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TIME FOR A NEW MARCH OF DIMES

Neurocysticercosis (NCC) is a leading cause of preventable epilepsy worldwide and is endemic in several continents. Despite the obvious mitigating factors of education and enhanced awareness, a surprising lack of investment has been made in cost-effective instructional initiatives at a community level. This needs to change. Because spread of the pathogen is largely a consequence of poor behavioral practices, it can be averted. We propose a disease awareness campaign as an important mechanism to achieve this, a crowd-sourcing strategy similar to the one championed decades earlier by the March of Dimes.

The March of Dimes is an early example of publicizing a neurologic disease of global significance, capturing the hearts and minds of everyday citizens. The March of Dimes was founded in 1938 as the National Foundation for Infantile Paralysis and achieved great success, in part because of the growing popularity of its founder, Franklin D. Roosevelt, and his personal experience with poliomyelitis. Through collection of mere pocket change, both science and awareness were advanced on poliomyelitis. The March of Dimes was one of the earliest campaigns to aid patients with a disabling neurologic disease through mechanisms that are now described by terms such as “microvolunteering” and “crowd-sourcing.” The March of Dimes, in its time, was highly influential (table). With the reduction in seasonal outbreaks of poliomyelitis and the eventual eradication of poliomyelitis in the United States, the March of Dimes successfully contributed to removing the threat and memory of poliomyelitis in the Western world.

Seventy-five years later, the March of Dimes is just one of several exemplary health awareness campaigns that demonstrate the role that outreach initiatives may have in disease elimination and eradication. Whether through celebrity advocates or social networking activities such as the amyotrophic lateral sclerosis ice bucket challenge, raising awareness is an effective strategy for communicable

and noncommunicable diseases alike. Some diseases benefit from health promotional activities through knowledge gains while others do so through funding. Public awareness is not to be underestimated. The power of the crowd may substantially affect the epidemiology of neurologic diseases.

A new March of Dimes. In the spring of 2015, we launched a *Multinational Neurocysticercosis Awareness Campaign*, funded by an educational grant from the World Federation of Neurology. The primary aim of this study is to design and implement practical educational materials on prevention, transmission, and treatment of NCC for a wide target audience, including: (1) the general public, (2) community health care workers, and (3) physicians, focused on countries where NCC is endemic. Popular cartoons, photographs, videos, and practical medical information have been incorporated into the campaign materials for physicians and patients. The power of the internet and the growing international network of neurologists can help this awareness grow.

The burden of NCC. Commonly known as the “pork tapeworm,” NCC is a CNS infection caused by *Taenia solium*.¹ *T solium* is one of the oldest known human tapeworms, yet its impact has remained underappreciated. Likely, it is one of the most common human parasitic diseases worldwide.² The current global burden of NCC is undocumented, since precise estimations of its prevalence are unavailable in most countries. It has been estimated that NCC causes 50,000 deaths each year with triple that number of people experiencing NCC-related morbidities; however, these basic estimates are more than 3 decades old.³ Even this estimate may be modest since subclinical infections can go undetected for months or even years. The tapeworm eggs are highly contagious, and in endemic areas, person-to-person transmission of *T solium* is likely the primary route by which infection is spread.⁴

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Table Campaigns to aid patients with a disabling neurologic disease through mechanisms that are now described by terms such as “microvolunteering” and “crowdsourcing”

Campaign	Year initiated	Target audience	Founders	Amount raised, US \$	Country of campaign origin	Purpose of campaign
March of Dimes	1938	Women, media, government	Patient	>\$2.3 billion since 1970 for March of Babies	US	Awareness, research, patient aid
Amiotrophic lateral sclerosis ice bucket challenge	2011	General public	Patient	>\$100 million	US	Research, advocacy, support, clinical care
Multinational Neurocysticercosis Awareness Campaign	2015	Neurology community, hospital staff, patients, families	Physician/World Federation of Neurology	—	US	Public and health care worker awareness
Bill & Melinda Gates Foundation	2000	Researchers, program implementation organizations	Private philanthropist	\$40-60 billion	US	Research, program implementation, vaccine development
Polio Eradication Initiative	1988	General public with a focus on children and their parents	WHO, national governments	\$10 billion	>200 countries	Vaccination and surveillance for poliomyelitis, a type of preventable acute flaccid paralysis
Global Alliance for the Elimination of Leprosy	1999	Patients, health care workers, governments, nongovernmental organizations	WHO	—	Global	Awareness and monitoring of leprosy, a bacterial infection
Global Campaign Against Epilepsy	1997	Clinicians in developing countries	ILAE/IBE/WHO	—	Global	Awareness, education

Abbreviations: IBE = International Bureau for Epilepsy; ILAE = International League Against Epilepsy; US = United States; WHO = World Health Organization.

Largely a consequence of poverty, there is limited knowledge about the pork tapeworm as well as a lack of awareness about preventive sanitation and hygiene practices.⁵ Awareness initiatives would not only make information more accessible, but could also destabilize one of the disease’s driving forces—infection through a lack of awareness.

A call to action for the neurology community. A partnership for the successful elimination of *T. solium* is a reasonable and worthy goal that could lift the burden of preventable neurologic disorders through basic awareness. If successful, efforts to improve awareness on NCC, currently focused on just one parasite, may soon act as a model of crowdsourcing, specifically “neurocrowdsourcing,” for neurologists and neuroscientists, so that educational materials can offset the severe lack of neurologic care and information where the least resources to combat neurologic diseases exist.

The NCC campaign is focused on expanding the materials to multiple audiences: the patient and family, health care workers, and food handlers. A secondary benefit to this work is the establishment of a network of neurologists and neurology-focused generalists for creation of a multinational team, able to disseminate educational information for neurologic patients. This includes benefits for the future such as a network of individuals who are able to reach patients in disease outbreaks and disseminate information on new medications and treatments.

Educational materials include several languages and media. The figure, part A, shows an English-language poster, also available in Spanish, for health care workers. It features the main character, Ap-Bokto, from an awareness cartoon designed for this campaign, currently being shown throughout the Kingdom of Bhutan, a Himalayan country where NCC education is absent. A poster promoting hygienic practices that will reduce transmission is also available (figure, B). Distribution of materials is ongoing for populations in South America, the Caribbean, Asia, and Africa.

Those who would like to contribute to our growing efforts with materials, ideas, donations, or translation expertise, or are interested in joining this initiative, are invited to e-mail the authors. Current NCC medical brochures and handouts are open access and can be downloaded from: <http://www.massgeneral.org/research/researchlab.aspx?id=1595>.

While there is little dispute that public health campaigns can positively affect the course of disease, their success hinges on collective efforts and commitment of the community. We hope that, with the enthusiasm and support of the neurology community, we can advance current practices surrounding NCC and

reduce its neurologic sequelae worldwide, reminiscent, in some way, of the triumph of the March of Dimes.

AUTHOR CONTRIBUTIONS

Mia Borzello drafted and revised the manuscript for content. Dr. Mateen conceived the concept and design of the manuscript and edited the manuscript. Both authors read and approved the final manuscript.

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