

## **Out of the Shadows**

### *The Global Campaign against Epilepsy*

The global *Out of the Shadows* campaign aims to stimulate public awareness and appropriate action by all nations to end the hidden suffering of people with epilepsy within their borders.

#### **International Sponsors:**

- World Health Organization (WHO)
- International League Against Epilepsy (international body of physician organizations concerned with epilepsy)
- International Bureau for Epilepsy (international body of patient and family organizations concerned with epilepsy)

#### **United States Sponsors:**

- Epilepsy Foundation (the leading national consumer organization for people with seizures and their families)
- American Epilepsy Society (the professional society for physicians and scientists who conduct research and treat seizures)

#### **Epilepsy around the World:**

Globally, 40 to 50 million people have epilepsy, including nearly 3 million in the United States. Nearly three-quarters of the affected – mostly those with epilepsy in non-industrialized nations – receive no treatment whatsoever for their seizures. Throughout the world, misunderstanding, fear and ill-informed public attitudes toward this common medical condition contribute to widespread discrimination, isolation and social rejection of people with epilepsy.

#### **Impact on People's Lives:**

The World Health Organization reports that, “In terms of productive life-years lost to disability and premature death, the burden of epilepsy ranks with depression and other affective disorders, Alzheimer’s disease and other dementias, and substance abuse; among all medical conditions, it ranks with breast cancer in women and lung cancer in men.”<sup>1</sup>

#### **A Global Call to Action:**

The global *Out of the Shadows* campaign was launched in Geneva, Switzerland with a “call to Governments, Departments of Health, international and national nongovernmental organizations, as well as bilateral and multilateral donors to join forces in creating conditions for people with epilepsy to step *Out of the Shadows* of ignorance and social stigma, and for the disorder to be drawn *Out of the Shadows* of public health priorities.”<sup>2</sup>

## **Two Parallel Goals:**

- 1) The raising of general awareness and understanding of epilepsy, a goal largely that of the Epilepsy Foundation and national consumer organizations around the world.
- 2) The rendering of assistance to Governments and Departments of Health in identifying needs and promoting education, training, services, research and prevention. The professional organizations lead this initiative with assistance from the patient community.

## **Out of the Shadows in America:**

Although an unknown number of epilepsy sufferers go undiagnosed and untreated in the United States, the vast majority of cases receive medical attention. The number-one problem for people with epilepsy in this country – other than their medical care – is society’s reaction to the disorder. The focus of the *Out of the Shadows* campaign in the United States is on increasing research for better therapies and an eventual cure for epilepsy, and on improving public acceptance and understanding of people with the condition.

## **Campaign Led by Grammy Award-winning Rock Star:**

Grammy Award-winner Amy Lee, lead singer and songwriter for the musical group Evanescence, is the American Chair of the International *Out of the Shadows* campaign. “I’m committed to this cause because epilepsy affects someone very dear to me,” she says. “And I’m humbled to know that I can be a catalyst for change. I want to enlighten people about the condition and erase their fears about reacting when someone has a seizure. If more people know how common it is, I’m convinced we will raise more money for research to cure it.”

Ms. Lee is a classically-trained pianist who helped Evanescence ([www.evanescence.com](http://www.evanescence.com)) earn two Grammy Awards in 2004, for Best New Artist and Best Hard Rock Performance for the song “Bring Me to Life.” Adding her voice to the growing international epilepsy movement is a dramatic step towards eliminating stigma and discrimination, particularly among teens and young adults.

## **Keystones to the Amy Lee Out of the Shadows campaign:**

The Amy Lee *Out of the Shadows* campaign will launch in the first quarter of 2006. Key elements of the awareness and research fundraising effort will be a dynamic web site ([www.outoftheshadows.com](http://www.outoftheshadows.com)) and a national toll-free hotline ((888) 886-EPILEPSY). Through audio, visual, and interactive elements, visitors to the internet site will learn about Ms. Lee’s personal commitment to bringing epilepsy out of the shadows. The site will also provide a means for people to learn more about epilepsy and seizures, and to donate to the cause or purchase campaign merchandise.

Ms. Lee’s participation will also include a series of media interviews, recorded broadcast public service announcements, and other initiatives to raise awareness.

Notes to Out of the Shadows:

1. Atlas: country resources for neurological disorders 2004, results of a collaborative study of the World Health Organization and the World Federation of Neurology, Neurology Atlas, Geneva, World Health Organization, 2004, p.48
2. Joint press release issued by World Health Organization, International Bureau for Epilepsy, and International League Against Epilepsy.



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