



POSITION PAPER

March 2004

EUROPEAN PATIENTS DEMAND ACCESS TO INFORMATION FOR ALL DISEASE AREAS

Well informed patients are better off themselves and they are an asset to society.

Well informed patients possess the tools to ensure that they are able to enjoy a better quality of life than would otherwise be the case. They can prove to be an asset, not a liability, to society.

Informed patients are likely to be more discerning about their health, to assume a greater degree of responsibility for its management and to be in a position to make more informed choices and decisions.

Information on health helps to improve citizens' well being, contributes to the prevention of illness and supports patients' understanding of their treatment. This can be achieved by information and education. This means the provision to patients and consumers of sufficient, accurate and objective information which is both easy to find and easily understood. The Internet is one obvious and important medium for that. Patients who are health literate tend to seek more appropriate medical treatment and seek it earlier.

Patients need to understand and believe their diagnosis. They should be fully aware of the treatment options available to them including benefits/side effects of their treatments as well as "how to use" medicines properly. Providing information to patients allows them to participate actively and responsibly in their own health management.

Higher public awareness enables patients to take greater responsibility for their own health and medical treatment. The patients themselves benefit, health care systems benefit and so do budgets through reduced wastage.

The fundamental right to know

The European Patients' Forum (EPF) believes that ALL patients, no matter their condition, background or nationality, have a fundamental and legitimate human right of access to all kinds of information about their health, medical conditions and the availability of treatments including knowledge of the best available management for their disease. They need to understand their condition and to be able to receive information on genetic and hereditary factors, where relevant, and on all available treatments." It is a question of solidarity, equity and patients' rights

From the EPF's perspective EU patients need factually accurate, reliable, easily understandable information to be able to make informed decisions. They need to understand their condition and do want to receive information on treatments available.

As patients, we welcome information from different sources provided they meet the above-mentioned criteria, the ownership of the source is clearly identified and agreed safeguards are in place.

Such information would enable patients all over Europe to:



- enhance the ability to make informed decisions about best disease management in full partnership with health care professionals;
- optimize health outcomes through improved treatment compliance based on our belief that the more informed patients are, the better they understand their treatment and how medicines must be taken;
- make more effective and rational use of the therapies that are available and prescribed;
- increase awareness of risks and benefits of prescription medicines and the importance of reporting and managing possible side effects;
- improve our quality of life by adopting preventative measures, eliminating risk taking activities, seeking earlier diagnosis, recovering faster from illness, avoiding hospitalisation and invasive surgery, and enabling us to carry on with our normal daily routines.

The EPF recognises that governments fear increased pressure on health care budgets since the informed patient might demand better and more effective drugs for his/her diseases. However, we consider this to be a positive consequence of enhanced and more extensive information being available to the public. We argue that informed patients are more efficient and prudent users of health care resources. Often underprescribing, non-compliance or irrational prescribing are a heavier overall financial burden for health care and social security budgets. Better disease management increases the quality of life and well-being of patients.

Information should be seen as an enabling tool to improve health care for all EU citizens - not as a cost/control instrument for EU Member States.

Those suspicious of patient information base their arguments on the US experience of advertising. However, advertising is not equivalent to the provision of information. While we do not want US style advertising, European patient groups that form the EPF are happy to contribute to a more thoughtful and constructive debate, to find a solution for Europe appropriate to the Information Age.

The above position paper was developed within the framework of the European Patients' Forum and was endorsed by the following full and associate member organisations:

Alzheimer Europe
EUROPA DONNA - The European Breast Cancer Coalition
European Alliance of Genetic Support Groups
European Coalition of Positive People
European Federation of Associations of Families of Mentally Ill People
European Multiple Sclerosis Platform
EURORDIS – European Organisation for Rare Diseases
GAMIAN Europe – Global Alliance of Mental Illness Advocacy Groups

The position paper was discussed with and endorsed by:

Standing Committee of European Doctors
Standing Committee of European Nurses



Notes to position paper:

The **European Patients' Forum** was created on 31 January 2003:

- To facilitate an open and inclusive Patients' Forum enabling ALL pan-European patients' groups to exchange information and points of view in the area of EU Health Policy and all other EU initiatives of interest or concern to patients.
- To share health experiences and examples of good practice in order to strengthen the role and voice of European patients' organisations
- To offer the views of patients, as external stakeholder in the European healthcare debate, by means of a broad, truly representative and independent patient group resource. To offer the views of patients, as external stakeholders in the European healthcare debate, by means of a broad, truly representative and independent patient group resource.
- To provide a forum for patients' organisations to develop common positions on European health policy issues and to lobby on behalf of those organisations, giving them a central position in the provision of healthcare in Europe.
- To become the natural first point of reference for the European Commission and other European institutions when seeking the opinions of patients and/or when seeking to consult patient groups.
- To co-operate in the formation and execution of joint projects aimed at improving health outcomes and the quality of life of European patients.

The following organisations are currently **full or associate members** of the European Patients' Forum:

Alzheimer Europe, AMD Alliance International (Age related macular degeneration), DEBRA Europe (epidermolysis bullosa), Euro Ataxia – European Federation of Hereditary Ataxias, EUROPA DONNA - The European Breast Cancer Coalition, European Alliance of Genetic Support Groups, European Coalition of Positive People, European Dystonia Federation, European Federation of Allergy and Airways Diseases Patients' Associations, European Federation of Associations of Families of Mentally Ill People, European Multiple Sclerosis Platform, European Network of (ex) users and survivors of psychiatry, EURORDIS – European Organisation for Rare Diseases, GAMIAN Europe – Global Alliance of Mental Illness Advocacy Groups, Retina Europe.