

How to develop a headache organization (WHA 2003)

Introduction

Headache disorders affect men, women and children everywhere in the world. They are often disabling and burdensome.

Developments in research in recent years have brought huge strides in the understanding of headache disorders and their management. But it may be many more years before "cures" emerge.

In the meantime, people with headache disorders and their families and communities need support and practical help. Creating a headache organization is one of the most effective ways to achieve help for the largest number of people possible. An organization can help to co-ordinate, guide and advise local activities. Once an association is up and running, it raises public awareness which leads to increased resources for both care and research.

First steps

Involve a few interested people—headache sufferers, their carers and professionals
Find out if your country already has similar organizations (ask Ministry of Health, WHA, WHO, Church)

Establish a contact name, address and telephone number

Organise a public meeting

Advertise the public meeting in newspapers, local radio, hospitals, clinics, pharmacies and libraries

Agree at the public meeting to setup an organization

Initial decisions

Form a small committee

Appoint a chairperson and treasurer with term of office

Nominate medical/scientific advisors

Hold regular meetings

Define initial aims

Divide up tasks

Establish priorities you need money for

Identifying aims and services

Your organisation may want to:

educate and raise awareness about headache disorders

help headache sufferers find quality care
provide community support for headache sufferers and their families
encourage the government to recognise the burden of headache disorders on the community and allocate resources to care, treatment and research
work with other groups to help headache sufferers around the world

To meet the aims established, you may wish to:

establish self-help groups
publish a newsletter
provide information
raise public policy issues with your government
set up membership to provide on-going support, communication (and raise money!)
provide support services such as helplines
offer training
raise awareness with public, media and government during Awareness Day/Week/Month activities
raise money to pursue the above aims and activities

Projects and activities

Find administrative/secretarial help (may need to be volunteer to start)
Advertise and appoint an Executive Director, if resources are available
Find space to maintain the organisation's records — an office or even a room or table will do to start
write a simple constitution (examples are available from WHA)

Useful characteristics of volunteers

Capacity to get along with other people
Experience and knowledge of the burden of headache disorders
Capacity to listen
Time to give
Business or fund-raising experience
Professional skills — e.g. doctor, social worker, nurse, psychologist, lawyer
Absence of major personal problems
People with energy, ideas and motivation
Willingness to learn and work

Recruiting volunteers

Ensure adequate preparation in the organisation before recruiting — by providing training, support supervision and practical resources such as phone, desk, chair and instruction manual!
Decide on role of volunteers in the organisation — caring, administrative, practical etc. and their relationship with paid staff
Agree on the skills needed by the volunteers — financial, PR (public relations), administrative, supportive, etc.

Think of where to find volunteers — other organisations in the community, colleges, universities, advertising in clinics, etc.

Consider how to find suitable volunteers — advertising, word of mouth, etc.

Decide what the organisation can offer volunteers — experience, satisfaction of meeting and helping people, training, etc.

Try to provide what volunteers want from the organisation — job description and satisfaction, information, guidance, support and recognition.

Likely reasons for needing money

Telephone

Answering machine

Fax

Postage

Rent of room/office

Computer equipment and email

Stationery

Photocopying

Travel expenses

Newsletter

Publications

Part-time or full-time person in office

Executive Director plus administrative assistance (ideally)

Ways of raising money

Subscription fees from members

Donations from members

National and local government grants

Grants from national religious organisations

Sponsorship from drug companies (but without conditions attached — WHA has policy guidelines to help)

Legacies

Sponsorships from business and industry

Fund-raising events

Direct mail

Donations in kind (services and office or other needed products instead of cash)

How to provide information

Answer enquiries quickly, efficiently and sensitively by telephone, letter and email

Have professional advice available

Prepare fact sheets

Develop publications for key stakeholders — public, people with headache, employers, government, funders

Circulate newsletter

Record videos

Offer helpline

Host web page or site

Ideas for a newsletter

Publish regularly — e.g. every 3 months

2-4 pages each issue

Include questions and answers regarding headache disorders

Call for letters

Highlight a personal account

Review an aspect of good lifestyle management

Use research article (WHA's website has wealth of material to choose from)

Interesting local and national events in your country

Information and advice on benefits and services

Information on national (or other) headache organisations and meetings

Funding and fund-raising information

Ensure an attractive appearance, perhaps photos

Include useful names and addresses

Review latest headache books

Avoid advertisements if finances allow (or contact WHA for policy guidelines on advertising and sponsorship)

Basic fact sheets and publications

Headache disorders backgrounder

The organisation and its aims

How to start a self-help group

Up-to-date research (see WHA's website at www.w-h-a.org for latest information)

written for people with headache disorders and those who care for them

Legal issues

Training materials — governmental affairs, clear language, media relations, etc.

Newsletter

Support services

Information and advice service — e.g. telephone helpline

Self-help groups

Government lobbying for treatment and research options, employment equity and disability protection

Instructional and support services to schools, clinics, and other groups

Work with headache clinics and physicians to increase value of patient visits through community support and follow-up

It is often difficult for small organisations with limited resources (both human and financial) to provide services. Look for opportunities:

to collaborate with statutory, voluntary and private organisations

to systematically provide training

to nurture and support your volunteers.

Ways of raising public awareness

Attractive, informative and understandable publications
Efficient information service
Membership campaigns
Newsletter circulation (try electronic newsletters as well as print)
People with headache and professionals giving public talks with slides/overheads
Open dialogue with politicians and forge links with governing and opposition members
Radio and television broadcasts
Staff telephone lines after media opportunities
Distribute posters and leaflets
Develop promotion materials: display stands, videos, T-shirts
Support research
Host awareness events –e.g. World Headache Awareness Month
Give the name and contact information for organization whenever possible.

Public policy issues

Establish high political priority for people with headache disorders
Increase resources (for treatment, government sponsored research, disability allowances) for headache disorders
Gain recognition by obtaining membership in World Headache Alliance
Create and improve services for people with headache disorders
Create and improve benefits for people with headache disorders
Encourage appropriate standards for care
Provide training and information in lifestyle management and support
Improve assessment and diagnosis

Research

Supporting research raises awareness
Both epidemiological and treatment research are important
Governments and non-pharmaceutical sources need to be encouraged to support research
Members need regular updated information

You can help by:

providing information to people with headache disorders
subsidising existing research activity
involving research scientists as advisors
ensuring focus of society remains on reducing the burden of headache disorders

How WHA can help you

World Headache Alliance (WHA) is a global cooperative of lay headache organisations from around the world whose mission is to reduce the burden of headache disorders.

WHA seeks to strengthen member organisations in their activities through capacity

building and encourage the formation of new associations where none currently exist.

WHA disseminates information, facilitates international training opportunities and networking meetings, encourages research and stimulates public and political awareness at national and international levels.

For more information email: info@w-h-a.org