



EPILEPSY

# action pack

A TOOL FOR CHANGE

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# EUCARE – past, present, and future

## Reflection & Reaction



### EUCARE—past, present, and future

The European Concerted Action and Research in Epilepsy (EUCARE) project was inaugurated in May 1998 in response to the publication of a paper by the Commission on European Affairs (CEA) of the International League against Epilepsy (ILAE), which set out appropriate standards for epilepsy care across Europe.<sup>1</sup> EUCARE was originally set up as a partnership between the CEA and the pharmaceutical company UCB SA. Members of the International Bureau for Epilepsy (IBE), which represents patients and carers, joined the team and an expanded scientific advisory board oversaw the programme. The objectives of EUCARE were to develop strategies for: improving the understanding of epilepsy, with emphasis on alleviation of its social consequences; promoting the exchange of knowledge between all disciplines that provide care for people with epilepsy; supporting research into the development, investigation, and management of seizure disorders; highlighting epilepsy as a public-health priority for governments and health authorities; and assessing the needs of affected individuals in order to identify the most effective organisation of health-care resources.

In 1998, leaders of European professional and lay organisations, representatives of WHO, and health experts from governments and universities came together under the auspices of the ILAE/IBE/WHO Global Campaign against Epilepsy to devise and adopt a European Declaration on Epilepsy.<sup>2</sup> As part of the Declaration, the Governments of Europe were urged to support the publication of a "White Paper" as a detailed public-health statement on epilepsy. This challenge was taken up by EUCARE, which brought together experts from 18 European countries to produce the document. The European White Paper on Epilepsy was launched at the European Parliament in Brussels on March 22, 2000. John Bowis, a Member of the European Parliament, announced on Nov 22, 2001, the formation of a political lobby group called Parliamentary Advocates for Epilepsy. More than 40 Members of

the European Parliament from all parties have pledged their association with this initiative, and representatives from WHO participated in its launch. In his presentation, Benedetto Saraceno, Director of the WHO Department on Mental Health and Substance Dependence, emphasised that "Initiatives such as the development and launch of the European White Paper on Epilepsy provide important tools to reduce the treatment gap in Europe". The White Paper was also formally endorsed by WHO.

The European White Paper on Epilepsy provides a summary, accessible to a lay readership, of the medical and lifestyle issues relating to epilepsy. It includes sections on epidemiology, diagnosis, treatment, living with epilepsy, quality of life, education, research, and epilepsy organisations. The book was originally produced privately, but it has now been published as a supplement to *Epilepsia*, the journal of the ILAE.<sup>3</sup> The White Paper was accompanied by a "Call to Action", available in 11 European languages, which invited intergovernmental bodies or institutions in Europe and individual Member States to implement and support the following three actions: to improve public understanding of epilepsy via educational programmes throughout Europe in order to raise awareness and reduce stigmatisation; to provide legislation to protect people with epilepsy from discrimination in the workplace in order to ensure equal job opportunities and thereby reduce the socioeconomic burden of the disorder; and to increase investment in epilepsy research to improve the diagnosis and treatment of epilepsy throughout Europe.

These publications are a valuable resource for raising awareness of the health-care requirements of people with epilepsy. EUCARE is developing an action pack to provide ILAE, IBE European chapters, and other organisations with the support, guidance, tools, and motivation they need to implement a political campaign in their countries. This pack will include information on how best to use the White Paper at a local level, how to

develop alliances, and how to handle the media.

After the publication of the White Paper, the scientific advisory board was formally disbanded. Discussions have taken place to develop a new EUCARE programme, the central project of which will be "An observational study of pharmacological outcomes and lifestyle consequences of newly diagnosed epilepsy in different countries of Europe". More than 100 EUCARE centres that diagnose, investigate, manage, and follow up patients will participate. A structured protocol will be devised, but no direct intervention will take place.

The aim of the programme will be to link patient outcomes with educational, scientific, and public-policy projects that will be designed and led by members of the new scientific advisory board. Some of these projects aim to maintain the link between EUCARE and Parliamentary Advocates for Epilepsy. Areas of interest include pharmacological response to antiepileptic drugs, progression of underlying brain dysfunction, and documentation of the effects of the diagnosis and treatment on everyday life. The programme, supported by an unrestricted educational grant from UCB SA, will be run by a management group that will report to the ILAE/IBE Joint Executive Committee. This project has the potential to develop a major resource of educational, scientific, clinical, and sociological data across Europe and represents a unique partnership between academia, patient-advocacy groups, and the pharmaceutical industry.

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#### References

- 1 Brodie MJ, Shorvon SD, Canger R, et al. Commission on European Affairs: appropriate standards of epilepsy care across Europe. *Epilepsia* 1997; 38: 1215–20.
- 2 European Declaration on Epilepsy. <http://www.elsevier.com/locate/healthdevelopment.chief1>. E-BOOK007 (accessed April 1, 2003).
- 3 Brodie MJ, De Boer HM, Ishikawa N. European White Paper on Epilepsy. *Epilepsia* 2003; 44 (suppl 7): in press.

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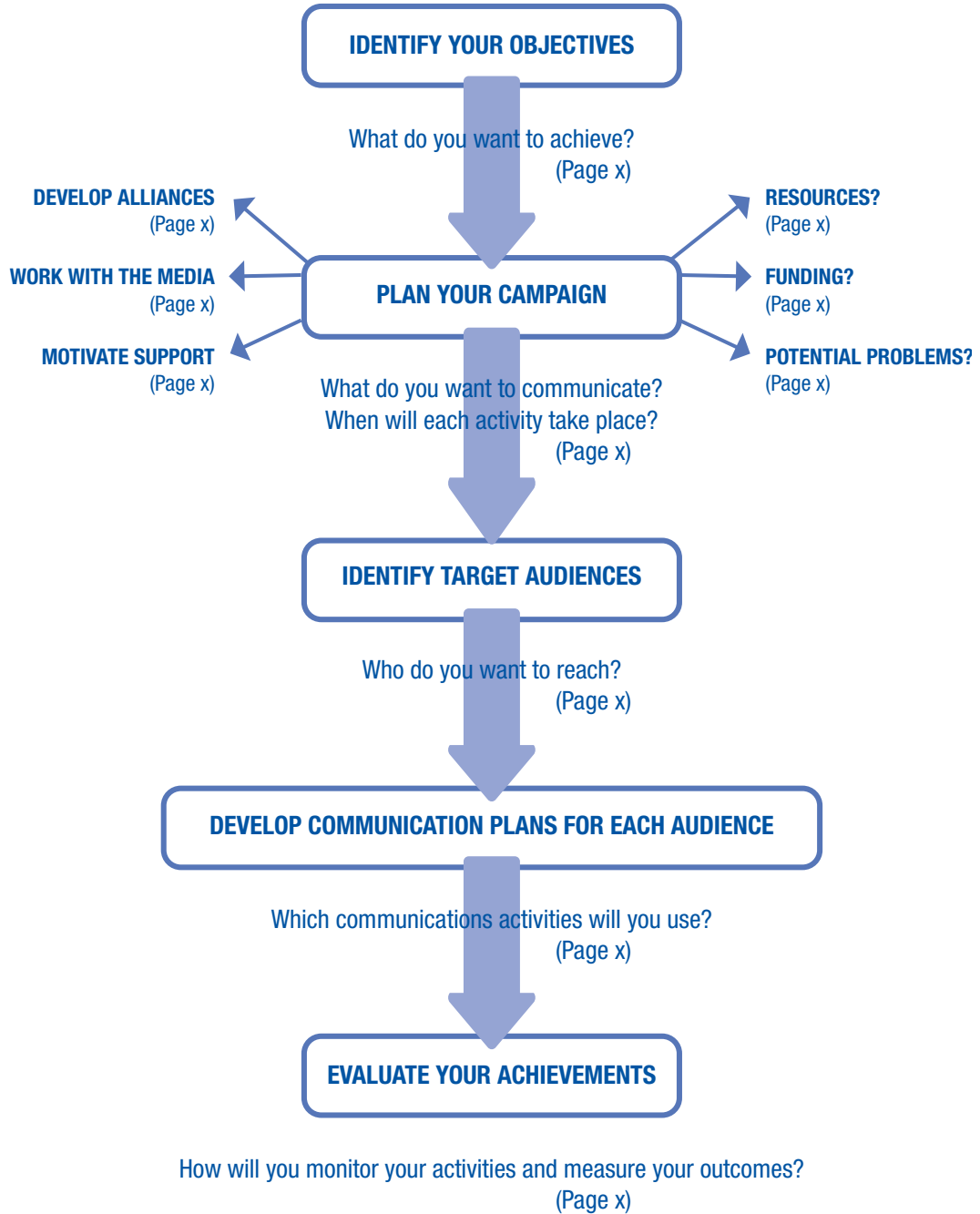
**EUCARE stands for European Concerted Action and Research in Epilepsy. It is a joint initiative of the International League against Epilepsy and the International Bureau for Epilepsy. Its aim is to raise the profile of epilepsy across Europe by undertaking new research and educational activities.** EUCARE is an initiative supported by an educational grant from UCB Pharma, Belgium

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# HOW TO TAKE ACTION Programme Plan



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# 1.0 Introduction

## 1.1 BACKGROUND

Epilepsy, the most common serious neurological condition worldwide, is surrounded by prejudices, discrimination and stigma and epilepsy services are poor in many countries.

***Governments and authorities consistently fail to recognise epilepsy as a priority.***

A recent inventory of epilepsy services in Europe revealed that ideal epilepsy care does not exist in any country<sup>1</sup> and that comprehensive care and epilepsy surgery, both essential services, are deficient in most areas. The alarming message from several countries is that even where services exist they are insufficiently used, or not available to many people with epilepsy.

The *ILAE* (International League Against Epilepsy) and *IBE* (International Bureau for Epilepsy), representing medical professionals and lay organisations, have established a cooperation on an international level which is considered exemplary. This partnership has gained the attention of the *WHO* (World Health Organisation) and led to the recognition that epilepsy is a major worldwide health problem.

This has created new possibilities and there are now a number of political reports adding another dimension to the work of local and international epilepsy communities. The publications of the 'European Declaration on Epilepsy' [*Appendix 1*], the 'European White Paper on Epilepsy' and its accompanying 'Call to Action' [*Appendix 2*] aim to put epilepsy on the political agenda at an international and national level throughout Europe.

***Declarations and the White Paper are not ends in themselves but tools which need to be used.***

The declarations and the *White Paper* are influential instruments. They have opened doors to Health Ministers, bringing epilepsy into national health plans in Georgia and Kyrgyzstan and stimulated epilepsy report publication in Germany and Switzerland.

However, despite these various initiatives, there has been no change in government policy in most countries relating to the 'Call to Action's' key recommendations [*Appendix 2*]. Feedback shows people are uncertain how to move the agenda forward. The *EUCARE White Paper Working Group* was formed to identify ways to increase the impact of the European *White Paper* on Epilepsy.

This Action Pack was developed to help you to take an active role in shaping the future of epilepsy policy and services throughout Europe.

Reference 1: Malgrem K *et al.* The Provision of Epilepsy Care across Europe. *Epilepsia* 2003; 44(5): 727-731.

## 1.2 ABOUT THIS ACTION PACK

**This Action Pack is designed to assist all epilepsy organisations and individuals to improve epilepsy care by:**

- *Using the European White Paper on Epilepsy*
- *Developing political support*
- *Running media campaigns*
- *Working with other professional organisations*

We encourage you to commit to such projects with the confidence and belief that **YOU** you can make a difference. You should believe that, with practical guidance and motivation, crucial changes can be effected that will make a real difference to people living with epilepsy.

This Action Pack outlines the steps essential for an effective campaign. It contains advice with real examples provided by the epilepsy community [*Examples of Best Practice, Case Studies*]. The appendices contain templates for you to adapt.

## 1.3 HOW TO USE THIS ACTION PACK

- *Select the parts that you find useful*
- *Follow successful ideas and examples of others*
- *Adapt these to suit your own issues*
- *Be innovative, committed and positive*
- *Be prepared to take ACTION*

**Action is required in all parts of Europe to improve the quality of life and care for people with epilepsy.** The ground has never been so well prepared with many dedicated people willing to cooperate. The preconditions are there - the rest is up to you!

***What will be your contribution?***

**Hilary Mounfield**  
Chair IBE European Committee

**Peter Wolf**  
Chair EUREPA

NB: To assist your understanding of this document some less common words (shown in italics in the text) are *defined* in the Glossary [*Appendix 12*].

## 2.0 Effective Communication

Communication is the process of exchanging information or ideas between individuals and groups and is a skill you must master if you wish to effect change. **Only via effective communication can you educate and shape opinion.** You will need to influence others in order to transform your ideas into practical actions.

The principles of good communication in the field of epilepsy are no different than for any other area:

### **THE PRINCIPLES OF GOOD COMMUNICATION**

- Design specific **campaigns** for different audiences
- Adapt key messages for different audiences
- Enlist the support of the most influential and credible people
- Choose the best method of communication (e.g. meetings, publications or media)

### 2.1 OBJECTIVES

Your objectives are your ambitions and the purpose of your *campaign*.

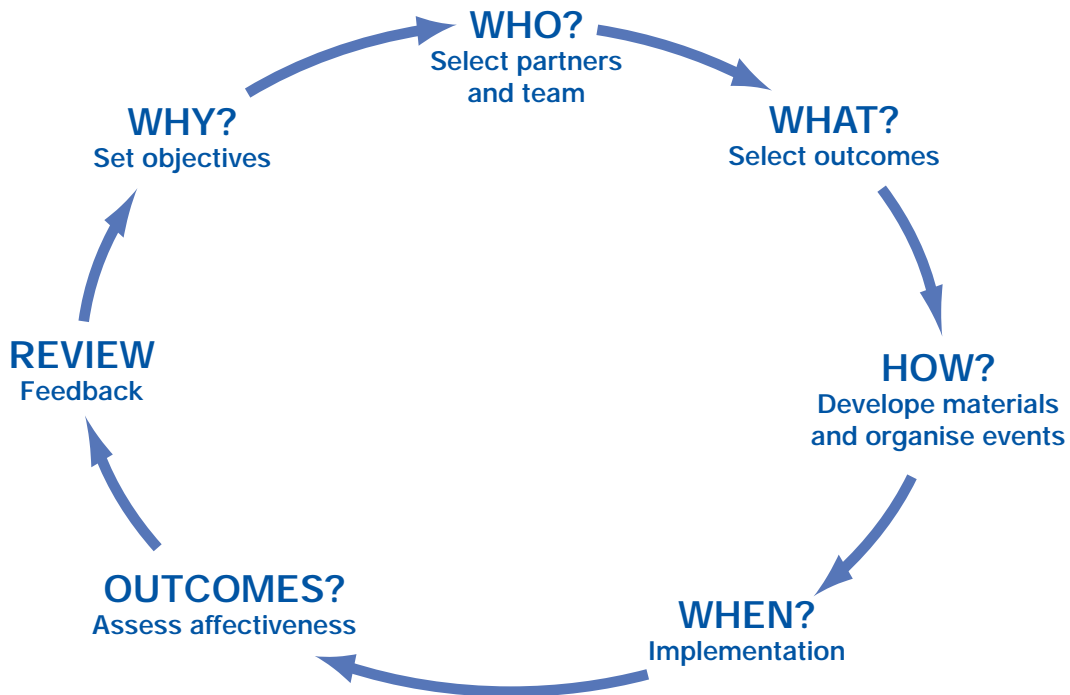
- Clearly **define** your objectives and desired **outcome(s)**
- Be specific and remain focused on these objectives
- Set realistic and measurable goals
- Set a **timescale** for achieving your objectives

**When working with governments and large institutions, plan for small steps incrementally over a long time, perhaps even years.**

## 2.2 THE COMMUNICATION PLAN

Working to a clear plan improves your chance of success and helps the preparation. Effort invested in the research and planning can be key to making your *campaign* effective. Involve others in the planning process to obtain their commitment and use your plan as a tool for presentations and discussions. [Appendix 3]

### ELEMENTS OF A COMMUNICATION PLAN :



#### TIPS FOR GOOD PLANNING:

- *Know your plan in detail*
- *Be able to provide a summary*
- *Anticipate any issues that may result*
- *Be able to respond to and answer concerns*
- *Keep others informed and involved*
- *Use other peoples ideas to strengthen your plan*
- *Identify the people and organisations in your community who can offer support*

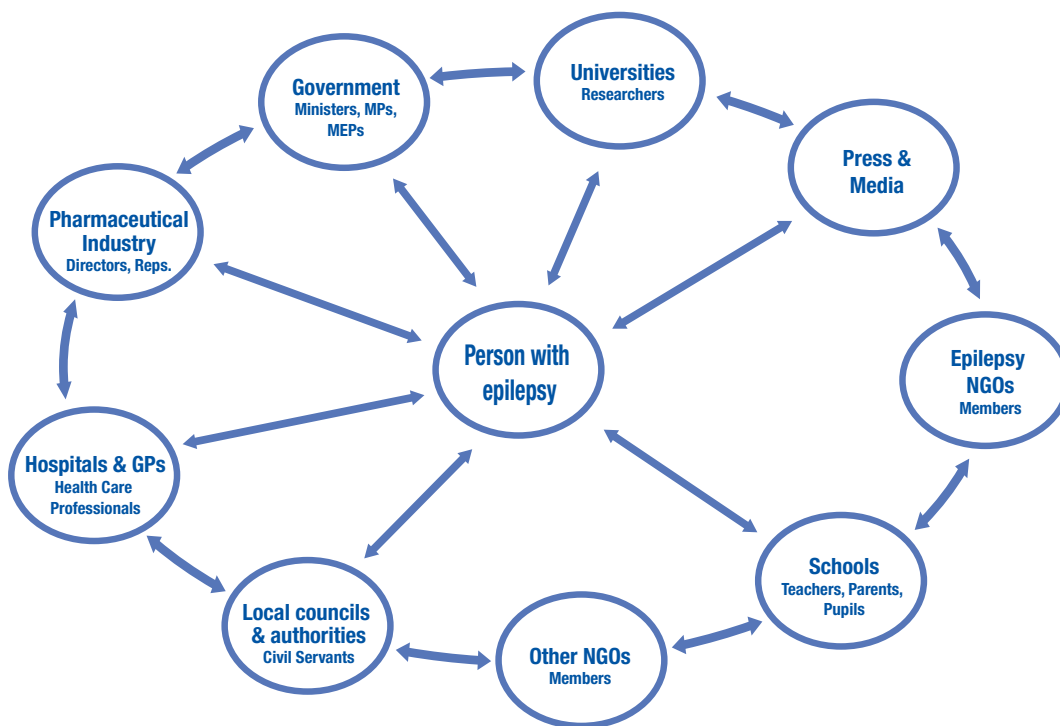
## 2.3 TARGET AUDIENCE

### Who should you influence?

**It is important to address the right people at the right time.** First identify organisations or institutions that can enable you to attain your objective. Then identify the departments and individuals to contact.

Some examples follow of the many people that may be implicated in developing policy concerning epilepsy:

#### POTENTIAL TARGET AUDIENCES:



**Build your strategy by developing a sound knowledge of your key audiences. If a group is new to you then find out as much as possible about them and their attitudes.** [Example of Best Practice, Case Study 1, Brainwave: The Irish Epilepsy Association’s Campaign to change the driving regulations for people with epilepsy in Ireland]

## 2.4 KEY MESSAGES

Each day public officials are bombarded with large amounts of information in the form of meetings, letters, emails, documents and *briefing papers* [Appendix 4]. Only a fraction of these will be remembered. Find a way for your message to create impact in a memorable way.

**Your message should directly address the problem you want to solve.** When defining your message, keep it simple. Below are a few suggestions:

### **DEFINING YOUR MESSAGE:**

- *Present the basic facts on epilepsy*
- *Dispel myths and misinformation*
- *Put a face and a voice to epilepsy*
- *Illustrate how epilepsy affects day to day life*
- *Explain the stigma associated with epilepsy*
- *Explain the importance of having a proper diagnosis*
- **Define** *what a person with epilepsy needs in terms of provision of care and treatment*
- *Describe the local access to treatment and services*
- *Tell people where to find more information*
- *Direct your audience as to what you want them to do*

Medical terminology is particularly complicated. Words that you use everyday may not be understood by someone with little or no experience of healthcare. Ask a non-medical person to read your text and tell you if there are any words they do not understand.

### **MESSAGE COMMUNICATION**

- *Create impact with a powerful, simple message*
- *Ensure your message is relevant to your audience*
- *Do not present more than three key messages*
- *Present your message in a memorable and exciting way*

*[Example of Best Practice, Case Study 2, 'Campaigning for Better Services', Swedish Epilepsy Association]*

## 2.5 COMMUNICATION TOOLS

Once you have decided who you need to reach and what you want to say, you must choose the appropriate medium by which to do this.

Workshops and printed materials allow more data and background information to be presented. Present detailed information only if you have time and it is relevant to the audience.

### Options for communication

TOOL	DEFINITION	AUDIENCE
Press Release	Short summary of news story	Journalists, television
Press pack	Contains background information and more detail	Journalists, television
Report	Detailed research and analysis on a topic	Governments, academic institutions
Letter	Personalised formal communication	Tailored to individuals and signed personally
e-mail	Direct informal communication	Personal or wide circulation
Internet website	Versatile	General public
Leaflets	Targeted summary of information	General public
Conference	Open forum for presenting new ideas	Professional and lay groups
Meeting	Focused subject usually by invite only	Small groups – defined representatives
Workshop	Closed forum for debate and discussion	Small selected groups
Television broadcast	Covers subject in simple terms	Broad and large audience

## 2.6

### KEY POINTS

- *Set clear realistic objectives*
- *Prepare a detailed plan*
- *Know who you want to influence*
- *Keep your message simple*
- *Use appropriate method and material for your audience*

## 3.0 Public Relations

Public Relations (*PR*) is the skill of delivering your message to your target audience, using influential **third parties**. *PR* is a powerful and flexible tool. Plans can be changed in response to developments to take advantage of new opportunities.

To use this technique you must identify and build relationships with **opinion leaders** who will communicate on your behalf.

***Third party endorsement will add credibility and greatly increase the impact of your message.***

### **EXAMPLES OF OPINION LEADERS IN EPILEPSY:**

- *Person with Epilepsy*
- *World Health Organisation (WHO)*
- *International League Against Epilepsy (ILAE)*
- *International Bureau for Epilepsy (IBE)*
- *Members of the European Parliament (MEPs) and representatives of European Commission*
- *Members of Parliament (MPs) and Ministers of Health*
- *Local Health Authorities*
- *Local epilepsy experts*
- *Local Patient Organisations*
- *Press and media*

Decide which key third parties will add most weight to your message. Approach organisations or key persons via the appropriate channels. Politely explain your *campaign* and enquire about procedures for securing their endorsement. Building relationships takes time and you may need to arrange several meetings to identify how their experience and contacts can best benefit you.

Create a mini-database for each person, listing contact numbers, information on the area of their work and special interests. Always document all relevant contacts.

### 3.1 WORKING WITH THE MEDIA

The media is an extremely influential communication vehicle, playing a key role in raising public awareness and setting the political agenda.

**The media generally comprises:**

- *Printed e.g. newspapers and magazines*
- *Broadcast e.g. television and radio*
- *Digital e.g. internet*

Media varies considerably in different countries. You should be familiar with all the newspapers, magazines, television and radio outlets in your area before preparing a strategy. Keep a comprehensive list of the media, its audience/readership, story types and illustrations used [Appendix 5] together with key contacts [Appendix 6]. Do not forget electronic media (Internet).

***Competition for media coverage is strong – adapt your story for the media channel.***

### 3.2 GETTING THE BEST FROM THE MEDIA

***FOLLOW BASIC PRINCIPLES FOR MEDIA SUCCESS:***

- *A strong, newsworthy story relevant to a significant proportion of the audience*
- *A good **news ‘hook’** – i.e. significant or unusual story angle to grab interest*
- *Independent endorsement of your story*
- *Personal stories to illustrate your message [Appendix 7]*
- *A Press Pack for providing background information (including facts and figures)*

### 3.2.1 HOW SHOULD YOU CONTACT THE MEDIA?

Start with your local newspaper or radio station. It is usually easier to get published in a local paper. All newspapers contain contact information. Firstly telephone and ask for the science or health reporter or contact a journalist who has written other articles on similar subjects.

#### **A POSITIVE ATTITUDE WILL HELP DEVELOP GOOD CONTACTS:**

- *Be confident to inspire belief*
- *Be clear and **concise** – avoid **jargon***
- *Keep control*

Journalists often ask the wrong questions. Acknowledge their question but take opportunities to emphasise your messages. Stick to what you consider to be relevant. [Example of Best Practice, Case Study 3, 'Handling Negative Media', The Slovenian League Against Epilepsy, turning negative media into an opportunity]

### 3.2.2 WRITING FEATURE ARTICLES

Feature articles are an excellent way to raise the profile of issues. They do not date and can tackle subjects in greater depth. Offering a feature involves negotiating and 'selling' the idea to an editor. Use your contacts! You will need to prepare your arguments in advance on the relevance of your story for the publication involved and why it is of interest its readership. Sometimes you will need to submit a proposal before the article is agreed.

***An unusual or dramatic story will hold more interest and impact*** [Appendix 8]

### 3.2.3 LETTERS TO JOURNAL EDITORS

Issues can also be raised by writing letters to The Media.

#### **USE THE FOLLOWING STYLES:**

- *Form a strong expression of opinion*
- *Keep the letter short and impactful*
- *Respond to previously published articles or information*
- *Request an **Opinion Leader** to write in support of your **campaign***
- *Obtain signatures of a number of parties representing different interests*

Editors sometimes edit your letters before they are published [Appendix 9]

### 3.3 MEDIA SPOKESPEOPLE

Developing successful media relations requires the involvement of ‘*experts*’ who are prepared to attend press *briefings*, talk to journalists and present at meetings; their credibility is based upon their position as independent third parties.

***Ensure that all spokespeople are comfortable and effective in dealing with the media [Appendix 10] by:***

- *Providing careful **briefing** in advance*
- *Preparing the communication of key messages*
- *Ensuring that they agree with your objectives*
- *Working together on their presentations or statements*
- *Rehearsing questions*

Professional training will improve the natural communication ability of your spokespeople so that their support is communicated strongly. [Example of Best Practice, Case Study 4, ‘Promoting Epilepsy Awareness’, Swiss League against Epilepsy and epi-suisse]

**KEY ASPECTS OF MEDIA TRAINING INCLUDE:**

- *Methods of communicating support while maintaining credibility*
- *Techniques to ensure key message communication*
- *Techniques to avoid being diverted*

### 3.4 PREPARING PRESS RELEASES

Hundreds of media releases are sent to editors every day. To ensure that yours stands out, design your Press Release [Appendix 11] to be:

- *Impactful with strong headline and first paragraph*
- *Newsworthy*
- *Well-written*
- *Relevant and suitably targeted*

Include key facts in the first paragraph, informing the reader of:

- **WHAT** (*the essence of the story*)
- **WHO** (*key individuals or organisations involved in the story*)
- **WHEN** (*the day or week in which the story 'occurred'*)
- **WHERE** (*location or publication where story originated*)
- **WHY** (*the importance of this story*)

More general information should come after these facts and attach a background Fact Sheet.

**Use a quote from an independent spokesperson to communicate your most important messages.**

*e.g. Hilary Mounfield, Chief Executive of Epilepsy Scotland said: 'The misdiagnosis for epilepsy is very high so it is crucial that patients see a specialist as soon as possible.'*

Personal opinion gives the Press Release impact and increases the chance that the story will be followed up. Obtain approval in writing for any quotes from the people concerned.

### 3.4.1 IMPORTANT CHECKPOINTS FOR A PRESS RELEASE

- Clearly titled '**PRESS RELEASE**'
- *Impactful title*
- *Use short sentences*
- *No longer than 500 words*
- *Include quotes from **experts***
- *Case studies and photographs to illustrate*
- *Names and details of at least 2 contacts for further information*
- *Date*
- *Additional background sheet*

Date it for the day on which it will be read. If you do not want the information to appear until a later date, mark the release '**Embargoed**', with a note of the time and date when it can be printed, e.g. 'Embargoed for: 00:01 hours, 12 November'. (Note: Just after midnight is the standard *embargo* time to ensure that new stories are first heard in early morning bulletins and do not 'break' late in the evening.)

### 3.4.2 TAILORING THE PRESS RELEASE TO THE AUDIENCE

Decide if your story has national, international, regional or local interest. Produce tailored Press Releases for different media sectors (e.g. medical press, consumer press, political press). Decide which aspects of your story will most interest different audiences, and tailor the Releases accordingly. Include quotations from spokespeople in the relevant sector (e.g. a nurse for a nursing journal). Distribute the Press Release appropriately.

### 3.4.3 CASE HISTORIES

Case histories are useful to illustrate a point and ‘personalise’ a story [Appendix 7]. Include this in the Release or attach it separately. Obtain written permission from any person agreeing to be featured in a newspaper or act as a *spokesperson* on radio or TV before releasing their details to the press. A personal story creates more interest amongst the general public and policy makers alike. People with epilepsy and their families make very effective campaigners. In addition, acting as both *spokesperson* and campaigner can be a very positive step. [Example of Best Practice, Case Study 5 ‘Using your voice, A fruitful cooperation between a person with epilepsy and the Danish Chapter’]

### 3.4.4 PHOTOGRAPHS

Photographs often assist in obtaining good quality media coverage. Indicate photograph availability on your Press Release or distribute them simultaneously. Invite a press photographer to your event or arrange photographs to be available for the media as soon as possible after the event. Label any photographs with names, titles, date, etc.

### 3.4.5 TIMING

Timing a Press Release depends upon when you want media coverage and the frequency of issue of your target publications. If targeting daily newspapers, send your Release no more than a day or two before you wish the story used. Stories in weekly and monthly publications will follow. For stories aimed principally at the medical press, dispatch the Release three or four days before you want it to appear. Remember all journalists work to tight deadlines, check these for your target publications.

## 3.5

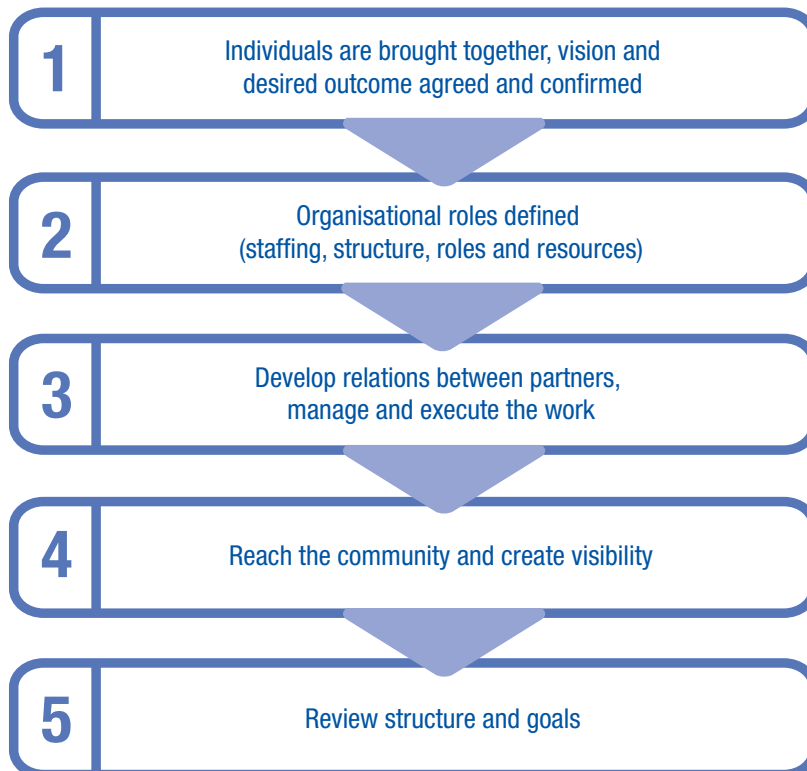
### KEY POINTS

- Seek support from **experts**
- Tailor your story for different audiences
- Develop good contacts with the media
- Use different techniques to get your message across (e.g. feature articles, letters to the editor etc)
- Plan carefully all Public Relations activity

## 4.0 Building Support

Collaborations and partnerships are fundamental to many organisations' existence. Most agreements are not contractual, but based on trust and shared decision making. A successful partnership will increase the power and capacity of the parties involved without compromising their own areas of responsibility. **There is strength in numbers and unity.**

Governments all over the world prefer to deal with *umbrella groups* with clear objectives. [Example of Best Practice, Case Study 6, 'Building Support and Working in Partnership', *Epilepsy Bereaved*]. The same message delivered by several different bodies is more difficult for policy makers to ignore. The building of alliances must be a stepwise process to ensure proper communication.



Partnerships are equally important at local, national and international level. The majority of policy makers operate at local level.

### **INVOLVE PEOPLE WHO:**

- Will derive mutual benefit from the supportive relationship
- Have similar goals and objectives
- Deliver a consistent message
- Have the same target market or audience

## 4.1 PLANNING COLLABORATIONS

*First identify the problem you want to solve or the situation you want to change.*

### **EXAMPLES OF COMMON AIMS**

- *To raise awareness*
- *To increase investment and resources*
- *To improve services*

Funding is an issue for all organisations. Do not compete for the same money, work together to enlarge the funding available for all. Government budgets only increase in response to pressure from vocal/active agencies demanding support. Hidden disability problems are often a low priority for most governments.

### **STEPS TO FORMING AN ALLIANCE**

- *Set your long term objectives*
- *Decide on the specific actions you want people to take to help solve the problem*
- *Determine baselines against which you can measure your achievements*

## 4.2 DEVELOPING PARTNERSHIPS

Consider the potential advantages and disadvantages of working with others. Decide what assistance you need and who can provide this. Ensure potential partners understand what you can offer in return and the benefits to them of becoming your partner.

### **PARTNERSHIP BENEFITS**

- *Sharing of financial and human resources*
- *Greater pool of knowledge and skills*
- *Increased networks*
- *Greater credibility*
- *More opportunities*
- *Greater impact with a consistent message*

List the other organisations already *promoting* changes you desire or who are already working closely with your audience.

- *Prioritise the list – working with established organisations may be easier*
- **Define** the opportunities
- *Be proactive – approach potential partners as early as possible in your planning process. This enables them to contribute more and develop a stronger investment in your joint success*
- *Face to face meetings are usually the best at first*
- *Start with a small nucleus and then gradually involve new partners*
- *Develop your networking skills and contacts – extend your contacts through others*

#### 4.2.1 POTENTIAL PARTNERSHIPS

FIELD OF WORK	POTENTIAL PARTNERS	OPPORTUNITIES
<b>Education</b>	Education officers School counsellors School nurses School doctors	Raise general awareness Awareness of childhood epilepsies Improved early diagnosis
<b>Social</b>	National NGOs Patients organisations Support groups Disability Groups & Commissions Legal aid Police Social workers	Reduction of stigma and discrimination
<b>Medical</b>	Professional Medical Associations Neurologists Pharmacists Researchers Pharmaceutical companies Employers	Professional education and training Improved care and treatment Clinical guidelines Best Practice models
<b>Political Organisations</b>	Health ministries MPs & MEPs (all political parties) Local council Civil Servants Regulators Unions	Increase resources Healthcare plans Local guidelines Policy formulation

Non-Governmental Organisations (NGOs) are often resourceful and creative with a strong sense of commitment. Before approaching anyone carefully research their activities and background.

#### **ESTABLISH AN IDENTITY FOR YOUR PARTNERSHIP**

- *Create an identity and name*
- *Have an office address and contact details with email address and fax*
- *Produce guidelines*

*[Example of Best Practice, Case Study 7 'Making an impact with the European White Paper on Epilepsy', Malta Epilepsy Association]*

### 4.2.2 GETTING INFORMED

Decide what information you will need to support your *campaign*. Use facts and figures about medical and social aspects in epilepsy.

Your research should include:

- *Data and numbers e.g. the number of patients, the socio-economic burden etc*
- *Information about the people and organisations who are in a position to make a difference*
- *Other organisations already **promoting** relevant changes*
- *Potential barriers to your objectives and how others have dealt with them in the past*
- **THE COMMUNITY'S ATTITUDE TOWARDS SIMILAR INITIATIVES**

Search for relevant articles and reports. Use only reliable sources of information e.g. The European *White Paper* on Epilepsy, Call to Action [Appendix 2].

### 4.2.3 POTENTIAL PROBLEMS

Avoid problems by:

- *Working to an agreed plan*
- *Ensuring that you have adequate resources (financial and human)*
- *Clearly **defined** roles*
- *Focusing on results*
- *Recognising cultural and language differences*
- *Paying attention to moral and **ethical** issues*

**Be proactive by predicting potential problem areas:**

- *Complex or long approval processes*
- *Conflicting agendas*
- *Time required to develop and support the partnerships*
- *Human and financial resources available*
- *Learning new skills*
- *Managing the partnership effectively*
- *Poorly **defined** roles and tasks*
- *Sustaining **momentum***

With perseverance most difficulties can be overcome. Be creative in finding solutions and ensure that all members of the partnership groups are able to actively contribute.

#### 4.2.4 WORKING WITH OTHER EPILEPSY ORGANISATIONS

***Epilepsy organisations are and have been involved in many different campaigns for improving epilepsy care. You can benefit from their advice and experience.***

Work with other epilepsy organisations who are members or committees of the IBE and ILAE, and liaise with other international groups through IBE/ILAE. Speak to the IBE/ILAE and contact them for advice. [Example of Best Practice, Case Study 4, 'Promoting Epilepsy Awareness', Swiss League Against Epilepsy and epi-suisse]

#### 4.2.5 WORKING WITH NON-EPILEPSY ORGANISATIONS

Your efforts may not focus on specific epilepsy issues but address wider health and social problems. Even if this is not the case you may learn a lot by studying other successful *campaigns*.

- *Liaise with other healthcare groups e.g. diabetes, asthma*
- *Partner with other neurological groups*
- *Liaise with national agencies for persons with disability*
- *Invite other groups to meetings*

You may have more in common than you first imagine!

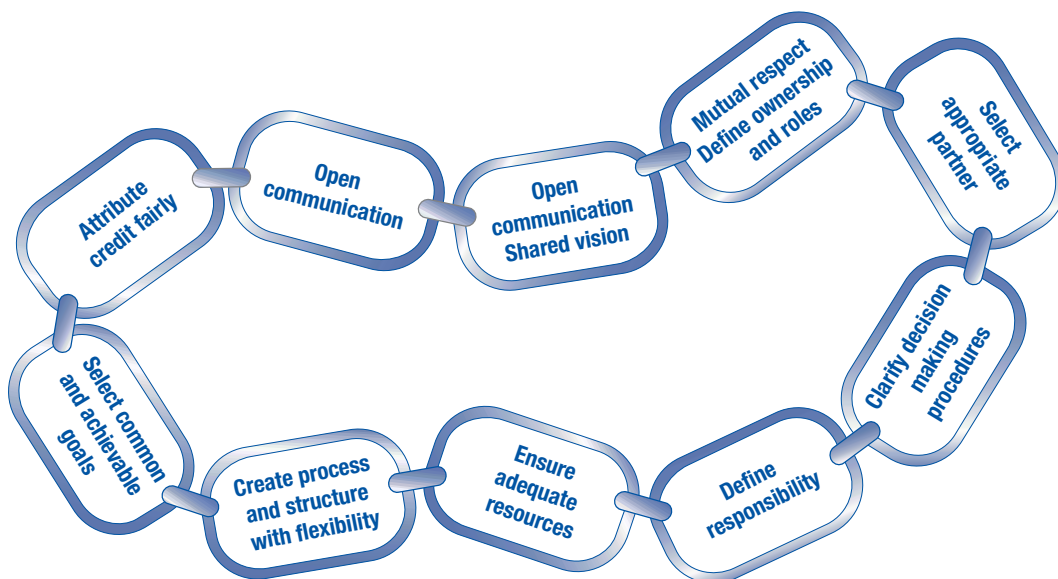
#### 4.2.6 WORKING WITH PHARMACEUTICAL COMPANIES

Increasingly, pharmaceutical corporations enter into social marketing *campaigns* with public and voluntary sector partners. These invest resources around a popular cause and enhance corporate image by demonstrating commitment to customers. Donations to *NGOs* also save on taxes and provide publicity.

Consider whether your *campaign* is of interest to a pharmaceutical company. Contact either the Public Relations, Marketing or Medical Department. Do not just ask for *sponsorship* but explain how the project will be of mutual benefit.

- Approach companies for **sponsorship** early in your planning
- Invite them to work with you
- Consider using other resources and **expertise** of value that they have
- **Define** clearly the involvement and how this should be credited
- Acknowledge and thank the company for their contribution
- Discuss any **ethical** concerns early in your relationship

#### 4.2.7 FACTORS FOR A SUCCESSFUL PARTNERSHIP



**Remember an alliance is only as good as its weakest link**

#### 4.3 KEY POINTS

- A strong partnership will bring mutual benefit
- Develop a group identity
- **Define** and allocate tasks for all members
- Use **expertise** that exists within **ILAE** and **IBE**
- Plan carefully to avoid problems

## 5.0 Using the European White Paper on Epilepsy as a tool for change

### 5.1 WHAT IS THE 'EUROPEAN WHITE PAPER ON EPILEPSY'?

A *White Paper* is a policy statement issued to provide information for Parliament on a particular topic together with appropriate recommendations for action. *White Papers* are commissioned by governments to prepare new laws or amendments to existing laws.

*The 'European **White Paper** on Epilepsy' was produced as a tool to enable the epilepsy community to lobby governments at a national and international level.*

The *White Paper* was designed for public officials and politicians i.e. people with little or no knowledge of epilepsy. It is a report designed to highlight epilepsy issues in Europe.

The 'European *White Paper* on Epilepsy' is supported by a document entitled 'Call to Action' which focuses on three of the *White Paper's* key recommendations. This forms the basis of the international *campaign*. The *White Paper* was designed as a political lobbying tool, it can also be used to approach other policy makers in your community or workplace.

### 5.2 HOW TO USE THE WHITE PAPER

There is no right or wrong way to use the *White Paper*. The most important element is your motivation. Below are suggestions as to how it can help you:

- *as a factual reference document*
- *as endorsement and support for your **campaign***
- *as a local **campaign***
- *as a basis for your own 'Call to Action'*

### 5.2.1 A REFERENCE DOCUMENT

Effective campaigning requires efficient information gathering and provision. Whoever you are approaching, act in a supportive and informative way. Most scientific publications are difficult to understand even by those who have epilepsy knowledge. Only use information relevant to your audience. Use the 'European *White Paper* on Epilepsy' in the following ways:

- *To provide your vital supporting evidence*
- *Refer to facts and points relevant to your cause*
- *Quote specific sentences or recommendations, and have available more supportive information should this be requested*

Epilepsy is complex. Do not attempt to communicate all the information contained in the *White Paper*. Busy professionals will not have time to read it.

*The 'European **White Paper** on Epilepsy' should be used to support your own message.*

### 5.2.2 ENDORSEMENT AND SUPPORT FOR YOUR CAMPAIGN

The *White Paper* and Call to Action represent a consensus of 35 international experts in epilepsy. They carry endorsement from the *ILAE*, *IBE* and *WHO*. Use this endorsement to add weight to your *campaign*. Do not forget to explain who these organisations represent.

*By using the '**White Paper**' or 'Call to Action' to supplement your request or **campaign** you are demonstrating the strength of support that exists.*

Strengthen your position by showing decision makers that your *campaign* is important to a wider community. Explaining that an international political *campaign* is being undertaken demonstrates that you are not acting in isolation.

### 5.2.3 A LOCAL CAMPAIGN

The 'Call to Action' is a much more important *advocacy* tool than the 'European *White Paper* on Epilepsy'. Three key clear, simple and relevant messages were chosen.

### **CALL TO ACTION, 3 KEY MESSAGES**

- *Improve public understanding of epilepsy via educational programmes throughout Europe to raise awareness and reduce stigmatisation of patients*
- *Provide legislation to protect people with epilepsy from discrimination in the workplace to ensure equal job opportunities and thereby reduce the socio-economic burden of the condition*
- *Increase investment in research in epilepsy in order to improve the diagnosis and treatment of epilepsy throughout Europe*

These three priorities were selected because the European Parliament has a remit and budget available to implement policy in the areas of research, employment and health education.

*The three key areas outlined in the 'Call to Action' are of major concern and relevance in every country.*

The advantages of using the 'Call to Action' as a basis for your *campaign* are:

- *The key recommendations will be relevant in your country*
- *The document is available in 11 languages*
- *It carries **ILAE, IBE and WHO** endorsement*
- *Synergy may be achieved with other organisations using the **campaign***
- *Electronic copies can be obtained from EUCARE*
- *The **campaign** has been shown to be effective*

National governments have a relationship with European Union (EU) institutions. You also have an elected Member of the European Parliament (MEP) representing you locally. Below are some suggestions that you may pursue with the 'Call to Action':

- *Write to your MEP and ask for their response to the 'Call to Action' [Appendix 2]*
- *E-mail your MEP or local ministers attaching an electronic copy available from EUCARE*
- *Ask your local MEP to join the Parliamentary Advocates for Epilepsy Group*
- *Ask your MEP to liaise with your local policy makers and government officials*
- *Prepare some questions that can be asked in parliament*

### 5.3 MOTIVATING INVOLVEMENT IN YOUR CAMPAIGN [OR 'CALL TO ACTION']

Find a local or newsworthy issue that will encourage them to read the 'Call to Action' e.g. 'local *expert* meets Member of European Parliament to discuss shortfall in epilepsy services'. Be alert to new developments, look for initiatives that could bring the 'Call to Action' to the attention of your audience.

People become involved in causes they see can make a real difference – a good *campaign* should excite and stimulate others to participate. They should understand and share your objectives, see progress made and have practical involvement. [Example of Best Practice, Case Study 7, Making an Impact with the European **White Paper** on Epilepsy, Maltese Epilepsy Association]

### 5.4 ESTABLISHING A LOBBY GROUP

All successful *campaigns* require an operational structure.

**Find a spokesperson or advocate who can take your cause forward from within the relevant institution.**

Once you have identified an appropriate *spokesperson* ask them to chair a group or meeting. The group does not need to be official, informal groups can be more active and effective. Even if people cannot commit to joining the group you may ask for their support.

### 5.5 CREATING YOUR 'CALL TO ACTION'

The 'European *White Paper* on Epilepsy' can be used to create your own *campaign* and local 'Call to Action'. All aspects of diagnosis and treatment are covered. More than 70 recommendations identified as major issues in most countries are highlighted. You may select any topics outlined in the '*White Paper*' to create your message.

*A 'Call to Action' is a request for change. Clearly state what you want and why you want it.*

Important rules to follow when producing your own *advocacy* material:

**Effective Advocacy Materials:**

- Choose a maximum of three key messages to communicate
- State your message at the beginning of your document
- Messages should be compelling
- Materials should be clear
- The layout should be visually appealing (use photographs and images)
- Ensure your requests are realistic and relevant to the institutions that you are targeting – your audience should relate to your issue
- Others should proof read your text to ensure it can be clearly understood

## 5.6 TARGETING THE ‘EUROPEAN WHITE PAPER ON EPILEPSY’ FOR DIFFERENT AUDIENCES

AUDIENCE	POTENTIAL ISSUES	POSSIBLE MESSAGES	RELEVANT SECTION IN WHITE PAPER
<b>Politicians/ policy makers</b> <ul style="list-style-type: none"> <li>• Prime Minister</li> <li>• Minister of Health/Treasurer</li> <li>• Members of Parliament</li> <li>• Local authorities</li> </ul>	<ul style="list-style-type: none"> <li>• New/Existing legislation</li> <li>• Public opinion</li> </ul>	<ul style="list-style-type: none"> <li>• Disparity in treatment/services</li> <li>• Access to best treatment is the right of every citizen</li> <li>• Opportunity for improvement</li> <li>• Comparison with other investments e.g. subsidies</li> </ul>	3. Epidemiology 18. Employment 19. Legislation and insurance 20. Economic aspects
<b>Journalists</b> <ul style="list-style-type: none"> <li>• Health reporters</li> <li>• Editors</li> <li>• Feature writers</li> <li>• Columnists</li> </ul>	<ul style="list-style-type: none"> <li>• News value</li> <li>• Timing</li> <li>• Spokespeople available</li> <li>• Photograph available</li> </ul>	<ul style="list-style-type: none"> <li>• Personal testimony or human interest story</li> <li>• New research or data</li> <li>• National epilepsy day</li> </ul>	26. Public education in epilepsy
<b>Healthcare providers</b> <ul style="list-style-type: none"> <li>• Hospitals</li> <li>• Universities</li> <li>• Health Authorities</li> <li>• Medical Professionals</li> </ul>	<ul style="list-style-type: none"> <li>• Budget implications</li> <li>• Legal implications</li> </ul>	<ul style="list-style-type: none"> <li>• New research or data</li> </ul>	14. Provision of care
<b>Schools</b> <ul style="list-style-type: none"> <li>• Unions</li> <li>• Teachers</li> <li>• Pupils</li> <li>• Parents</li> </ul>	<ul style="list-style-type: none"> <li>• Time available</li> <li>• Overloaded curricula</li> </ul>	<ul style="list-style-type: none"> <li>• First aid for seizures</li> <li>• Education and children with epilepsy</li> <li>• Childhood epilepsy syndromes</li> </ul>	17. Epilepsy education within schools 30. Adolescent epilepsy
<b>Corporations and industry</b> <ul style="list-style-type: none"> <li>• Directors</li> <li>• Human resources</li> <li>• Employees</li> </ul>	<ul style="list-style-type: none"> <li>• Financial implications</li> <li>• Impact on workforce</li> </ul>	<ul style="list-style-type: none"> <li>• Improved Corporate image</li> <li>• Improved Marketing capacity</li> </ul>	28. Professional organisations 35. Epilepsy research
<b>General Public</b> <ul style="list-style-type: none"> <li>• People with epilepsy</li> <li>• Patients</li> <li>• Electorate</li> </ul>	<ul style="list-style-type: none"> <li>• Misconceptions</li> <li>• Public interest</li> </ul>	<ul style="list-style-type: none"> <li>• Prevalence of epilepsy</li> <li>• Causes of epilepsy</li> <li>• Risks associated with epilepsy</li> </ul>	1. The history and stigma of epilepsy 26. Public education

## 5.7

### KEY POINTS

- *The **White Paper** is a political document*
- *Use it to endorse and strengthen your cause*
- *Establish a relationship with your politicians*
- *Prepare your own **briefing papers** and ‘Call to Action’*
- *Keep motivated as policy change is often slow*

## Examples of Best Practice

# CAMPAIGN TO CHANGE DRIVING REGULATIONS

## Brainwave, The Irish Epilepsy Association

### Objectives

Brainwave began its *campaign* in 1995, aiming to change the law to allow all people with epilepsy in Ireland equal driving status, both those living under British (Northern Ireland) or Irish law. The seizure-free period was the most immediate change required with other driving regulation issues also important. In summary Brainwave was seeking to change the Irish law on driving by:-

- *Using its European and International contacts*
- *lobbying at local level through its members*
- *Networking with any possible allies*
- *Establishing its Driving and Epilepsy members group*
- *Seeking meetings with Government*

### Lobbying at EU and National levels

Brainwave's President, Dr. John Kirker, a leading epileptologist in Ireland and Chair of the *IBE's* Driving Commission initiated two *IBE* Workshops on Epilepsy and Driving (Brussels 1995 and 1996) organised by Brainwave. For these meetings Marion Wilkinson, Director of Services, researched the existing driving regulations in each of the 16 participating countries (15 *EU* and Switzerland). Ms Nuala Fennell, a former Irish Government minister, also participated in the Workshops. These Workshops produced what has become the definitive document on Epilepsy and Driving in Europe and the recognition of its recommendations by the *EU* was critical to effecting change in Ireland.

Following publication of the Driving Workshops proceedings in 1997, Brainwave commenced political lobbying under the direction of Nuala Fennell who met in 1998 with Ms Mary Banotti, an Irish *MEP*, influential in *EU* disability matters. Brainwave established a Driving and Epilepsy Members Group, a key member being the Chairman, Ms Margaret McCahill, who developed epilepsy in her twenties. Brainwave personnel sought meetings with the Minister for the Environment and his staff and investigated possible alliances with other disability groups also seeking driving regulation changes e.g. cardiac, diabetes.

In early 1998 Brainwave increased their *campaign* at a political level, raising questions in the Irish Houses of Parliament. The Minister's early responses indicated no intention to alter the regulations, stating the *EU* Directive 91/439/EEC guideline

of 2 years seizure-free and Ireland's compliance with this. The breakthrough came when EU Commissioner for Transport, Neil Kinnock, responded to Mary Banotti MEP's questions in the European Parliament on the 15th July, informing her that Directive 97/26/EC established a European Committee on Driving Licences which had discussed seizure-free periods prompted by the IBE Driving Workshops Report. Significantly, he added that EU Directive 91/439/EEC '*is indicative: no seizure in the last two years, for example*'. This confirmed that the Directive was not binding. A new one page bulleted summary was prepared and seen by the Minister in early 1999. Intensive lobbying achieved a meeting with him to discuss the issue.

It was then discovered that newly drafted driving regulations included a 1-year seizure-free period for people with epilepsy, but none of Brainwave's other proposals. Despite the suggestion that continued lobbying might reverse the seizure-free period change, a Press Release was issued on the 15th October 1999 welcoming the 1-year seizure-free period but outlining additional changes believed necessary.

## Outcome

**New regulations including the 1-year seizure-free period came into effect on 26th November 1999.** A new Irish Government in 2002 gave driving regulation responsibility to the Department of Transport. Brainwave is continuing to *lobby* for a review regarding:-

- *nocturnal seizures*
- *changes of medication; provoked and unprovoked seizures*
- *non-epileptic seizures or situations in which the diagnosis is uncertain*
- *single seizures; provoked and unprovoked*
- *simple partial seizures where awareness is retained*

All in Brainwave [The Irish Epilepsy Association] are confident of obtaining further changes that will benefit all people with epilepsy in Ireland who wish for the option to drive.

**Mike Glynn, CEO**

**Brainwave, The Irish Epilepsy Association**

### Key Points

- *Thoroughly research the situation and update your information regularly*
- *Use all political contacts at national and international level*
- *Get to know how institutions work – who does what, where are decisions made and by whom?*
- *Set up a **task force** or members group*
- *Get **MPs/MEPs** to ask questions in parliament*
- *Prepare a summary or **briefing paper** for officials*
- *Be persistent – you will encounter barriers and obstacles*
- *Plan for the long term (it can take years to make change happen)*

## Examples of Best Practice

**CAMPAIGNING FOR BETTER SERVICES**

## Swedish Epilepsy Association

**Objective**

**The aim was to improve the epilepsy services in a small community in Sweden by:**

- *bringing epilepsy issues to the attention of local politicians*
- *increasing the quality of life for people with epilepsy*
- *improving knowledge of epilepsy amongst the local population*

Although local medical care was satisfactory, resources for a comprehensive approach for psychological and social care were lacking, despite individual health care professionals efforts. However, more comprehensive resources and services were available for people suffering from other medical conditions, such as diabetes. The lack of understanding and awareness amongst members of the general public was also considered to be a problem.

**Plan**

Members of the local branch of the Swedish Epilepsy Association initiated contact with local politicians who were first approached in writing. The members were anxious to clarify what they wanted to achieve and to create a good climate for discussions before taking any further steps. Two key requests were made for:

- *Improved service provision for the transition from child to adult care*
- *Specialist epilepsy nurses with educational skills to deal with special needs*

Politicians were approached and listened to the requests for improved epilepsy care. A further meeting was held with health care professionals at the hospital providing the opportunity for a local epilepsy *opinion leader* to present the problems that people with epilepsy meet in daily life. The disparity with other health care conditions and patients was also stressed.

The Swedish Epilepsy Association provided a document outlining its view of satisfactory comprehensive epilepsy treatment. This additional support was helpful to the local branch and it also provided a higher status for the group.

**Outcome**

The politicians listened, understood and were convinced and wished to contribute to change the situation. In October 2001 an epilepsy nurse was employed at the

## CASE STUDY 2

hospital specifically to support epilepsy patients and to provide epilepsy education. In addition to a general public education brief there have been special target audiences identified for external education:

- *schools and kindergarten*
- *groups of employers and employees in community services*
- *local branches of patient groups.*

This service is not yet permanent and is being evaluated. The local branch who took the initiative is very satisfied with the present and will to continue to enlist support for the service to continue in the future.

**Susanne Lund**  
**Chief Executive Director**  
**Swedish Epilepsy Association**

### Key Points

- *Communicate your request(s) in writing*
- *Requests/messages should be specific, **concise** and clear*
- *Seek advice and support of other professionals before launching your **campaign***
- *Take a stepwise approach with your audiences*
- *Enlist support from national epilepsy organisations in addition to local*
- *Establish contact with influential people*

## Examples of Best Practice

# HANDLING NEGATIVE MEDIA

## The Slovenian League Against Epilepsy and local self-help groups

### Background

Members of a local council in Izola, Western Slovenia agreed that their council session payments should be reduced and the money saved awarded to an humanitarian goal. Two possible recipients were proposed by rival local political parties, namely **‘a self –help group for people with epilepsy’** or **‘an elementary school for new materials’**, the former being selected. Around the same time, there were media reports alleging financial fraud in the national Red Cross Office, and journalists were alert to ‘hot topics’ related to humanitarian associations.

Local newspapers reported that ‘epileptics in Koper’ were to receive a grant from council members with the ‘money being awarded to a non-existing association’ (the local epilepsy self-help group having no official office). The story was subsequently covered in a national TV programme with the main focus on political rivalry and possible fraud related to the poorly directed use of the money and ended with the words: *‘is charitable money sometimes going to groups that do not really exist?’*

A member of the epilepsy self-help group was invited to discuss events informally with a journalist who was interested only in the political aspects of the story, not the group’s activities or aims. Members of the local self-help group were offended feeling that their existence and activities had been questioned morally on National TV. Consequently their representative, invited by a local newspaper journalist to discuss the group’s work, responded aggressively and accused the journalist of reporting only negative events. He insulted the journalist and demanded an apology. Others in the community, previously supportive, expressed doubts about the group’s moral integrity and it became difficult for them to organise their meetings.

### Objectives

Medical colleagues and acquaintances felt that the critical accent of the TV programme could be harmful, not only for the self-help group, but also for other epilepsy organisations. The self-help group contacted the Executive Council of the Slovenian League Against Epilepsy (SLAE) requesting support. The SLAE’s professional body agreed to respond to the TV programme, aiming to restore the image of epilepsy organisations in Slovenia.

## Plan

The SLAE President called the main editor of the TV programme to discuss the problem, proposing that SLAE and affiliated self-help group activities could be shown to a national audience to improve the situation. This proposal was favourably received, with the TV station agreeing to produce a further programme, presenting the reality of the situation.

The SLAE invited a *national celebrity* to comment on the misreporting and damage done to people with epilepsy in Slovenia. This celebrity is a Professor of Journalism at the University of Ljubljana but was a well known film actress. She has pledged her support and will speak on behalf of the organisations supporting people with epilepsy.

The SLAE has just obtained new premises (for the first time in its history) from the municipality. The media will be invited to the formal opening on November 18, 2002; all media contacts were postponed until this event as it offers more positive coverage opportunity.

### The following key messages were chosen to include in the press event:

- *epidemiology and stigma of epilepsy in Slovenia*
- *activities of the Slovenian Chapter of **ILAE** and the local support available from self-help organisations for people with epilepsy*
- *inauguration of new office*
- *improvements achieved so far*

## Campaign

- *local information to be given via local TV on the coast and in other districts*
- *to re-consider formal status of self-help groups*
- *to report activities more frequently in the media at national and district levels*
- *to increase coverage in the media about the League and groups' activities*
- *to show a film on epilepsy at cinema for broad audience of medical and allied professionals, students of Theatre/Film/Television academy, and journalists to extend public awareness and debate*
- *a doctor (neuro-psychiatrist) with media experience (previously with the SLAE), was designated the League's Press Representative in future similar situations and for any activities related to mass media*

### Key Points

- *Be aware of the political climate*
- *Consider your response to the media, do not just react*
- *Challenge the media when it reports epilepsy inaccurately*
- *Seek opportunities to turn negative and misrepresented stories into positive stories*
- *Enlist support of credible agencies and well respected people*
- *Establish direct contacts with media*
- *Nominate an experienced person to deal with the media*

## Examples of Best Practice

# PROMOTING EPILEPSY AWARENESS

## Swiss League against Epilepsy and epi-suisse (Swiss Epilepsy Association)

### Background

The Swiss League Against Epilepsy aims to improve the professional knowledge of epilepsy. epi-suisse, a chapter of *IBE*, works to support people with epilepsy all over Switzerland. In May 2002 the members of the Swiss League against Epilepsy (SLgE) transferred all aspects of its social activities to the newly founded Swiss Epilepsy Association (epi-suisse). Both organisations work closely together and share office facilities.

### Objectives

One aim shared by both organisations is to raise the general public awareness of epilepsy. A joint initiative to organise the first National Epilepsy Day was held on 5<sup>th</sup> October 2002.

### Plan

The event theme was ‘Epilepsy and Employment’ with several events around the country:

- *A National Press Conference featuring an interview with a well known actor*
- *Swiss Epilepsy Report launch aimed at political and social organisations*
- *3 regional meetings inviting members of the public to meet epilepsy **experts***
- *20 local events*

Topics were presented by *experts* in a variety of fields to increase the attraction of these events. The press conference agenda, held in the prestigious National Swiss Museum was as follows:

- *Interview: Michael Birkenmeier (actor) – Personal experience of living with epilepsy*
- *Presentation: Dr Günter Kramer (epilepsy specialist) – Swiss epilepsy report*
- *Discussion: Mr Jürg Vogel (lawyer) – Choice of profession*
- *Case studies: Dr Klaus Meyer – Examples of problems in the workplace*
- *Mr Wittwer: The impact of epilepsy on a variety of professions*
- *Questions from the audience*
- *Concluding remarks*

## Outcome

The national press conference was attended by more than 150 delegates including more than 50 journalists and extensive media coverage was obtained. Since the inauguration of the new offices and national epilepsy day, epi-suisse has benefited from increased financial support from private donors. The size of the organisation has also grown by recruiting more members.

### Key Points

- *Set indicators to measure your success (e.g. counting press articles, membership etc)*
- *Consider both local, regional and national locations for your event*
- *Include **experts** representing different professions (e.g. lawyers, social workers)*
- *Arrange for a person with epilepsy to tell their story to the press*
- *Include data on the wider social impact (loss of earnings etc)*

**Ernst Zweife**  
epi-suisse

## Examples of Best Practice

## USING YOUR VOICE – A FRUITFUL COOPERATION BETWEEN A PERSON WITH EPILEPSY AND THE DANISH CHAPTER

The Danish Epilepsy Association's (DEA) aim is to promote the Danish Chapter and focus attention on epilepsy. Thus we wish to cooperate with people with epilepsy, personal stories being of greater media interest than facts and stories from members of the national or local boards.

In 2002 we cooperated closely with a determined young woman with epilepsy who found the courage to 'use her voice' to raise both the public's and media's epilepsy awareness. Both parties had strong interests in being heard; the woman wishing to write a book of her personal story and to raise awareness of this and the DEA wanting to raise both awareness of epilepsy and the Danish Chapter, particularly since the latter's 40<sup>th</sup> anniversary was that same year.

The young woman's story is that she was diagnosed with epilepsy in her teens, having grown up with the fear of her mother's seizures. She became seizure-free on valproate, seeing her neurologist only once a year. Later, wishing to start a family she suffered some miscarriages, she then decided to try to conceive without her antiepileptic medication.

Her first child was born the next year, shortly after this she experienced a seizure and so recommenced her valproate medication. In following years she had two more children, the youngest being born with **Foetal Valproate Syndrome**. He has suffered 7 major surgical operations to correct abnormalities in his cranium (50 plates protect his brain), arm and penis. Throughout her pregnancies the young woman received neither information nor counselling on the risks of taking antiepileptic drugs during pregnancy, her doctor accepting no responsibility for this. Frustrated and concerned that this might be a common problem she decided to take action and so stepped out of the shadows to 'use her voice'.

This woman contacted and worked with a national television journalist who made a documentary about her family, including filming her son during surgery. Articles appeared in newspapers and the Danish Epilepsy Magazine encouraging other affected families to come forward. The woman appeared on national television news, together with doctors and politicians.

She also contacted a lawyer (DEA provided funding for this) who took the case to court, the first of its kind in Denmark. The case was successful and other families have since followed this example. The woman's book is her life story, her own experiences

and feelings. The DEA knew of this story and felt it to be of media interest. We also knew that this woman was able to communicate with the media but did not know whether she could make an interesting book of her personal story; which she did.

### Key Points (for individuals)

- *It requires courage to reveal your own and your family's lives to public scrutiny*
- *Do not be afraid to challenge the system*
- *Do not be intimidated by professionals*
- *Keep motivated*
- *Work with your local Epilepsy Association*

The DEA assisted the woman in writing and publishing her book and so has raised both its own profile and that of epilepsy with key audiences among the media and politicians. We also provided her financial support while she wrote her manuscript and assisted with its publication. The DEA approached the Danish Minister of Social Affairs to review the book and the resulting favourable review was published in the DEA's own epilepsy magazine.

The book's launch date was chosen to coincide with the DEA's 40<sup>th</sup> anniversary, ensuring interest and support from DEA's patron, Prince Henrik of Denmark (the Danish Queen's husband), Members of Parliament and other VIPs, helping to generate media interest. Pre-launch publicity and promotion resulted in several popular magazine articles and features about both this personal story and others from people with epilepsy.

The Danish Government has since decided to fund both a nurse and a person with epilepsy to continue *promoting* and communicating the important messages of living with epilepsy, especially to medical professionals. To support this, the DEA has approached politicians and the Minister of Social Affairs, presenting further opportunities to inform them about the DEA's work.

### Key Points (for Epilepsy Associations)

- *Be sensitive to the individual's personal situation*
- *Identify mutual goals and benefits*
- *Link events and activities to maximise their impact*
- *Maximise your opportunities by phasing a launch*
- *Pre-publicity planning*
- *Launch your activities*
- *Exploit your actions and plan and execute follow up measures*

**Jutta Houmøller**  
**Chief Executive Officer**  
**Danish Epilepsy Association**

## Examples of Best Practice

## BUILDING SUPPORT AND WORKING IN PARTNERSHIP

### The National Clinical Audit of Epilepsy-Related Death – Epilepsy Bereaved

#### Introduction

The National Clinical Audit of Epilepsy-Related Death resulted from a ten year campaign, begun in 1992 by four families affected by sudden unexpected death in epilepsy (SUDEP). These families identified a need for a better understanding of epilepsy-related deaths and improved knowledge of whether preventative measures could reduce them.

The campaign succeeded when Epilepsy Bereaved became the first voluntary sector organisation to conduct and deliver a National Audit of epilepsy related deaths, conducted as a partnership between voluntary sector and health professional organisations. This model enabled key questions, previously considered too sensitive, to be addressed. Those directly affected by epilepsy-related deaths maintained ownership throughout whilst multidisciplinary professionals ensured the campaign's scientific validity.

#### The obstacles

The campaign was controversial. In 1992 the issue of SUDEP was addressed only by a few clinicians and researchers, no organisations being involved. The campaign was complex, involving several issues e.g. legal and medical, and had to be implemented across the four countries of the UK. Epilepsy was considered a low priority with policy makers.

#### The Objectives

- *To develop an organisation to champion the campaign*
- *To raise awareness of SUDEP among scientists and general public*
- *To prepare an action plan involving ALL UK **stakeholders** (including the epilepsy voluntary sector and organisations representing GPs, neurologists, nurses and pathologists)*
- *To coordinate a political **lobby** by individuals and **stakeholder** organisations*

#### Support and Education

Epilepsy Bereaved, founded as a self-help group in 1993 and becoming a registered charity in 1995, convened an international workshop in 1996 bringing together leading SUDEP experts. A special supplement to *Epilepsia*, the ILAE's Journal, was published on SUDEP. Increased SUDEP research activity followed including important new studies highlighting

optimum seizure control as a key preventative measure. The workshop called for a national confidential enquiry to establish how many epilepsy deaths were potentially avoidable and set up a Taskforce. Taskforce members helped to *promote* the campaign to relevant professional organisations. The campaign, endorsed by the Joint Epilepsy Council (JEC), ILAE (British Branch), Association of British Neurologists and Royal Colleges of Pathologists, General Practitioners, Physicians, Paediatrics and Child Health, Psychiatrists, and Nursing, involved petitions (signed by 600 health professionals and 9,000 members of the public); written questions and meetings with ministers and civil servants.

A *lobby* was conducted by JEC members to influence policy makers in England, Northern Ireland, Scotland and Wales. Effectiveness was added by bereaved families writing and meeting with their local politicians. One bereaved mother met her local *MP* who subsequently led a Parliamentary debate on epilepsy and sudden death and agreed to chair the All Party Group of *MPs* for the Westminster Parliament.

## Outcome

A key finding of the Audit was the potential to avoid premature deaths (about 40% of deaths). The Audit, welcomed by all four UK Chief Medical Officers as a 'landmark report', was summarised in *The Lancet* as a 'wake-up call' to epilepsy management. Responses so far include:

- *The first Department of Health Action Plan to improve epilepsy services in England*
- *Welsh Assembly promise of a stakeholders meeting and epilepsy strategy*
- *Northern Ireland stakeholders meeting and promise of a national epilepsy strategy*
- *New guidelines from the Royal College of Pathologists on epilepsy deaths*
- *Examples from individual hospitals and primary care organisations in the UK of actions e.g. new epilepsy protocols, epilepsy audit and in one major teaching hospital - ten action points for clinicians*

Our intention is to continue to work in partnership with all stakeholders to monitor and build on these initial responses.

**Jane Hanna**  
**Epilepsy Bereaved**

### Key Points

- *If obstacles appear huge, identify your strengths and build on these step by step*
- *Enlist specialist support early – consider using expertise from abroad*
- *Be persistent – the Audit was commissioned after 10 years of campaigning!*
- *Individuals directly affected by issues are powerful campaigners*
- *Establish a taskforce including members of all relevant stakeholder organisations*
- *Ensure you have sound evidence as a basis for your campaign*
- *Be prepared to take the lead*

The National Sentinel Clinical Audit for Epilepsy Related Death can be downloaded at [www.sudep.org](http://www.sudep.org)

## Examples of Best Practice

# MAKING AN IMPACT WITH THE EUROPEAN WHITE PAPER ON EPILEPSY

Caritas (Malta) Epilepsy Association

### Background

The Malta Epilepsy Association was set up in 1996. One of its aims is to *lobby* for appropriate policies, legislation and epilepsy services. In order to be more effective the association developed with the support of one of the largest *NGOs* in the country. Their pre-existing infrastructure (offices, meeting rooms, computer facilities, legal advisors and training provision) has allowed the epilepsy association to grow quickly and professionally. Following the official appointment of a committee (President, Secretary, Treasurer, and *Spokesperson*) and preparation of a *Statute* the association became members of the *IBE* in 2001.

### Objectives

The launch of the European *White Paper* on Epilepsy provided the Malta Epilepsy Association with a platform to initiate its own national *campaign* aiming to raise public awareness of the organisation and enlist political support for improved epilepsy services.

Four priorities were identified:

- *To increase the availability of drug treatment*
- *To introduce video telemetry*
- *To improve access to vagal nerve stimulation*
- *To address the lack of qualified EEG technicians*

### Plan

The following activities were undertaken:

- *Regular meetings were organised with the associations' members to discuss a variety of recommendations outlined in the European **White Paper** on Epilepsy. A different issue was chosen for each meeting*
- *Lectures have been delivered to local councils and authorities using the 'Call to Action' to explain epilepsy in lay terms*
- *Two national conferences were held inviting other chapters of the **IBE** to speak about their political activities, including the presentation of the European **White Paper** on Epilepsy at their national parliament*
- *New material has been developed to inform policy makers about the association and the main issues*
- *Liaison with National Commission for Persons with Disabilities and the manufacturers of vagal nerve stimulation devices to enlist additional support*

## Lobbying government

The organisation wrote to the Maltese Health Minister and Director General for Health using the *White Paper* to support the requests. The response was positive and several face to face meetings followed. The four key priorities were discussed. These meetings were also used as a Public Relations exercise for the Ministry of Health.

Debate was stimulated within Parliament by requesting *MPs* to ask questions. The opposition spokesman for education and youth asked about the number of children with epilepsy in Malta, provision for support services for these children, and specific cases of employment discrimination.

The group has set up meetings between Mr. John Bowis (Chair of Parliamentary Advocates for Epilepsy) and Mons Dun Victor Grech, Director of the largest *NGO* in Malta, Caritas Malta, to which the Maltese Epilepsy Association belongs. This demonstrates the international aspect to the work and provides opportunities for identifying and addressing certain shortfalls in our national work. This important meeting has been followed up by inviting Mr Bowis to speak about the European *White Paper* on Epilepsy at a national conference which was attended by local politicians and members of the public. Press releases are issued about all events – even small meetings between ministers. Copies of the ‘European *White Paper* on Epilepsy’ and ‘Call to Action’ are distributed to all delegates and meeting participants. Several articles and letters in local newspapers covered the event and we were invited as guests on TV and radio programmes.

## Outcome

Awareness of the association has increased significantly and membership has increased to over 200 as a result of its activities. The two national conferences we had to date attracted more than 500 delegates. Excellent relationships have been built with *MPs* from all political parties. Video Telemetry has been ordered and new EEG technicians are in training. The supply of antiepileptic drugs is improved. We are still striving for vagal nerve stimulation availability in Malta.

**Connie Baker, Godwin Cachia, Anna Debattista, Mario Dimech, Janet Mifsud**  
**CaritasMalta Epilepsy Association**

### Key Points

- *Work with other organisations to increase your impact*
- *Enlist the support of the IBE*
- *Issue press releases about your political activity*
- *Encourage your political contacts to network at national and international level*
- *Encourage **MPs/MEPs** to ask questions in parliament*
- *Have the **White Paper** available to support your requests at all times*

# EUROPEAN DECLARATION ON EPILEPSY



**25 October 1998**

At a meeting in Heidelberg, Germany, 25 October 1998, over 100 leaders of European professional and lay bodies, WHO representatives and health experts from governments and universities unanimously agreed the following declaration:

- *Six million people in Europe currently have epilepsy. Fifteen million will have epilepsy at some time of their lives.*
- *Epilepsy has profound physical, psychological, and social consequences*
- *Children, adolescents and the elderly are especially afflicted by*
- *non-detection and undertreatment.*
- *With appropriate treatment over three quarters of people with epilepsy could lead normal lives free of seizures.*
- *Epilepsy costs the countries of Europe over 20 billion ECU every year, an amount that could be significantly reduced with effective action.*

We call on the governments of Europe, the European Union, and all health care providers to join us in taking strong and decisive action to meet the objectives of the Global Campaign against Epilepsy launched by the WHO, ILAE, and IBE.

Specifically, we urge action:

- *to improve public understanding of epilepsy and thereby reduce its stigma*
- *to remove discrimination against people with epilepsy in the workplace*
- *to help people with epilepsy to understand their condition and to empower them to seek appropriate treatment and lead fulfilled lives*
- *to improve the knowledge of health care professionals and other professionals about epilepsy*
- *to ensure the availability of modern equipment, facilities, trained personnel and the full range of antiepileptic drugs, so that an accurate diagnosis can be made leading to the most effective treatment*
- *to encourage research on epilepsy and its management*
- *to encourage close liaison among governments, health and social authorities and agencies, and the national chapters of the ILAE and IBE*
- *to support the publication of a 'white paper' as a detailed Public Health statement on Epilepsy in Europe*
- *to provide practical assistance for countries with underdeveloped epilepsy services within and beyond Europe.*



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World Health Organization  
1211 Geneva 27  
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Tel: +41 22 791 2111 . Fax: +41 22 791 0746  
Cables: UNISANTE GENEVA  
Telex: 415 416



International League Against Epilepsy  
Epilepsy Zentrum Berlin  
Mara 1 . Maraweg 21  
Berlin . 13617 Bichsfeld . Germany  
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## Background Note

Epilepsy, affecting at least 40 million people worldwide, is the commonest serious brain disorder and probably the most universal of all medical disorders. It occurs at all ages, especially in childhood and old age, and in all races and social classes. One hundred million people will have epilepsy during their lives. Epilepsy is widely misunderstood, leading to fear, secrecy, stigmatisation, and the risk of social and legal penalties. Still unrecognised in some European countries as a brain disorder, up to 40% of people with epilepsy may be untreated. In specific risk groups the mortality may be twice or more that of the general population. The *ILAE* has published a document on 'Appropriate Standards of Epilepsy Care across Europe. However, many professionals treating people with epilepsy have insufficient specialised knowledge about the condition and in some countries, antiepileptic drugs are either unavailable or unaffordable and diagnostic facilities lacking or inadequate.

Epilepsy has profound physical, psychological, and social consequences:

- *Many children with epilepsy receive inadequate schooling.*
- *Unemployment is disproportionately high for people with epilepsy*
- *Many people with epilepsy hide their condition contributing to social isolation, low self esteem, helplessness and depression.*
- *Many people with epilepsy lack knowledge and women with epilepsy often have inadequate information about pregnancy and child-bearing.*
- *Quality of life in elderly people is often impaired due to unrecognised epilepsy.*
- *Many people with epilepsy have a severe problem with independent mobility.*

The objectives of the *WHO's* Global Campaign against Epilepsy, the *ILAE* and *IBE* are:

- *to increase public and professional awareness of epilepsy as a treatable brain disorder*
- *to raise epilepsy acceptability in the public domain*
- *to promote public and professional education about epilepsy*
- *to identify the needs of people with epilepsy, nationally and regionally*
- *to encourage governments and departments of health to address the needs of people with epilepsy*

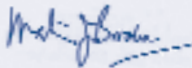
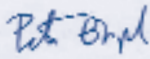
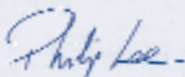
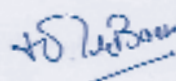
# CALL TO ACTION, EUROPEAN WHITE PAPER ON EPILEPSY

**European White Paper on Epilepsy – Call to Action**

We call upon the intergovernmental bodies and institutions in Europe, and individual Member States, to implement and support the following three actions:

- improve public understanding of epilepsy via educational programmes throughout Europe to raise awareness and reduce stigmatisation of patients
- provide legislation to protect people with epilepsy from discrimination in the workplace to ensure equal job opportunities and thereby reduce the socio-economic burden of the condition
- increase investment in research in epilepsy in order to improve the diagnosis and treatment of epilepsy throughout Europe.

We kindly request a response from the European Parliament following the presentation of the European White Paper on Epilepsy to its members on 22<sup>nd</sup> March 2001.










**Martin J Brodie**  
 Chair of the Scientific Advisory Board  
 EUCARE

**Jerome Engel Jr**  
 President of the ILAE

**Philip Lee**  
 President of the IBE

**Hanneke M de Boer**  
 Chair of the Executive Board of the ILAE/IBF/WHO Global Campaign against Epilepsy

# PROGRAMME PLAN: OUTLINE

**Title of Programme:**

*What is the name of your **campaign**?*

**Objectives:**

*What are you trying to achieve?*

**Key Strategies:**

*How are you going to do this?*

**Sponsoring Agency:**

*Who will you fund your activities?*

**Contact at Agency:**

*Name of person at **sponsoring** agency*

**Description of Need: (why the programme is being developed)**

*Rationale for your **campaign***

**Estimated Costs:**

*Funds required to carry out your **campaign***

**Other Resources Required:**

*e.g. Staff, Computers, Design*

**Primary Target Audiences: (in priority order)**

*e.g. Professional groups, Age, Gender, Ethnic characteristics, Other*

**Potential Problems: (that you and other staff must addresses)**

*e.g. scheduling conflicts, policies, approval*

**Key Strategies:**

*List for each target audience*

**Methods of Evaluation:**

*Include formative, process, and final evaluation strategies*

**Secondary Target Audiences:**

*In priority order*

# MEP BRIEFING PAPER

## Introduction and Background

People with epilepsy in Europe are still discriminated against. Discrimination takes many forms:

- *There is inadequate service provision for those diagnosed with the condition*
- *There is an unbelievably high and unacceptable rate (20-30%) of misdiagnosis across member countries of the European Union delaying treatment and options*
- *There is a disparity in 'inclusive' employment legislation, which fails to support the vulnerable*

The status quo is unacceptable.

The launch of the European *White Paper* on Epilepsy in March 2001 and the accompanying 'Call to Action' was a small step in the struggle to achieve a 'fair deal' for those with epilepsy. The documents highlight several areas that governments must address in order to improve the situation in Europe.

## Parliamentary Advocates for Epilepsy Group

The purpose of this short paper is to set out the aims and scope of an informal *advocacy* group that has been set up to respond to the *white paper*. In bringing about the required change, political support is essential and we hope that you will use your influence in a range of policy areas to improve the daily life of those who live with epilepsy. We believe that the Parliamentary Advocates for Epilepsy Group (PAG) has a fundamental role to play in *campaigning* for change.

## Objectives

The primary aim for members of the PAG is to develop an informed debate about epilepsy issues within the European Parliament. We have identified a worryingly low level of knowledge amongst governments and general public alike about the prevalence and long-term implications associated with epilepsy. These issues need to be addressed before the epilepsy community can realistically look to the future with hope.

In addition to raising the frequency and tone of epilepsy discussion at *EU* level, the PAG will be able to promote the recommendations laid out in the European *White Paper* on Epilepsy's Call to Action, namely to:

- *improve public understanding of epilepsy via educational programmes throughout Europe to raise awareness and reduce stigmatisation of patients*
- *provide legislation to protect people with epilepsy from discrimination in the workplace, to ensure equal job opportunities and thereby reduce the socio-economic burden of the condition*
- *increase funding for research in epilepsy in order to improve the diagnosis and treatment of epilepsy throughout Europe*

We require your efforts to help us improve the state of epilepsy care in each member state. Central to any work that you undertake, as a Group will be your

relationships with not only European institutional officials but with your individual ministries back home (on a political and official level) e.g. we would encourage the Parliamentary Advocates to undertake or commission some research to look at employment legislation in individual countries.

## Opportunities to Increase the Public's Awareness of Epilepsy

Several key politicians have publicly supported the epilepsy community and have called for change. However, we simply do not yet have enough politically experienced speakers to get our messages through to the media and to the public. We are very keen for the Group to develop a plan that would help to address this. We would like to suggest that each member of the Group aims to represent the Group, to a non-medical audience, twice a year. The Secretariat would, of course, assist in the co-ordination of these activities.

## Day to Day Operations

In order to support members of the PAG, a secretariat will be provided which will undertake the following tasks:

- *Produce briefing papers*
- *Organise meetings, produce agendas, take and circulate meeting minutes*
- *Act as central point for enquiries from interested parties*
- *Co-ordinate members of the Group's responses*
- *Keep a comprehensive list of media and speaker opportunities and will assist with the organisation involved in ensuring that the Group has a presence at such events*

We are particularly keen to assist you in any way we can (e.g. provision of relevant case studies, statistics) to help you place pressure at member state and European level to achieve change.

## Relationship with Non Governmental Organisations

Central to the success of the Parliamentary Advocates Group for Epilepsy will be ensuring a constructive and consistent dialogue with patient and *expert* groups within all the member states you represent. The International League Against Epilepsy (*ILAE*) and the International Bureau of Epilepsy (*IBE*) are fully supportive of the Parliamentary Advocates Group. The *ILAE* is the international body of healthcare professionals in the field of research and care in epilepsy. The International Bureau for Epilepsy (*IBE*) is the umbrella group for lay epilepsy organisations. The *IBE* has a network of chapters across the world, which can be called upon to conduct localised lobbying. Both the *ILAE* and the *IBE* are committed to advancing and disseminating knowledge, improving the quality of life of those with epilepsy, the encouragement of increased research and the promotion of prevention, diagnosis, and treatment in epilepsy care.

The *IBE* and *ILAE* will nominate a person responsible for liaison with the PAG.

For more information please contact:

**Karen Donaldson**  
**EUCARE Programme Manager**  
**kdonaldson@eucare.org**

**Hilary Mounfield**  
**Chair IBE-European Committee**

# WORKING WITH THE MEDIA CHECKLIST

## Newspapers / television / radio

- *What sort of news do they print/ broadcast?*
- *Do they cover health issues?*
- *How long / detailed are the stories?*
- *Do they use quotes from third party groups?*

## Features

- *Are there regular health pages?*
- *Does the publication 'crusade' on particular health issues?*

## Medical journals

- *Do they carry news?*
- *Do they carry clinical features?*
- *Do they place articles from **opinion leaders** or physicians?*

## Photographs

- *What sort of photographs does the publication use?*
- *Do they want colour or black and white?*
- *Do they prefer transparencies or prints?*

## Regular columns

- *Do they include regular columns by named journalists?*
- *Do they offer any opportunities for stories in your therapy area?*

## Letters page

- *What types of issues does the letters page cover?*
- *Who are they written by?*
- *Is this a good vehicle for generating discussion about management in your disease area? (especially valuable tool for medical journals)*

## USEFUL CONTACTS

### **Epilepsy Congresses**

ILAE/IBE Congress secretariat  
16 Mountdown Road  
Dublin12  
Ireland  
Tel: +353 1 4097796  
Email: [info@epilepsycongress.org](mailto:info@epilepsycongress.org)  
[www.epilepsycongress.org](http://www.epilepsycongress.org)

### **Epilepsy South Africa**

P.O. Box 73  
Observatory 7935  
SOUTH AFRICA  
Tel:+ (021) 447 3014  
Email: [info@epilepsy.org.za](mailto:info@epilepsy.org.za)  
[www.epilepsy.org.za](http://www.epilepsy.org.za)

*Epilepsy South Africa have developed guidelines for self advocacy for people with epilepsy*

### **EUCARE**

P.O. Box 187  
Leeds LS16 9WA  
Tel: +44 1132 037508  
Email: [kdonaldson@eucare.org](mailto:kdonaldson@eucare.org)  
[www.eucare.org](http://www.eucare.org)

### **European Epilepsy Academy**

EUREPA  
Marawag 21  
D-33617 Bielefeld  
Germany  
Tel: +49 521 144 4310  
e-mail: [eurepa@owl-online.de](mailto:eurepa@owl-online.de)  
[www.epilepsy-academy.org](http://www.epilepsy-academy.org)

*EUREPA is building up a network of co-ordinated, certified epileptological education activities throughout EUROPE*

**European Parliament**

Rue Weirtz  
 B-1047 Brussels  
 Belgium  
 Tel: +32 2 284 2111  
 Fax: +32 2 284 6974

*The European Parliament represents some 375 million European citizens. Citizens have the right to petition the European Parliament. The EU currently has 15 member states and is preparing for the addition of 13 eastern and southern European Countries.*

**International Bureau for Epilepsy**

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 Dublin 12  
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 Tel: +353 1 456 0298  
 Email: [ibedublin@eircom.net](mailto:ibedublin@eircom.net)  
[www.ibe-epilepsy.org](http://www.ibe-epilepsy.org)

*IBE is a global organisation that represents 26 national patient organisations at European level*

**International League Against Epilepsy**

Address: Avenue Marcel Thiery 204, B-1200  
 Brussels Belgium  
 Tel: +32 (0) 2 774 9547  
 Email: [dsartiaux@ilae-epilepsy.org](mailto:dsartiaux@ilae-epilepsy.org)  
[www.ilae-epilepsy.org](http://www.ilae-epilepsy.org)

*ILAE is a global professional organisation which aims to promote research, education and training in epilepsy*

**World Health Organisation**

Avenue Appia 20  
 1211 Geneva 27  
 Switzerland  
 Tel : +41 22 791 2111  
 Email : [info@who.int](mailto:info@who.int)  
[www.who.int](http://www.who.int)

*The WHO promotes cooperation for health among nations and carries out programmes to control and eradicate disease worldwide.*

# MEDIA CASE STUDY: LIVING WITH EPILEPSY

*Remember that personal stories can be used to illustrate your campaign objectives.*



## Sally's Story

Sally Gomersall, 38, was diagnosed with temporal lobe epilepsy before her second birthday. She suffered complex partial seizures, later developing convulsive seizures, before having successful surgery in 1996.

**FEAR** is the word I would use to describe living with epilepsy. Not only *my* fear of a seizure but that of *others* on hearing I had epilepsy. I felt prejudice, stigma and isolation arising from other's lack of understanding of epilepsy. I was embarrassed and became withdrawn. Why was it only me who took pills at school and carried spare clothes in case of a seizure with incontinence? Why me? I felt different and very aware of how others reacted to me. It was worse when I started work. My first manager could not cope with my epilepsy, he pressurised me to stop my seizures – leading to more seizures and I resigned. My next manager also found my epilepsy difficult, transferring me to an office 20 miles away. The extra travelling tired me, increasing my seizures. Once, waiting for a train, I wandered onto the railway line during a seizure. *Not one* person helped me; they thought I was strange or drunk.

My General Practitioner was also ill informed. When pregnant, I asked about possible risks to my baby, he told me foetal damage would have already resulted from my medication. I was anxious during my pregnancy about possible problems with my baby, fortunately he was perfect. However, the disturbed sleep of early motherhood led to more frequent seizures and more anxiety. I thought Social Services would consider me an unfit mother and take my baby away. My weight fell, I couldn't eat or sleep and suffered dreadful anxiety, agoraphobia, low confidence and depression. A specialist epilepsy referral did not happen until after my second child's birth and he told me I was unlikely to reach my 40<sup>th</sup> birthday unless my seizures could be stopped. I was finally confident that someone understood my epilepsy. Just nine months and many tests later, I was referred for surgery. I was not frightened – I just wanted to be free of my 'fear'. After surgery I *knew* I was OK immediately I awoke in intensive care. The 'fear' disappeared with each seizure-free day and my confidence grew proportionally.

Five years later I can say my life has been transformed. I now work to help raise epilepsy awareness; the stigma is not as great as it was, but it will not disappear until we improve public understanding.

**I call upon all MEPs, MPs, journalists and all in the public arena to help us to achieve this.**

**Sally Gomersal**  
**Epilepsy Awareness**  
**148 Winthorpe Road**  
**Newark, Notts**  
**UK NG24 2AP**  
**Email: [epilepsy.awareness@ntlworld.com](mailto:epilepsy.awareness@ntlworld.com)**  
**[www.epilepsyawareness.co.uk](http://www.epilepsyawareness.co.uk)**

FEATURE ARTICLE



Emerging from the shadows

Epilepsy affects over 400 million people in the world, but it remains one of the most misunderstood and stigmatised disorders

By Susan Barry

It was another day at work when I felt the familiar fluttering sensation that has become a constant presence in my life. It was the same as always, a sudden jolt of electricity that seemed to come from nowhere. I had just finished the monthly deadline and was sitting at my desk, trying to catch up on the backlog of work. I felt a sharp pain in my head, and I knew I was going to have a seizure. I tried to hold on, but it was too much for me. I fell back in my chair, and the world around me went black. I woke up in a hospital ward, with a doctor by my side. He told me I had a seizure, and that I was safe. I felt relieved, but I also felt a sense of shame. I had embarrassed myself in front of my colleagues. I had let them see me at my weakest. I had let them see me as a person who was out of control. I had let them see me as a person who was a burden. I had let them see me as a person who was a shadow.



It was only a few days later that I was diagnosed with epilepsy. The doctor told me that I had a seizure, and that I was safe. I felt relieved, but I also felt a sense of shame. I had embarrassed myself in front of my colleagues. I had let them see me at my weakest. I had let them see me as a person who was out of control. I had let them see me as a person who was a burden. I had let them see me as a person who was a shadow. I had let them see me as a person who was a shadow.

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## LETTER TO THE EDITOR



### **Mistakes in diagnosis of epilepsy all too common**

THE disturbing report that a Leicester Royal Hospital consultant misdiagnosed epilepsy in nearly a third of his child patients is not really a surprise.

Research studies over the past five years have consistently revealed that, when patients treated for epilepsy were reviewed, between 25-30 per cent did not have the condition.

There was no public outcry, as has happened with high-profile errors in cancer screening – for epilepsy has never been a health priority.

There is no simple straightforward test for epilepsy. The world's most common serious brain disorder requires expert diagnosis and treatment.

Sadly, what has happened in Leicester is not unique – epilepsy misdiagnosis is certainly UK-wide.

Epilepsy Scotland is working with Scotland's paediatricians to ensure children suspected of epilepsy have an accurate diagnosis.

As Scotland's voice for epilepsy, we must protect vulnerable individuals and their families who have to live with the social consequences of appalling human error. In future, with a Scottish paediatric network, this will not be allowed to happen.

*Allana M Parker,  
Epilepsy Scotland  
Glasgow*

# TEN TIPS FOR MEDIA INTERVIEWS

## 1. Remember your rights

Ask the journalist for information to help you prepare for the interview. What type of story is being written? What's the angle (what is their interest)? Are other people being interviewed? What questions will you be asked?

## 2. Plan your points and make them early

Remember an interview is an opportunity to tell your story. Prepare your key messages in advance and use every question as an opportunity to address your agenda as well as the journalist's.

## 3. Anticipate opposing points of view

Opposing perspectives make news stories more interesting. Learn about the other side and be prepared to present your story without appearing defensive.

## 4. Prepare yourself by knowing the media

You will be more effective if you know other stories the newspaper/journal or programme have recently reported.

## 5. You do not have to know everything

If the journalist asks questions outside of your experience/*expertise* do not make up an answer. You can say that you 'don't know'. However, try to make sure that someone from your team provides the answer in time for the journalist's deadline.

## 6. Be brief

Identify two or three key messages and try to repeat these. It is better to get two important messages across clearly by repeating them several times, than trying to cover more ground.

## 7. Speak the language everyone understands

Avoid *jargon* and technical medical terms. Remember what may seem simple to you can be overwhelming to people with no medical or scientific background.

## 8. If a statement is made that is not true, correct it immediately and politely

Explain why it is incorrect and explain what the true situation/answer is, and why.

## 9. Don't get involved with complex statistics or numbers

Complicated figures can distract from your argument. Use them sparingly.

## 10. Beware of hypothetical statements

If a journalist asks you 'would you say' and then quotes a statement for your agreement or disagreement, don't accept it – make your own statement instead.

# PRESS RELEASE TEMPLATES

## Press Release

### YOUR CONTACT INFORMATION:

Name  
Address  
Telephone  
e-mail  
Fax



### [Title (to attract attention)]

*For example: National scandal – epilepsy services totally inadequate*

### Subtitle *[give more information about the title]*

*For example: Research published today provides evidence of major gaps in the quality of epilepsy health services*

### Embargo *[if there is one date]*

### Date

**Contact Person:** [Name]  
[Organisation]  
[Telephone number]

**Spokesperson** [Name]  
[Organisation]  
[Telephone number]

- Do not write more than one page
- Put the most important facts at the beginning
- Be clear
- Emphasise the message
- Use a quote from a **spokesperson**
- Try to give some background information

### Press Release: ‘European White Paper on Epilepsy’

**PRESS RELEASE – Medical and Consumer**  
**Embargoed until 14.30 CET Thursday 22 March 2001**

## **European Parliament Calls for Action in Epilepsy**

*Epilepsy community unites to raise the profile of the most common serious brain disorder<sup>1</sup> and bring improved levels of care across Europe*

**European Parliament, Brussels – 22 March 2001** – Today *experts* in epilepsy called upon members of the European Parliament, the public and the medical community to share their knowledge and unite in action to improve the lives of the six million people with epilepsy in Europe<sup>2</sup>, with the launch of the European *White Paper* on Epilepsy. Eradication of Stigma, Discrimination in the Workplace, and Inadequate Research Funding were cited as three key focus areas requiring rapid improvement across Europe.

The *White Paper* on Epilepsy, supported by Mr John Bowis *MEP* in conjunction with EUCARE (European Concerted Action and Research in Epilepsy), an educational initiative from UCB Pharma aimed at raising the profile of epilepsy across Europe, has been produced in a timely manner to take advantage of the European Parliament's new remit for Public Health. The *White Paper* has been created by EUCARE in partnership with the Commission on European Affairs of the International League Against Epilepsy (*ILAE*) in support of the *WHO*-led epilepsy 'Out of the Shadows' Campaign – which has recently launched Phase II of its Campaign.

Epilepsy is the most common serious brain disorder in every country<sup>1</sup>, and yet still does not receive the attention it deserves. Mr John Bowis, *MEP* for London, host of the *White Paper* launch meeting in parliament and a campaigner for improved epilepsy care, states: *'This initiative is long overdue and provides us with the opportunity to focus our minds on what can and needs to be achieved for those with epilepsy. I cannot stress enough the urgency of action. Everyone, regardless of position in society, can affect the change outlined in this White Paper on Epilepsy.'*

John Bowis continues: *'I am demonstrating my personal commitment by setting up 'Parliamentary Advocates for Epilepsy' a group of key MEPs specifically dedicated to bringing epilepsy to the forefront of parliamentary health issues, campaigning to improve existing legislation – particularly within the workplace. I urge you to follow suit and take up your role in this bid for change.'*

Epilepsy can affect anyone – it has no age, racial, professional or geographical bounds. It is estimated that 15 million people in Europe will have epilepsy at some time in their life<sup>2</sup>. The real burden of epilepsy cannot be quantified – not only does it have a huge economic impact, costing Europe an estimated 20 billion ECU every year<sup>2</sup>, but epilepsy also has profound physical, psychological, and social consequences on society.

Professor Martin Brodie, Chair of Commission on European Affairs, and Director, Epilepsy Unit, Western Infirmary, Scotland, comments that: *‘The stigma associated with epilepsy is often harder to live with than the condition itself, impacting on many aspects of life, for example, employment. For years epilepsy has been ignored, and I believe this European White Paper on Epilepsy has come at the perfect time. Epilepsy remains notoriously underfunded and misunderstood. This is not a call ‘for’ action, but a call ‘to’ action. Everyone, whether or not they are currently involved in the epilepsy agenda should pick up the banner and support this campaign.’*

The *White Paper* on Epilepsy is intended to be a platform on which local epilepsy programmes can be built. The three key recommendations highlighted for change have a European focus and are achievable goals based upon the public health remit of the European Parliament. John Bowis continues, *‘For maximum impact, the White Paper must be taken up at local country level where specific areas needing improvement must be identified. We hope that the White Paper can act as a springboard from which local action plans can be developed in accordance with their needs.’*

Ends –

To broadcast live from the European Parliament permission is required.  
Please contact Alexander Watson – details provided below.

**For further information on EUCARE, please log on to the website or contact:**

**Karen Donaldson**  
**[www.eucare.org](http://www.eucare.org)**  
**EUCARE Programme Manager**  
**[kdonaldson@eucare.org](mailto:kdonaldson@eucare.org)**

**EUCARE**  
**P.O. Box 187**  
**Leeds LS16 9WA**  
**UK**

## Notes to Editors

**White Paper** – is a statement on a particular topic with appropriate recommendations for political action. The European *White Paper* on Epilepsy has been developed by 37 authors from 18 European countries.

**EUCARE (European Concerted Action and Research in Epilepsy)** – was established in 1998 by UCB Pharma, a Belgian pharmaceutical and chemical company operating globally. EUCARE is a third party organisation dedicated to raising the profile of epilepsy, through educational and political actions, its aim to advance the efforts made to relieve the impact of the condition on the individual and their family across Europe. Activities are guided by a committee of international *experts*.

**ILAE** – International League Against Epilepsy – is the international organisation of healthcare professionals in the field of epilepsy care or research in epilepsy. Its objectives are to advance and disseminate knowledge concerning epilepsy throughout the world; to encourage research, promote prevention, diagnosis, treatment, *advocacy* and care for persons suffering from such disorders; and to improve epilepsy education and training.

**Commission on European Affairs of the International League Against Epilepsy** – chaired by Professor Martin Brodie, the Commission was set up in 1993 to stimulate and coordinate all aspects of epileptology across Europe and has 12 members and 4 subcommissions dealing with specific aspects of the European agenda. The Commission reports to the executive of the *ILAE* and organises biannual European epileptology congresses.

**IBE** – International Bureau for Epilepsy – is an international body of lay epilepsy organisations, clinics and individuals dedicated to the social aspects of epilepsy. The goal of the *IBE* is to improve the quality of life of all adults and children with epilepsy.

**WHO** – World Health Organisation – is a specialised agency of the United Nations. *WHO* promotes technical co-operation for health among nations, carries out programmes to control and eradicate disease and strives to improve the quality of human life.

**‘Out of the Shadows’ Global Campaign against Epilepsy** – is a joint initiative between the *ILAE*, *IBE* and *WHO*, to improve the acceptability, treatment, services and prevention of epilepsy world-wide. The Campaign includes international, regional and national components, which are interrelated.

### References

1. Brodie MJ *et al*, 1997. Commission on European Affairs: Appropriate standards of epilepsy care across Europe. *Epilepsia* 1997; 38 (11): 1245-1250.
2. European Declaration on Epilepsy, 25 October 1998. Issued by the International Bureau for Epilepsy, the World Health Organisation and the International League Against Epilepsy.

# GLOSSARY

<b>Advocacy</b>	.....Active support of an idea or project
<b>Briefing</b>	.....A summary of facts and instructions given for a particular task
<b>Campaign</b>	.....An organised series of actions intended to gain support
<b>Concise</b>	.....Brief but comprehensive
<b>Define</b>	.....To describe, explain or make clear
<b>Embargo</b>	.....To restrict or place under restriction
<b>Ethical</b>	.....Concerning morals, justice or duty
<b>EU</b>	.....European Union
<b>Expert(ise)</b>	.....One with great skills in, or knowledge of a particular subject/area
<b>IBE</b>	.....International Bureau for Epilepsy
<b>ILAE</b>	.....International League Against Epilepsy
<b>Jargon</b>	.....Specialised vocabulary of a particular group or profession
<b>Lobby</b>	.....A group of people who try to influence the government, politicians to favour their cause
<b>MEP</b>	.....Member of European Parliament
<b>MP</b>	.....Member of Parliament
<b>Momentum</b>	.....The speed of progress
<b>News ‘hook’</b>	.....Significant or unusual story angle to grab interest
<b>NGO</b>	.....Non-Governmental Organisation
<b>Outcome</b>	.....The result of an action or situation
<b>Opinion leader</b>	.....A person regarded to be a professional expert
<b>PR</b>	.....Public Relations
<b>Promoting</b>	.....To work for or publicise a cause
<b>Spokesperson</b>	.....A person appointed to speak on behalf of others/group
<b>Sponsor(ing)</b>	.....A person/Organisation that finances an event in return for advertising/promotion
<b>Sponsorship</b>	.....Support (usually financial) for a cause or event
<b>Stakeholder</b>	.....A person with a specific interest in something
<b>Statute</b>	.....A law made by the law making body of a country
<b>Task force</b>	.....A grouping of individuals to undertake a specific task/project
<b>Timescale</b>	.....The time set for completion of a particular project
<b>Umbrella groups</b>	.....A number of groups that are provided protection/cover by a larger organisation
<b>White paper</b>	.....A policy statement issued for the information of Parliament
<b>WHO</b>	.....World Health Organisation







