### Striking Out Against Stroke

a report by Arne Hagen

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Stroke is the term applied to the sudden death of brain cells when a blockage or rupture of an artery impairs blood flow to the brain. Typically, a clot forms in a small vessel in the brain that has been narrowed due to long-term damage. Stroke may also result from:

- a blood clot or fatty deposit breaking lose and lodging in an artery of the brain, thus stopping the flow of blood;
- a blood clot forming in the chamber of a heart that is beating irregularly, breaking off and forming a plug in the brain artery; or
- bleeding in the brain caused by the widening and weakening of a blood vessel in the brain.

#### The Effects of Stroke

In its acute stages, stroke represents a medical emergency and the fatality rate is high. Survivors of stroke have complex care needs, may suffer longterm disability and may need admission to long-term care. Data from the UK indicate that approximately 30% of patients die in the first month after a stroke, 35% are still significantly disabled after one year and 5% have to be admitted to long-term residential care.

Depending on which part of the brain that is affected and how widespread the damage is, the effects of stroke can include difficulties in movement, balance, walking, swallowing, speaking, dressing, feeding, controlling bladder or bowel movements, vision and mood. Stroke survivors also experience much higher rates of depression than non-stroke patients. In a four-year study of stroke survivors, no one reported that their life had returned to normal.

#### **Risk Factors for Stroke**

High blood pressure (hypertension) is the leading risk factor for stroke and is present in the majority of stroke sufferers. In many cases, it is the only risk factor identified in people who go on to have a stroke. The risk of stroke increases the longer a person has uncontrolled hypertension and the higher the level of blood pressure is allowed to climb. Worryingly, patients and the general public alike underestimate the seriousness of hypertension, with two-thirds stating that it was not a serious health concern to them. Other identifiable risk factors for stroke include obesity, type 2 diabetes, high cholesterol levels, smoking, heavy alcohol consumption and the use of recreational drugs, such as cocaine, amphetamines and ecstasy.

While often considered a disease of ageing, approximately one-third of strokes occur in patients under 65 years of age. Stroke events are more common among low-income groups.

#### Incidence of Stroke in Europe

Stroke is the third leading cause of death in Europe, after heart disease and cancer, and the most common cause of adult physical disability, with an estimated 1.4 million stroke deaths each year. By way of comparison, hypertension is 60% more common in Europe than on the North American continent, and stroke is also approximately 60% more common in Europe. Globally, the World Health Organization (WHO) estimates that by 2020, heart disease and stroke will become the leading causes of both death and disability worldwide, with the number of fatalities projected to increase to over 20 million a year and by 2030 to over 24 million a year.

#### The Economic Impact of Stroke

Stroke imposes a significant burden on society and healthcare budgets, accounting for 3–4% of the total healthcare costs in Western European countries. Eastern and Central European countries have higher stroke rates, and with the forecast growth in Europe's older populations, incidence across Europe is set to rise, with a corresponding impact on healthcare budgets.

#### **Preventing Stroke**

The good news is that of all neurological diseases, stroke is the most preventable one. In fact, research shows that two-thirds of physicians consider most first strokes to be avoidable.



Arne Hagen is the President of the Stroke Alliance for Europe (SAFE). He is also a board member of the European Federation of Neurological Associations (EFNA) and President of the Norwegian Stroke Association. Prior to his stroke in August 1997, he was a colonel in the Royal Norwegian Air Force, His service in the air force included Aide de Camp for HM King Olav, Commanding Officer at Bardufoss Air Force Station, Chief of the Foreign Liaison Office Norway and Branch Chief of the NATO headquarters in High Wycombe, UK.

Country	<b>Population</b> (Millions, 2002)	<b>Stroke Disability</b> (DALYs Lost Per 1,000 Population)	<b>Stroke Mortality</b> (Number of Deaths, 2002)
Belgium	10,296	4	9,234
Denmark	5,351	4	4,871
Finland	5,197	4	4,875
France	59,850	3	37,750
Germany	82,414	4	79,326
Hungary	9,923	8	17,148
Ireland	3,911	4	2,650
Israel	6,304	3	2,233
Italy	57,482	4	69,075
The Netherlands	16,067	4	12,459
Norway	4,514	3	4,817
Portugal	10,049	9	20,069
Slovenia	1,986	6	2,003
Spain	40,977	3	34,880
Sweden	8,867	3	9,984
UK	59,068	4	59,322
US	291,038	4	163,768
Canada	31,271	3	15,621

#### Table 1: Data on Stroke Disability and Mortality

\*2003 or latest available data. DALY = disability-adjusted life year.

Three steps that can help reduce the stroke risk are:

- to have regular blood pressure checks;
- to speak to a physician about appropriate treatment for hypertension, diabetes and high cholesterol levels; and
- to make lifestyle changes to improve overall health (such as losing weight, increasing physical activity or giving up smoking).

Even a modest reduction in blood pressure pays large dividends, with as many as four in 10 strokes considered preventable.

#### **Further Steps**

The EU and its Member State governments need to do more through direct intervention in healthcare to reduce the incidence of stroke and its devastating impact on patients, their families and the economy.

#### Raising Awareness of Stroke Prevention

More work needs to be carried out in raising awareness of the link between stroke and hypertension, as well as other contributing risk factors for stroke, and the EU should facilitate the sharing of information and best practices between Member States to develop national stroke prevention strategies across Europe. Realistic targets should be established for stroke reduction across Europe, and progress should be regularly measured and evaluated. Data should be collected on risk factors, incidence, prevalence and the impact on healthcare economics. Member States should be made aware of the clear economic and social benefits of preventive treatment, and should recognise the true financial impact of failing to take early preventive action. Governments should promote programmes for healthy lifestyles and educate people on other risk factors for stroke, such as obesity, high cholesterol levels, smoking and lack of physical activity.

#### **Ensuring Effective Preventive Treatment**

Should lifestyle changes be ineffective, there are proven preventive treatments to reduce stroke in hypertensive patients (e.g. angiotensin receptor antagonists), but access to the most appropriate treatments can be patchy across Europe. The EU should ensure that its citizens do not experience inequalities in access to these important and potentially life-saving treatments. Healthcare professionals need to ensure that best practice is implemented in the management of hypertension and diabetes. Guidelines should recognise anti-hypertensive treatment specifically for stroke risk reduction beyond blood pressure control.

National education programmes should be established to communicate the link between hypertension and stroke and to communicate the importance of early

1. http://www.who.int/cardiovascular\_diseases/en/cvd\_atlas\_29\_world\_data\_table.pdf



For STROKE patients at risk of atherothrombotic events
PROTECTION BEYOND THE ORDINARY





primary stroke prevention in hypertensive patients. Such educational programmes should also focus on the underlying causes for hypertension, as well as lifestyle-related risk factors for stroke.

#### Improving Acute Treatment and Care for Stroke Survivors

More specialised stroke units are needed in much the same way as coronary care units were established more than 20 years ago. It has been shown that acute interventions as well as specialised, dedicated care for acute stroke victims can not only be lifesaving, but also result in long-lasting and substantial decreases in longterm disability. In addition, the disease burden for carers can be minimised when comparing stroke unit care to the care offered on general medical wards.

#### Stroke Alliance for Europe

Stroke Alliance for Europe (SAFE)<sup>2</sup> represents a range of patient groups from across Europe whose mutual goal is to drive stroke prevention up the European political agenda and prevent the incidence of stroke through education. SAFE was launched in October 2004, and was born out of a workshop held in the European Parliament in June 2003 that led to a declaration calling upon the EU and its Member States to tackle stroke as a preventable catastrophe.

SAFE's aim is to:

- · promote awareness and understanding of stroke;
- promote prevention of stroke;
- identify those at risk of stroke;
- improve access to appropriate treatment and care for persons affected by stroke;
- improve the quality of life of people affected by stroke and their families;
- promote better access to accurate and understandable information about stroke;
- increase the priority given to stroke by policy- and decision-makers as well as by healthcare providers;
- promote research in stroke-related areas; and
- co-ordinate the efforts of national stroke patient groups in Europe.

By combining the resources of patient organisations across Europe, SAFE is working to champion stroke prevention, save lives and suffering, and save the European economy millions of euros in healthcare costs. The association will also encourage the creation of national stroke patient groups in Europe where none yet exists.

2. http://www.safestroke.org

#### Stroke Alliance for Europe (SAFE) - Member Organisations

Austria – Österreichishe Gesellschaft für Schlaganfall-Forschung http://www.schlaganfall-info.at

Denmark – The Danish Stroke and Aphasia Association/Hjernesagen http://www.hjernesagen.dk

Finland – The Stroke and Dysphasia Federation in Finland http://www.stroke.fi

France – Fédération Nationale France-AVC http://www.franceavc.com

Germany – Stiftung Deutsche Schlaganfall Hilfe http://www.schlaganfall-hilfe.de

Hungary – ESzME Egyesület a Stroke Megelozéséért http://www.eszme.hu

Ireland – The Irish Heart Foundation http://www.irishheart.ie Israel – The Neeman Association for Stroke Survivors http://www.neeman.org.il

Italy – Associazione per la Lotta all'Ictus Cerebrale http://www.alicecampania.org

The Netherlands – De Nederlandse CVA-vereniging Samen Verder http://www.cva-samenverder.nl

Norway – Landsforeningen for Slagrammede http://www.hjerneslag.org

Slovenia – Zdruzenje bolnikov s cerebrovaskularno boleznijo http://www.zdruzenjecvb.com

Spain – Fundación Española del Corazón http://www.fundaciondelcorazon.com

Sweden – STROKE-Riksförbundet http://www.strokeforbundet.org

UK – The Stroke Association http://www.stroke.org.uk

# EUROPEAN FEDERATION OF NEUROLOGICAL ASSOCIATIONS (EFNA)



# A PARTNERSHIP FOR PROGRESS



In the world of patient advocacy (providing support for people and their families who live with severe illnesses) groups which have formed at a national level often find that there is a need to unite with other countries in a federation to try to influence policy and decision makers at the European level. There are many such federations - in heart disease, cancer and neurological illnesses such as Alzheimer's, headache, Parkinson's, stroke, dystonia, multiple sclerosis and so on. These federations work to focus attention on their particular condition but, often, an even broader coalition can prove to be a more effective lobbying instrument. In this larger format, it is possible to work more effectively on common problems, common legislative needs, common policies. So, EFNA was formed to concentrate on the area of neurology, which is a more easily understood concept for policy makers at the European level who usually work to an agenda of 'public health' rather than the needs of individuals.

EFNA is a 'federation of federations'. It brings together pan-European umbrella organisations of neurological patient advocacy groups, including the groups mentioned above, to work with medical and other associations in the field of neurology in a "Partnership for Progress". Launched in the European Parliament in Strasbourg in 2001, it has grown steadily in strength and influence. EFNA's mission is to contribute to the advancement of neurology and related areas to improve the quality of life of people living with neurological conditions.

Our work covers a broad range. Here are a few of the more recent activities in brief.

**Stem Cell Research in Europe, Brussels, December 2005** - a televised debate with experts from science, religion, ethics, media and politics, to discover the Patient's view. 500 participants, 60% patients.

Helping to form new European patient federations - Closer co-operation at a high level helps individual patients. EFNA recently helped to form the Stroke Alliance for Europe and the European Headache Alliance.

**Parliamentary Partners for the Brain** - An influential group of MEPs interested in brain disorders, who promote our cause in the Parliament.

Working with the **European Commission** in Health and Research.

European Medicines Evaluation Agency - EFNA is represented on the EMEA Managing Board.

**Education** - Among a number of education initiatives, EFNA organises a yearly Awareness Day for patients, carers and scientists within the framework of the congresses of the European Federation of Neurological Societies (EFNS).

**European Brain Council** - EFNA is an active founder member of this broad coalition, with basic scientists, neurologists, psychiatrists, psychiatric patients, neurosurgeons and industry.

Mary Baker, EFNA President, with Janez Potočnik (right), European Commissioner for Research and Martyn Lewis, former BBC newsreader and anchorman, at the recent very successful debate on stem cell research.

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