long reported medical consultation of 50% or less. In other parts of the world, medical consultation is even lower.

Research into the prevalence and consultation patterns supports the belief that many patients fail to achieve satisfactory reduction in the burden of headache disorders due, in part, to what the World Health Organization (WHO) refers to as "complacent perceptions of headache disorders as minor, trivial and undeserving of treatment" [2].

WHA acknowledges that the lack of awareness of headache disorders as being real, burdensome and, importantly, treatable, is a core contributor to low consultation. To address this, WHA's initiatives are developed to increase public awareness and government support to better meet the needs of people suffering with headache disorders worldwide. By increasing capacity of lay support groups to raise

awareness and speak with their governments, WHA hopes to provide a conduit that will encourage sufferers to seek and have access to appropriate treatment.

## Methods and materials

WHA provided a global platform for headache awareness through a number of initiatives. Member organizations were provided with materials, training workshops and networking opportunities to build their capacities to raise awareness. Materials included the printed and electronic How-To Kit for Governmental Affairs, Media Kit, 4-color posters with title translated into 22 languages, awareness ribbon kits, and informational brochures in English, French, Spanish, Portuguese, Japanese and German.

Capacity building workshops examined key message development and media relations, and provided live training sessions. A comprehensive media search in September 2000 assessed the success of the training.

A focal point of the 4-color poster, WHA's Web site ([www.w-h-a.org](http://www.w-h-a.org)) provides current information for the public and an intranet for maximizing interactions between WHA and member organizations. Usage was analyzed from WebTrends reports; placement on search engines was tracked throughout the year.

Analysis from a follow-up questionnaire provided valuable information on the organizational characteristics of each member group. The results were compiled and presented to an international expert panel in June 2001 [3]. Recommendations from the international expert panel were presented to WHA Council to facilitate strategic planning in March 2002.

## Results and Discussion

### WHAM

World Headache Awareness Month (WHAM) was first called in September 2000 to coincide with Headache World 2000, the joint meeting which encompassed WHA's First Global Convention, the Fifth Headache Congress of the European Headache Federation (EHF), and the Migraine Trust International Symposium. The Global Convention focussed on governmental relations with the development and distribution of a How-to Kit and a communications binder which contained clear, useable methodology. To supplement the campaign, a 4-color poster was developed to represent the components of care that reduce the burden for headache sufferers. The simple title, Headache, was translated into the 22 languages of member organizations.

The voluntary participation rate for the campaign was less than 30%. Although low participation marred the campaign, those who followed the template reported 100% success in achieving a proclamation from their governments.

Twelve governments on four continents supported the proclamations of the first World Headache Awareness Month. Proclamations were translated into French, Italian, Finnish, Yugoslavian and Spanish. Important to consider, of all member organizations, over one-quarter have no paid staff and less than 10% have more than 5 paid staff.

Subsequent campaigns have expanded by including ribbons with translated awareness cards in 2001 and a campaign to raise awareness of local ties to WHA in 2002 with the production of promotional leaflets in English, French, Spanish, Portuguese, Japanese and German.

### Elizabeth Garrett Anderson Award

Along with the first World Headache Awareness Month campaign, September 2000 heralded the first presentation of the Elizabeth Garrett Anderson (EGA) Award. Elizabeth Garrett Anderson, the first female physician in the UK, was compelled to write her doctoral thesis on a non-fatal illness as she was deemed too delicate to look on cadavers. Her thesis, *Sur la Migraine*, provided insights and treatment options that remain in use today. The EGA Award was established to recognize the woman whose lifetime achievements had helped reduce the burden of those affected by headache. The award is supported through an unrestricted educational grant from GlaxoSmithKline.

The inaugural EGA Award went to Dr. Marcia Wilkinson. Dr. Wilkinson established the City of London Migraine Clinic, translated and revived Elizabeth Garrett Anderson's thesis, and provided insights through her extensive research and publications. In doing so, Dr. Wilkinson is unrivaled as the leading woman in an area that affects the quality of life of women around the world.

The 2001 EGA Award was presented to Mrs. Jo Lidell, a headache sufferer herself whose support of others strengthened and guided the British Migraine Association (now known as Migraine Action Association) and led to the establishment of similar patient organizations in Ireland, New Zealand and Iceland.

Dr. Anne MacGregor was awarded the 2002 EGA Award. In her remarks, Dr. MacGregor noted that her in-depth exploration of menstrual migraine started from a challenge by Dr. Wilkinson. Dr. MacGregor's work in headache and hormones has been fundamental in helping women receive appropriate care. Dr. MacGregor was selected from the strongest nomination list to date: 8 nominees from 7 countries.

Each award presentation was spotlighted within the largest professional congress of the year, providing valuable recognition of WHA, the lifetime achievements of the winners and the true beneficiary of their efforts: the headache sufferer.

## Global Conventions

WHA has hosted two global conventions: first during Headache World 2000 and second during IHC2001. Each provided the opportunity to bring a large, diverse membership together to meet, share and learn from one another and from experts in advocacy, government relations, media and the latest research in the world of headache itself. The underlying premise for WHA's third global convention will be the core message of headache awareness: headache disorders are real, common, exist everywhere, affect both sexes and all age groups and are treatable.

In 2001, WHO published its annual World Health Report which outlined the Global Burden of Disease (GBD). Migraine was one of the twenty causes of years lived with disability in the world. In fact, the report noted that migraine accounts for 2.0% of years of life lived with disability in women of all ages. In both sexes and all ages, migraine is responsible for 1.4% of total years of life lived with disability. WHO noted that collaboration with non-governmental organizations (NGOs) is necessary in order to adopt sufferer-focussed and sufferer-driven approaches to education programs and address specific cultural issues. WHA will focus on an extensive project to strengthen patient organizations utilizing the research behind the World Health Report findings in 2001 in development of usable awareness tools to ensure the world better understands the magnitude of the burden of headache disorders.

## Web site

WHA provides the latest in headache information to the global community via its state-of-the-art Web site. Headache sufferers, their families and friends have an opportunity to speak directly to each other, find a patient group in their area or find links to relevant information elsewhere on the Internet. In 2002, the site hosted over 90 000 user sessions and total number of hits topped 2 million. With over 3000 unique users each month, the Web site's reach increased 96% from the previous year. There are over 200 articles, close to 250 links and content in seven languages.

When searching "headache" on Google, arguably the Internet's largest search engine, WHA appeared fifth after long-time leaders NHF, ACHE, AHS and IHS. Similarly WHA was third after NHF and the Excedrin Headache Resource Centre on AltaVista.

For 2003, WHA will strengthen the Web site's international appeal through additional translation, increased functionality of the intranet to improve interactions between member organizations and promotion of the discussion board as a forum for sufferers to speak directly to each other. WHA and IHS Web site Task Force continue to develop the global portal that will direct both professional and public visitors to quality information and provide greater visibility for member organizations at [www.headachehelp.org](http://www.headachehelp.org).

## Conclusions

Since 1997, WHA has developed and delivered initiatives to assist member organizations raise awareness of the core message: headache disorders are real, common, occur everywhere in all age groups and are both burdensome and reducible by appropriate treatment.

While some of these programs have yielded successful results, it is apparent that there is a great deal more to do. Dispelling the myths and overcoming stigma remain at the heart of the hidden burden of headache. Raising awareness is the key to a better understanding for sufferers, families, professional communities and governments. The importance of allocating appropriate resources to support research on incidence, prevalence, assessment and treatment as well as to ensure availability of effective treatment options cannot be overemphasized and requires substantial investment of time, energy and resources on behalf of the sufferer.

WHA will continue to build on its successes, learning from the lessons of the past:

*"Never doubt that a small group of thoughtful, committed people can change the world. Indeed, it's the only thing that ever has."* Margaret Mead

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## References

1. Lipton RB et al (2002) Migraine in the United States: epidemiology and patterns of health care use, *Neurology* 58:885-894
2. - (2000) Headache disorders and public health: education and management implications. World Health Organization, Geneva
3. - (2001) Best practices in raising headache awareness: global capacity building strategies. A World Headache Alliance Expert Panel Meeting Report. World Headache Alliance, Toronto