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THE GLOBAL FUND FOR EPILEPSY: A PROPOSAL

There are an estimated 50 million people living with epilepsy (PLWE) worldwide.¹ In the United States and other high-income countries, PLWE are offered a wide range of advanced diagnostic and therapeutic services. In stark contrast, the vast majority of PLWE in poorer regions of the world receive no care and treatment. Epilepsy is the most common neurologic disorder seen in primary care in developing regions of the world and accounts for 0.7% of the total burden of disease measured in disability-adjusted life years lost.^{2,3} The prevalence of epilepsy is highest in low- and lower middle-income countries according to the World Health Organization.¹ Symptomatic epilepsy may be more common due to greater incidence rates of obstetrical complications, perinatal conditions, neurocysticercosis, malaria, HIV/AIDS, and traumatic brain injuries. In sub-Saharan Africa, many countries have a treatment gap approaching 100%, indicating an absence of health investments, both domestic and external (nongovernmental and official development assistance), to support epilepsy diagnosis, care, and treatment.^{4,5}

PLWE in resource-limited regions experience stigma and discrimination leading to reduced education and employment opportunities. Lack of knowledge about the biological and medical causes and treatment of epilepsy allows the persistence of superstitious beliefs. For example, I treated a young boy with complex partial seizures in rural Kenya with carbamazepine. His mother had similar recurrent seizures but refused to accept medical treatment because she believed her condition was the result of a curse placed upon her by her husband's first wife. PLWE are more likely to have traumatic injuries, including burns sustained from falling onto open cooking fires on the floor (figure). Health care providers are not adequately trained to diagnose and treat epilepsy in many countries, resulting in underdiagnosis, misdiagnosis, and suboptimal dosing of antiepileptic medications. Inexpensive older-generation antiepileptic drugs manufactured in India are widely available but stocked in less than one-third of public sector facilities in developing countries.⁶

International funding for epilepsy-specific programs providing patient care, treatment, and support is extremely limited. A number of neurologic organizations and societies engage in short-term training exchanges, research mentoring, courses, and symposia but do not have the financial or human resources to support large-scale sustainable projects for treating PLWE in resource-limited countries. More than four-fifths of annual funding in the US Global Health Initiative is targeted for HIV, malaria, and tuberculosis (TB). The recent resolution adopted by the United Nations (UN) member states at the World Health Assembly 2012 to reduce preventable deaths from noncommunicable diseases by 25% by 2025 will hopefully raise awareness and funding for treatment of other chronic diseases like epilepsy.

Ministries of Health in lower-income countries are cash poor and rely heavily on the financial assistance, policy guidance, and technical expertise of external partners like The Global Fund to Fight AIDS, Tuberculosis, and Malaria (GFATM). This fund was first publicly proposed in 2001 by UN Secretary General Kofi Annan and awarded its first grants in 2002. The GFATM is self-described on its Web site as “a unique, public-private partnership and international financing institution dedicated to attracting and disbursing additional resources to prevent and treat HIV and AIDS, TB and malaria.” Since inception, over \$16 billion in grants have been disbursed to government agencies and nongovernmental organizations. Donors to the GFATM include high-income countries (United States, United Kingdom, Germany, France, Japan), private foundations (Bill and Melinda Gates Foundation), corporations (Chevron, Takeda Pharmaceuticals), and faith-based organizations (United Methodist Church). A similar public-private financing institution was created to increase access to immunization in poor countries (GAVI Alliance).

A global fund for epilepsy is needed to launch an organized, meaningful, and sustainable response to the massive treatment gaps for epilepsy, which are greatest in low-income countries and rural areas.⁵ Establishing this fund will require the collaboration of major neurology and epilepsy societies and foundations,

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Figure Scars from burns sustained during a seizure



A 21-year-old Ugandan man with untreated epilepsy. Photograph by author.

international public health organizations, thought leaders, and industry. Grants could be awarded to support expert and peer training of primary health workers, procurement of antiepileptic drugs, diagnostic testing, information and telecommunication technologies, and social services. Epilepsy care and treatment should be integrated into established health systems if possible and modeled after successful chronic care programs like those used for the management of HIV/AIDS.⁷ Programs to reach rural or remote populations such as mobile clinics and telemedicine could be developed and tested for feasibility. Grants would be renewed based on the fund's evaluation of a program's impact, cost-effectiveness, and financial transparency and accountability.

The number of PLWE worldwide will continue to rise as a result of projected population growth.

According to the UN Population Division, the population of sub-Saharan Africa is estimated to double by 2050 to over 1.75 billion. With the majority of PLWE in the poorest countries currently receiving no treatment, the time for a global fund for epilepsy is now.

STUDY FUNDING

No targeted funding reported.

DISCLOSURE

The author reports no disclosures relevant to the manuscript. Go to Neurology.org for full disclosures.

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Neurology[®]

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Neurology 2013;80;754-755

DOI 10.1212/WNL.0b013e31828250c5

This information is current as of February 18, 2013

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