Epilepsy remains the “black sheep” among neurologic diseases. Numerous reports have emphasized that of various neurologic conditions such as stroke, Alzheimer’s disease, multiple sclerosis, and Parkinson’s disease, epilepsy is underrecognized and often poorly funded with regard to clinical care and research. This may be due in part to the ancient nature of epilepsy, with the association of being possessed by demons and spirits. This leads to persistent restrictions in different cultures that stigmatize people with epilepsy over many generations.

An important way to “bring epilepsy out of the shadows” and educate the public about modern concepts that epilepsy is a disease like any other is through awareness. This means taking the opportunity to showcase that people with epilepsy are not much different than anybody else. In fact, most people with epilepsy are successfully treated so that they can lead essentially near normal lives, get married, have children, and participate in modern social and family life. It also is a chance to emphasize that not all people with epilepsy can be treated for their condition and that resources are needed to develop new and better treatment for the 30% or more whose seizures are not controlled with modern medications.

Various efforts have developed over the past decade in different parts of the world to bring awareness about epilepsy to the public. What has been a bit of a debate, however, is whether there should be a single day that celebrates epilepsy around the world, and if so what is a uniformly acceptable date. The International Bureau for Epilepsy (IBE) has taken up this matter and recently announced the creation of an International Epilepsy Day.

The International Epilepsy Day is the focus of this month’s series with several letters and commentaries on the topic. We start with a letter we received from India suggesting a World Epilepsy Day. This is followed by a response by the IBE leadership discussing the creation of the International Epilepsy Day, and the process they went through in selecting a day. Thereafter are commentaries from Emilio Perucca as ILAE President, leaders of the ILAE regional commissions, and from invited nonprofit organizations.

In addition to the letters and commentaries, we offer the readers of Epilepsia the opportunity to express your own views on this subject. Should there be an International Epilepsy Day and if so, what might be appropriate dates to celebrate around the world?
Please go to: http://surveys.verticalresponse.com/a/show/1539433/d7fd0d0199/0 and complete the following poll. We will report the results of this survey in a future edition of *Epilepsia*.

The poll will remain open until January 15, 2015.

1 Which of the following would you most strongly support regarding an international day devoted to epilepsy awareness?

A A single International Epilepsy Day celebrated throughout the world  
B An International Epilepsy Week where different countries, regions, and organizations could organize their celebrations  
C An International Epilepsy Month where different countries, regions, and organizations could organize their particular celebrations  
D Different regions, countries, and organizations should have their own epilepsy awareness days without regard to a single international day  
E There is no need for an International Epilepsy Day  
F Other (please specify)

2 If there was to be a single International Epilepsy Day, which of the following would you most strongly support as THE day?

A Start of the Global Campaign against Epilepsy by the IBE, ILAE, and WHO (June 29)  
B Same day as the European Epilepsy Day proposed by the IBE (second Monday in February)  
C Purple Day (March 26)  
D September 6 (start of the International Epilepsy Congress for 2015)  
E Other (please specify)

**References**

LETTER: WORLD EPILEPSY DAY

Dr MA Aleem is President of Trichy Neuro Association and Former Executive Committee member of Indian Academy of Neurology, a neurologist, and an epileptologist working for the epilepsy awareness in rural area of the central part of Tamilnadu India.

Epilepsy is one of the most common serious brain disorders. Up to 5% of the world population may have a single seizure at some time in their lives. People in many parts of the world continue to perpetuate many myths and misconceptions about epilepsy. These often prevent people with epilepsy from seeking proper medical treatment.

To overcome this problem, three leading international organizations working in epilepsy—World Health Organization (WHO), International League Against Epilepsy (ILAE), and International Bureau for Epilepsy (IBE)—launched the “Global Campaign Against Epilepsy (GCAE)” in 1997 to bring epilepsy, epilepsy patients, their family, and community “out of the shadow.”

To encourage governments, various health sectors, and nongovernmental organizations (NGOs) to address the needs of people with epilepsy—including awareness, education, diagnosis, treatment, care, research services, and prevention—we feel it is necessary to have a “World Epilepsy Day” (WED). We further propose that WED fall on the day when the GCAE campaign in 1997 was declared or when the day ILAE was born on August 30, 1909 in Budapest.

By proclaiming a World Epilepsy Day it is also useful to plan action regarding the incidence, prevalence, economic burden, treatment gap, and above all the stigma of epilepsy in all parts of the world.

There are already examples of epilepsy awareness days in different parts of the world. For example, in India our epilepsy day is on November 17 every year. Each year we can adopt a central theme for the world epilepsy day. This can include topics like epilepsy and women, epilepsy in elderly, epilepsy in transgender, epilepsy in children, and epilepsy in adolescents.

As a neurologist and epileptologist from a developing country and as a professor of neurology dealing with rural patients with epilepsy, I am requesting that the ILAE proclaim World Epilepsy Day to improve global epilepsy awareness, cost-effective treatment, and research activity for epilepsy.

Disclosure

I have no conflicts of interest to disclose. I confirm that I have read the Journal’s position on issues involved in ethical publication and affirm that this report is consistent with those guidelines.
RESPONSE: INTERNATIONAL EPILEPSY DAY

Ann Little is Executive Director of the International Bureau for Epilepsy.

The International Bureau for Epilepsy would like to respond to the letter of Dr. M.A. Aleem, concerning a world day for epilepsy, which was published in Epilepsia.

The International Bureau for Epilepsy (IBE) is very pleased to read of Dr. Aleem’s desire for the creation of a world day for epilepsy, which echoes the voices of a significant number of people who have been calling for the introduction of just such an event for some time.

For many years, IBE and International League Against Epilepsy (ILAE) have been working on a series of initiatives and campaigns to increase public awareness about epilepsy and to improve treatment options for people with epilepsy around the world. As Dr. Aleem mentions, since June 29, 1997 the three-way partnership of the ILAE, the IBE, and World Health Organization (WHO) has been involved in the high profile ILAE/IBE/WHO Global Campaign Against Epilepsy “Out of the Shadows” initiative.

More recently, in February 2011, European Epilepsy Day was introduced, and this has been very successfully celebrated each year since then, by both IBE and ILAE, with activities in the European Parliament in Brussels and Strasbourg, by IBE member associations and ILAE chapters, and by epilepsy centers, schools, and groups across Europe. Since 2012, European Epilepsy Day has been organized by the ILAE/IBE Joint Task Force on Epilepsy—Epilepsy Advocacy Europe—which is co-chaired by Dr. Athanasios Covannis (Greece) and Prof Philippe Ryvlin (France). Each year we mount awareness events in the European Parliament, hosted by Members of the European Parliament. This has provided extensive exposure and a high profile for epilepsy right in the heart of Europe where decisions are made that affect the lives of all those living within the European Union.

In addition to these two successful campaigns, it has also been a long-held desire of both IBE and ILAE to establish an international day for epilepsy. Discussion and consideration of such a day dates back some years. However, deciding a date and developing a strategy for such an event has proved to be difficult for a number of reasons:

1. Initially it had been hoped to have an international day for epilepsy under the partnership of the Global Campaign Against Epilepsy, and for some time ILAE and IBE worked toward this goal. Unfortunately, with a decision made by WHO a few years ago not to introduce any further world health days, this was no longer an option.

2. The second problem, which proved to be the biggest obstacle, was the selection of a suitable date. Unlike a European event, which is less problematic, choosing a day that will suit everyone around the globe is virtually impossible:

   a. When it is summer north of the equator, it is winter in the southern hemisphere. An international day for epilepsy should not be planned to take place either during the annual summer holiday period when people travel away from home and schools are closed, or in mid-winter when days are short and the weather is inclement;

   b. Because a major aim is to draw the attention of national governments to the need for improved services and legislation, the event should take place when parliaments are in session (and not in recess);

   c. Religious events, such as Ramadan, Diwali, Easter, Christmas, and Jewish festivals (to name but a few), must also be respected;

   d. There is the need to avoid overlap with other major world days in order to maximize exposure.

More recently, the decision was made to survey IBE and ILAE members on a choice of three possible dates: March 26 (Purple Day); June 29 (anniversary of the launch of the Global Campaign); and September 6 (opening date of the International Epilepsy Congress, Istanbul 2015). Countries were divided concerning which of the above dates was best, and concerns were raised about each of the dates proposed. The decision was made therefore to reopen discussion, following which a different date was identified and approved by a majority vote of both IBE and ILAE committees.

This new date is the second Monday in February and is suitable for a number of reasons not solely because, to the best of our knowledge, it does not clash with festivals and religious events and is neither mid-winter nor mid-summer.
The date lies close to the celebration of Valentine’s Day, a day that is celebrated around the world. It is a commonly held belief that Valentine had epilepsy.

As an unforeseen bonus, the second Monday in February also happens to be the date on which European Epilepsy Day has been successfully celebrated for the past 4 years. Having both the European Day and the International Day at the same time also helps members in Europe who would have struggled, both in terms of finance and man-hours, to celebrate both events.

Dr. Aleem suggests that August 30 as a world day for epilepsy, marking the anniversary of the foundation of the ILAE. While selecting this date would have merit in bringing focus to ILAE, it would not be appropriate to do so since this is a joint ILAE-IBE initiative. It is also high summer in the northern hemisphere with parliaments in recess.

Now that a date has finally been decided and rubber-stamped, we are confident that International Epilepsy Day will grow to be an important annual event to raise the profile of epilepsy around the world. Between now and the February 9, 2015, ILAE and IBE will be working on plans for the launch of the 1st International Epilepsy Day. With both organizations in official working relations with WHO, and with IBE having Special Consultative Status on the Economic and Social Council of the United Nations (ECOSOC), our organizations can bring a high level of distinction and prestige to the celebration of an international day for epilepsy when we will highlight at international, regional, and national levels, the huge problems still faced by the estimated 60 million people living with epilepsy today worldwide.

We trust that all interested stakeholders will join with us in the launch and celebration of International Epilepsy Day in 2015. Because together we can make a difference.

**Disclosure**

I have no conflicts of interest to disclose. I confirm that I have read the Journal’s position on issues involved in ethical publication and affirm that this report is consistent with those guidelines.
COMMENTARY: WHY AN INTERNATIONAL EPILEPSY DAY?

To address effectively gaps in epilepsy care and awareness, all stakeholders must join forces in implementing coordinated advocacy activities directed to the general public and, ultimately, local and national governments and policymakers. The International League Against Epilepsy (ILAE), the International Bureau for Epilepsy (IBE), and their partners, including the World Health Organization (WHO), have worked for many years toward this goal. The recent ILAE-IBE deliberation to establish an International Epilepsy Day on the second Monday in February, starting in 2015, is one of many steps along this strategy. The rationale and the process behind the establishment of the International Epilepsy Day are explained by Dr. Alleem and Ms. Little in this issue of Epilepsia. We recognize that the selected date is not ideal for all countries of the world, and we are aware that some nations already celebrate an epilepsy day. In fact, we expect and encourage continuation of preexisting national epilepsy days, in addition to the international day. We believe that raising epilepsy awareness on more than one day can only enhance public attention toward a disease that impacts 60 million affected people, their families, and their friends. Establishing an International Epilepsy Day sends a strong message to all communities that epilepsy is a global disease, and that the entire world is mobilizing resources in raising awareness to address its many unmet needs.

The importance of promoting public awareness cannot be underestimated. Having personally participated in such activities in Europe, I could witness how establishing an European Epilepsy Day and bringing Epilepsy Day activities into the EU Parliament became a crucial step in facilitating the preparation and approval of the 2011 EU Written Declaration on Epilepsy by the Parliament. That document led, in the subsequent 2 years, to the European Commission allocating close to €50 million for epilepsy research, and to several member states reviewing the quality of their epilepsy services and epilepsy-related legislation. Through initiatives such as the European Written Declaration, the U.S. Institute of Medicines Report, and the Pan-American Action Plan for Epilepsy, epilepsy is gradually becoming a front runner among health-promoting initiatives in many parts of the world. We are confident that the International Epilepsy Day will improve public awareness in all parts of the world, leading eventually to improved services for diagnosis and management, improved access to antiseizure medicines, and improved funding for epilepsy research.

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DISCLOSURE

The author has no conflicts of interest to disclose in relation to this commentary except for his position as President of the International League Against Epilepsy. The author confirms that he read the Journal’s position on issues involved in ethical publication and affirms that this report is consistent with those guidelines.

REFERENCES

As a member of ILAE, I would like to respond to the letter of Dr. MA Aleem proposing an International Epilepsy Day.

Epilepsy, one of the most common and serious chronic neurologic illnesses, is unique for its high social impact including a high mortality and morbidity, stigma depriving social rights from people with epilepsy (PWE), and a large treatment gap, whereas a majority of PWE are able to carry on a normal life with relatively inexpensive treatment. Burden of epilepsy is a global problem; however, it is much more devastating in poorer regions, where the treatment gap is estimated at around 90%. This unique situation of epilepsy convened a special project, the Global Campaign Against Epilepsy (GCAE), which was implemented in June 29, 1997, by joint partnership among International League Against Epilepsy (ILAE), International Bureau for Epilepsy (IBE), and World Health Organization (WHO). The aim of GCAE was to improve global awareness, fight stigma, and address the treatment gap over the globe. Demonstration projects consisting of public education, training of local physicians or health care workers, and providing free antiepileptic drugs (AEDs) were also implemented in several regions of the world. Outcomes of GCAE were not universally successful, but variable to different regions despite exhaustive efforts and intense investment of available resources. The precept from GCAE was that assignment of project ownership to community members, who are the main body carrying the project into effect, is crucial for long-lasting improvement of treatment gap in the community. GCAE, after 15 years of its implementation, still remains the most important action against epilepsy in many regions including Asia.

In principle, I fully agree with Dr. Aleem in the necessity of having an officially appointed International Epilepsy Day for improvement of global awareness, treatment, education, and research for epilepsy. However, I have some reservations too for his proposal.

One counterargument is that International Epilepsy Day will compete in some way with national and regional epilepsy days or weeks, which already exist in many chapters or regions. The proposal for International Epilepsy Day is based on the premise that we are able to promote ongoing actions against epilepsy in a more efficient way by condensing sporadic activities into one planned action being conducted on a specific day around the globe to maximize its impact. This seems to be an attractive proposal for its being a focused strategy using limited resources in a more efficient way. Events for International Epilepsy Day are usually targeting policy-makers and the general public. Both of are highly characteristic of complex diversities being related to traditions, cultures, social environments, or interests of stakeholders in different regions. Therefore, approaches need to be customized to each society and they will be best thought and most effectively executed by individual chapters, which casts a concern to the formulation of unified joint actions for International Epilepsy Day.

Another concern is related to the appointment of a specific date for International Epilepsy Day. As addressed by the accompanying article written by Ms. A Little, it is almost impossible to find a suitable date for all constituents of ILAE/IBE. After intense discussions at the Executive Meeting on June, 27, 2014, in Stockholm, a majority voting determined the second Monday of February as International Epilepsy Day, which has also been the European Epilepsy Day (EED) since 2011. As she illustrated in the article, ILAE/IBE have been deploying active campaigns toward EU Parliament as well as all across European chapters on EED, thus International Epilepsy Day seems best fit to European chapters for further promotion of EED, while it is a disaster to China. The holiday season of Chinese New Year varies every year from late January to early February, which makes it impossible for China and many other chapters in the Southeast Asia to do anything for the public or policymakers. It should not be overlooked that these chapters have been engaged in very active agenda for actions against epilepsy on their national epilepsy day over many years (since 2007 in China), which is now exposed to a serious threatening by the appointment of International Epilepsy Day. It seems also possible for some other chapters...
in the globe that are running active social agendas on their national epilepsy day, which was determined by their best preference, are now exposed to similar threatening.

Lastly, I am concerned about the cost-effectiveness of International Epilepsy Day. Planning and execution of worldwide events on International Epilepsy Day may require dedicated human resources, meetings, and conferences for communications among central offices of ILAE/IBE and individual chapters, and a large investment of financial resources, which may draw available resources away from many important projects for the interest of regions or individual chapters to the setting up of unified worldwide events for International Epilepsy Day, which may not be cost-effective at all.

It should be noted that the success of International Epilepsy Day depends on the concept and strategy being equally shared and respected by each stakeholders of the global epilepsy community. The appointment of a specific date for International Epilepsy Day requires a flexible approach considering the position of individual chapters or regions rather than its being a subject for a majority voting.

Resource allocations for International Epilepsy Day should be made on the basis of harmonization, applying more weight to developing countries. ILAE/IBE needs to provide guidelines for the planning and execution of events for International Epilepsy Day and organize networks for cross-communications and support, whereas individual chapters and regions should take initiatives in planning and execution of suitable actions for their societies. Annual reports and audits for the events and outcomes of International Epilepsy Day are an essential process for future progress of the day. As all chapters agreed to have International Epilepsy Day, it may be the right time to organize a task force for its successful promotion.

**DISCLOSURE**

I received honorarium for lectures from UCB Pharmaceutical, Inc. and Korean GlaxoSmithKline. I received a research grant from UCB and Janssen Korea. I confirm that I have read the Journal’s position on issues involved in ethical publication and affirm that this report is consistent with those guidelines.
The Commission on European Affairs of the International League Against Epilepsy (ILAE-CEA) read with great pleasure the letter by Dr. MA Aleem, concerning a world day for epilepsy, which was published in Epilepsia. We agree that an international day for epilepsy would contribute significantly to overcome the problems caused by misconceptions and myths about epilepsy.

The ILAE-CEA together with the International Bureau for Epilepsy (IBE) has successfully organized the European Epilepsy Day since 2011. These events proved to be extremely helpful in attracting the attention of the society and of the political decision makers to epilepsy. We are convinced that an international day for epilepsy would be even more efficient in doing this; therefore, the ILAE-CEA fully supports this initiative. CEA is also in favor of merging the regional and the International Epilepsy Days. Celebrating one and the same day all over the world is likely to be more effective than to split the attention into different days. However, regional and national activities should continue to play important roles in the International Epilepsy Day.

It is difficult to find the best timing for an International Epilepsy Day, as one has to take into account various competing events worldwide. The IBE and ILAE executive committees suggested the second Monday in February. The CEA supports this date. Fortunately it coincides with the European Epilepsy Day, facilitating the merging between the regional European and the international events.

We suggest naming the event International Epilepsy Day.

Best wishes

Disclosure

I have no conflicts of interest to disclose. I confirm that I have read the Journal’s position on issues involved in ethical publication and affirm that this report is consistent with those guidelines.
The North American Commission of the ILAE applauds the establishment of an International Epilepsy Day. This venture has been a result of fruitful collaboration between major advocacy and professional epilepsy organizations, the International Bureau for Epilepsy (IBE) and the International League Against Epilepsy (ILAE). The process of choosing a single day for this important recognition has been difficult. After much concerted effort to balance differing worldwide schedules, holidays, and even seasons, we feel that the February date can be embraced internationally and utilized to best promote epilepsy awareness, education, and advocacy across nations.

**Disclosure**

I have no conflicts of interest to disclose. I confirm that I have read the Journal’s position on issues involved in ethical publication and affirm that this report is consistent with those guidelines.
Seizure disorders are widely misunderstood by the general population, yet most people know someone who has been diagnosed with epilepsy. Treatment and quality of life can be enhanced through improved awareness and understanding of epilepsy—or “the epilepsies”—by those affected by recurrent seizures and by their friends, family, health care providers, teachers, colleagues at work, and strangers met in restaurants or on sidewalks. Epilepsy does not respect international borders. To this end, a day to raise awareness of epilepsy around the world can have meaningful impact.

The tuberous sclerosis complex (TSC) community understands the consequences of misunderstanding and the impact of increased understanding. TSC is a rare genetic disorder affecting roughly 50,000 individuals in the United States and 1 million worldwide. TSC causes nonmalignant tumors to form in many different organs, primarily in the brain, eyes, heart, kidney, skin, and lungs. The aspects of TSC that most strongly impact quality of life are generally associated with the brain: seizures, developmental delay, intellectual disability, and autism. Thus, TSC can be considered one of “the epilepsies” in the sense that approximately 85% of those affected by TSC will experience seizures during their lifetime—most commonly in early childhood when the developmental consequences can be severe. Everyone with TSC is affected somewhat differently, much in the way that no two people with epilepsy have identical experiences, which makes it all the more important to make others aware of how such a disorder does or does not affect one’s life.

Since 2012, TSC organizations around the world have celebrated TSC Global Awareness Day annually on May 15. Through various activities on social media, a radio media tour, a Congressional briefing, face-to-face gatherings, and lighting Niagara Falls “TSC blue,” more people become aware of TSC each year. Equally important, those affected by TSC and their loved ones have become more empowered to advocate for themselves. There is no single best way to care for someone with TSC; not everyone has access to the same types of medical care, and not everyone is affected by the disorder in the same way. TSC Global Awareness Day brings basic education to the general population and provides those affected by TSC with specific information to help them advocate for themselves and their loved ones in their own way, and in their own language, to best meet their own needs.

An International, Global, or World Epilepsy Day to empower those with epilepsy and to educate the global population can make a difference. The epilepsies know no calendars, no religious traditions, and no languages. The choice of date and title should be made rapidly by representatives of the major international epilepsy organizations so that the educational process can begin as soon as possible. The TSC community is eager to participate in a worldwide day for epilepsy education and advocacy to improve the lives of those affected by seizure disorders everywhere.

**Disclosure**

I have no conflicts of interest to disclose. I confirm that I have read the Journal’s position on issues involved in ethical publication and affirm that this report is consistent with those guidelines.
A Call to Action

It is well known that epilepsy is a common, often devastating disease leading to great disabilities, lost wages, lost productivity, and emotional burden for individuals and nations. Epilepsy has, for decades, been identified as a large contributor to death and disability in every nation around the world. Despite calls to action by the World Health Organization (WHO), Institute of Medicine (IOM), and others, this serious and common disease is overlooked, underfunded, underdiagnosed, undertreated, and overly stigmatized. There are many possible causes of our sad state of affairs with regard to epilepsy. I propose that stigma has stopped individuals from talking about epilepsy and has led to a lack of public awareness and lack of public outrage. I argue that creating and sustaining a state of public outrage over the many challenges posed by epilepsy is paramount to creating change in public policy, funding, diagnosis, treatment, and stigma.

I recommend that the WHO, International Bureau for Epilepsy (IBE), and International League Against Epilepsy (ILAE) collaborate to create an International Epilepsy Day with strong media coverage as a first step toward international public policy change. It is the responsibility of those involved in the epilepsy communities to join together in raising epilepsy awareness. It is imperative that such a day be about those affected by epilepsy, with the goal of raising awareness (not funds), and without “ownership” by any one group. It is time for us to put our alliances to individual groups, causes, specific patients, or fundraising aside. It is time now for the logical, yet somehow radical, step of joining together with egos set aside to improve the plight of persons with epilepsy and their communities with our unified support of an International Epilepsy Day.

Disclosure

I have no conflicts of interest to disclose. I confirm that I have read the Journal’s position on issues involved in ethical publication and affirm that this report is consistent with those guidelines.