BRINGING EPILEPSY OUT OF THE SHADOWS IN AFRICA
Ill-informed Attitudes Prevent up to 80% of Africans Suffering From Epilepsy From Being Treated,
Says WHO

Dakar, Senegal. An estimated 3-4 million Africans, who are affected by epilepsy and suffer from social and cultural stigmas attached to it, will benefit from "Out of the Shadows – A Global Campaign Against Epilepsy", which saw its regional media launch for Africa here today.

The campaign was initiated by the World Health Organization (WHO) and two nongovernmental organizations (NGOs): the International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE). Both NGOs operate worldwide – ILAE representing doctors and scientists and IBE acting for patients and their families.

Out of the Shadows is aimed at improving health care services, treatment and social acceptance of epilepsy as a serious, yet treatable, brain disorder. Raising public and professional awareness and dispelling myths about epilepsy was one of its key elements, especially in Africa, the organizers said.

"An estimated 70% of patients with epilepsy could leave normal lives if properly treated. The cost of the anti-epileptic drug phenobarbitone, which alone can control seizures in a substantial proportion of those with epilepsy, could be as low as US$5 per person per annum," commented Dr Ebrahim Malick Samba, WHO’s Regional Director for Africa, from Harare.

"Yet, in Africa, up to 80% of people suffering from epilepsy did not receive any treatment at all. In very many instances, the reasons for that are not only economic but rather social," he said.

According to the campaign organizers, myths and superstition surrounding epilepsy are to blame. In many African cultures, this brain disorder is associated with evil spirits. In Cameroon, for example, it is still
believed that people with epilepsy are inhabited by the devil. They are not seen as evil themselves – just that the devil invades them and causes them to convulse from time to time. In Liberia, as in many other parts of Africa, epilepsy is related to witchcraft or evil spirits. Most traditional healers in Swaziland mention sorcery as the cause of epilepsy – an enemy sending spirits to invade the body and cause convulsions.

As a result of such misconceptions, the majority of Africans, who have seizures and need proper diagnosis and treatment, do not seek medical advice even when they can afford. Rather, they consult traditional healers, who cannot really help them either get rid of the disorder or control their seizures. Uncontrolled seizures make lives of these people miserable.

It is precisely for this reason that an accurate estimate of the number of Africans with epilepsy is difficult to arrive at. WHO stressed that the existing estimates of 3 to 4 million people with epilepsy in Africa were very conservative.

The organizers emphasized that the available evidence made it possible to suggest that Africans, like populations in other developing countries, suffered more from ill-informed attitudes and social stigma, than from epilepsy itself. At the same time, WHO admitted that as far as epilepsy was concerned, every region of the world was a "developing" region.

"Epilepsy can be treated. Epilepsy must be treated. From a medical point of view that is so obvious," stated Hanneke de Boer, Chairperson of the Executive Board of the ILAE/IBE/WHO Global Campaign against Epilepsy can an epilepsy patient herself. "To promote better services and treatment of epilepsy, we need to encourage patients and their families to step out of the shadows, on the one hand, and to create the conditions, in which they can seek medical help without fear of prejudice or penalty, on the other," she said.

"Out of the Shadows is part and parcel of the new global strategies of the World Health Organization in coping with the hidden and ever-increasing burden of mental illness," commented from Geneva Dr Derek Yach, WHO Executive Director responsible for this area. "Human rights of patients, including those with epilepsy, are at the core of our new strategies and WHO’s work in the field of mental and neurological disorders."

According to WHO’s "World Health Report 1997", more than 40 million people worldwide suffer from different types of epilepsy. Around 85% of these people live in developing countries. The World Bank report "Investing in Health" (1993) states that in 1990 epilepsy accounted for nearly 1% of the world’s disease burden. Epilepsy commonly attacks young people in the most productive years of their lives, often leading to avoidable unemployment.

The media launch of Out of the Shadows in Africa was organized within the framework of the regional conference on epilepsy "Epilepsy: a Health Care Priority in Africa" that was held in Dakar, Senegal, 4-5 May 2000. The conference was cosponsored by WHO, ILAE and IBE. It adopted the African Declaration on Epilepsy, which proclaimed epilepsy a healthy priority in Africa and called for public health measures to improve its treatment and raise public and professional awareness that could counter ill-informed attitudes towards this brain disorder.
MENTAL DISORDERS CAN BEGIN IN TEENAGE YEARS AND GO UNTREATED FOR LIFE

Mental disorders are becoming more common, often beginning in the teenage years and afflicting many sufferers for the rest of their lives, according to an international psychiatric study. Almost half of those who are ill don’t seek help, most are not treated at all, and often the treatment is inadequate – even though effective therapies exist, the research shows.

The findings are published in the latest issue of *The Bulletin of the World Health Organization*. The issue, dated April 2000, is devoted to mental health, and in an accompanying editorial, Who’s Director-General Dr Gro Harlem Brundtland says: "Mental illness suddenly bulks very large indeed. All predictions are that the future will bring a dramatic increase in mental problems. It is a crisis of the 21st century."

The WHO International Consortium in Psychiatric Epidemiology examined data from 30,000 people in seven countries – Brazil, Canada, Germany, Mexico, the Netherlands, Turkey and the United States – Researchers found that 48% of those studied in the US experienced at least one disorder in their lifetime, compared to 40% in the Netherlands, 38% in Germany, 37% in Canada, 36% in Brazil, 20% in Mexico and 12% in Turkey.

Overall, the median age of onset for anxiety disorders was just 15 years, 21 years for substance use disorders and 26 years for mood disorders. Delays in seeking treatment were especially pervasive among people with early onset of symptoms. All three classes of illness were most common in disadvantaged sectors of society, and linked particularly to people with low income and below-average education, or who were unemployed or unmarried.

Anxiety disorders were most likely of the three to become chronic, and more common in women than men, as were mood disorders. Substance use disorders were more common among men.

"The proportion of the life course during which people with mental disorders are actively in [a mental disorder] episode is substantial", the researchers report.

"This substantial burden is especially important in the light of the fact that mental disorders often have a devastating effect on role functioning and quality of life.

"They also have powerful adverse effects on critical life course transitions such as educational attainment, teen childbearing, marital instability and violence."

The researchers add: "It is discouraging to find that the vast majority of recent cases, even those who report substantial impairment, are not in treatment". Whereas it is not yet known whether early treatment
could prevent the adverse life course effects of mental disorders that have early onset, the researchers say it is "critically important" that early "outreach treatment" efforts are refined, implemented and evaluated.

In her editorial, Dr Brundtland says there are several reasons why effective treatment for disorders such as depression is not provided. "The main reasons are the low, priority given to mental health, the traditional centralization of mental health services in large, ineffective and often downright harmful psychiatric institutions, and poor application of cost-effective mental health strategies.

"There is also the stigma of mental illness, which inhibits sufferers from seeking treatment, and which may even limit the willingness of mental health care providers to intervene.

"Mental health depends on some measure of social justice, and mental illness, given its scale, must be treated effectively at primary level where possible."

Dr Brundtland has identified mental health as one of WHO’s main priority areas. The World Health Report, published annually by the Organization, will be devoted to mental health in its 2001 issue.