BRINGING EPILEPSY OUT OF THE SHADOWS
A Global Campaign Is Launched

The hidden suffering of more than forty million people throughout the world, who are affected by epilepsy and have to live secret lives because of ill-informed public attitudes, was highlighted today when the World Health Organization (WHO) announced in Geneva jointly with two nongovernmental organizations (NGOs) the start of "Out of the Shadows -- A Global Campaign Against Epilepsy"

The two NGOs are the International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE). Both ILAE and IBE operate worldwide - the League representing doctors and scientists and the Bureau acting for patients and their families.

"We call upon policy makers, lawyers, health professionals, international and national nongovernmental organizations, as well as donor organizations to join forces in promoting conditions for people with epilepsy to step Out of the Shadows of social stigma, and for this disorder to be drawn out from under the shadow of public health priorities," declared WHO's Assistant Director-General, Dr Fernando Antezana, at a press conference in Geneva.

According to the three organizations, the campaign is aimed at improving health care services, treatment and social acceptance of epilepsy, the world's most common serious -- yet treatable -- brain disorder.

It is medically possible for up to 70% of people with epilepsy to have their condition brought under successful control. However, mainly for social reasons, three-quarters -- or approximately 30 million -- of those affected with the disorder do not receive any treatment at all, and these people are mostly in developing countries.
The global campaign will follow two parallel and simultaneous tracks: the raising of general awareness and understanding of epilepsy, and the rendering of assistance to Departments of Health in identifying needs and promoting education, training, services, research and prevention.

WHO, ILAE and IBE are establishing a common protocol for assessing epilepsy needs in a range of countries. Special target groups for raising awareness about epilepsy include local governments, the general public (including teachers), health professionals, people with epilepsy and their families.

"Out of the Shadows delivers a powerful message to people with epilepsy who feel isolated, misunderstood and neglected," stated ILAE President, Dr Edward Reynolds. "Cancer, leprosy and epilepsy were the three great unmentionables until as recently as 30 years ago. Now cancer is more openly discussed while leprosy is less of a taboo, and we would like epilepsy to go that way. We have to make people aware that epilepsy is a universal brain disorder which responds to treatment. Scandalously, three out of four people in the world with epilepsy are not getting any treatment at all, mainly because of social reasons," said Dr Reynolds.

Another crucial need is to establish a commonly-accepted means of assessing the true cost of epilepsy, its management and the cost-benefit of interventions all over the world. Hanneke de Boer, IBE President, explained: "The human and social consequences of epilepsy must never be understated or forgotten. My colleagues in the Bureau live with the tragedy of epilepsy every day, and our focus is on people and their own unique problems.

"However, we fully accept the reality that an economic case has to be established and actively promoted if we are to persuade governments that greater resources should be apportioned to epilepsy. Similarly, it will be essential to persuade the pharmaceutical industry that it will be in everybody’s interests to make anti-epileptic drugs affordable and easily available for the majority of those who need them, especially people in developing countries," she said.

In 1990, epilepsy accounted for nearly 1% of the world's disease burden, and is comparable in this respect to breast cancer in women, or lung cancer in men. Epilepsy commonly attacks young people in the most productive years of their lives, often leading to avoidable unemployment.

John Bowis, former United Kingdom Health Minister, said: "If nearly three-quarters of people with epilepsy can be treated it makes sense in humanitarian and economic terms to make an effort and face this challenge. One of the first steps in this direction is to create the conditions in which people with epilepsy can seek help without fear of prejudice or penalty, and begin to live normal lives."

Out of the Shadows will be decentralized to answer cultural and economic realities in different regions and countries where the driving force behind it will be ILAE and IBE national chapters assisted, where appropriate, by WHO regional and country offices.
The campaign budgets in each country will depend largely on how active local organizers are. Such budgets could differ widely -- ranging from relatively modest public awareness programmes to training programmes for health workers so that they can identify and treat patients in the community. In Europe, for example, an Academy is being established by ILAE to coordinate and integrate the training programmes hitherto offered separately at some national epilepsy centres.

Supporters of the campaign include former United States Congressman Tony Coelho, who chairs the United States President’s Committee on the Employment of People with Disabilities. Mr Coelho came “out of the shadows” about his epilepsy many years ago.

"Discrimination against individuals with a disability has always concerned me greatly," commented Mr Coelho from Washington DC -- his schedule did not allow him to be in Geneva.

"A few years ago I initiated the Americans with Disabilities Act. It is now US Federal Law which protects people in the United States with disabilities -- including individuals with epilepsy -- from being unjustly denied employment or any of the rights that Americans routinely enjoy. Out of the Shadows is an important step towards a world in which the rights of people with epilepsy everywhere have the same kind of legal protection," said Mr Coelho.

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