

MICHIGAN STATE
U N I V E R S I T Y

18 March 2011

Selection Committee
C. Peter Magrath/WK Kellogg Foundation Engagement Award
C/O Ms. Jean Middleton
A*P*L*U
1307 New York Avenue, NW
Suite 400
Washington, DC 20005

Dear Selection Committee:

Thank you for considering our enclosed application for the 2011
C. Peter Magrath University Community Engagement Award.

**WORKING TOGETHER TO IMPROVE THE LIVES OF PEOPLE AFFECTED BY
EPILEPSY IN ZAMBIA**

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**INTERNATIONAL
NEUROLOGIC &
PSYCHIATRIC
EPIDEMIOLOGY
PROGRAM
(INPEP)**

Regional Location: North Central

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My partners and I are very honored that Michigan State University has endorsed our application for this award. In today's global neighborhood, transnational partnerships offer important opportunities for US engaged scholarship that enhances academic development while also working with our community partners to address the unmet needs of vulnerable international populations.

Thank you for consideration of this application.

Gretchen L. Birbeck, MD MPH DTMH FAAN
Director & Associate Professor
International Neurologic & Psychiatric Epidemiology Program

Abstract

Epilepsy is a neurologic disorder that results in recurrent, unprovoked seizures. The biomedical burden of epilepsy can be substantial, but for many the social consequences may be just as extreme with epilepsy victims suffering from social abandonment and economic and physical vulnerabilities. For more than 10 years, the Chikankata Epilepsy Care Team, a collaborative project between Michigan State University and the rural Zambian community of Chikankata, has worked to improve the lives of people with epilepsy. What began as a local nurse-medical student partnership in one small rural Zambian hospital has grown into a program that supports and enriches clinical services and advocacy programs throughout Zambia. The scholarly contributions from this work are regularly utilized by the World Health Organization in the development of more optimal programs of epilepsy care and care delivery in Africa. In March 2010, this MSU-Zambia collaboration was declared to be “a global success story” by the US National Institute of Health’s Fogarty International Center.

Epilepsy Care Team members serve as expert advisors on community-based epilepsy care for the Zambian Ministry of Health, the World Bank and the US Institute of Medicine. Through research and advocacy, they have identified global problems in drug access for people with epilepsy in low income countries, famine-related drug toxicity and the lack of appropriate treatment for co-morbid HIV and epilepsy in most of Africa. Recognizing the imperative for knowledge to impact policy, they work tirelessly to bring their findings to the attention of key stakeholders and policy makers.

In 2007, Dr. Birbeck, an Associate Professor at Michigan State University and Director of the Chikankata Epilepsy Care Team, was selected as an Ambassador for Global Research by the Paul Rogers Society. She has been featured in the Lancet Neurology and has over 60 publications related to her research in sub-Saharan Africa. Since joining MSU in 2000, she has been awarded over 2 million dollars in funds for research and capacity building in sub-Saharan Africa.

Narrative Response

Relationship and Reciprocity between the University and Community

As a medical student, I undertook an elective rotation at Chikankata Hospital in rural Zambia, curious to see how medicine was practiced without the advanced technologies and extensive resources available in the US. Among the many devastating conditions I observed, I found the realities of epilepsy the most disturbing. Epilepsy, a condition characterized by recurrent, unprovoked and usually unpredictable seizures, is a treatable condition. My experience in the US had led me to believe that most people with epilepsy could live full and active lives, but the social and medical realities of the lives of people with epilepsy in the Chikankata community were soul crushing.

No one with epilepsy was receiving treatment for their seizure disorder and I found myself caring for children and adults with fatal and/or seriously disabling burns that occurred during a seizure often while the family stood by too paralyzed by contagion fears to pull them from the fire. Children with epilepsy were routinely ejected from schools and often prevented from playing with other children—dooming them to social isolation and long term economic vulnerability. In moments of confidence, women with epilepsy offered details of spousal and familial abandonment with subsequent social vulnerability, physical violence and sexual assault. Epilepsy wasn't formally recognized as a common chronic condition in the community and yet the consequences of untreated seizures filled the hospital. This paradox deserved formal investigation. After completing my training in neurology, I returned to Zambia and with other concerned healthcare workers at the hospital undertook a formal study hospital-based study of epilepsy at Chikankata.

The hospital-based study confirmed several disturbing facts. People with epilepsy were presenting to the hospital with their seizure-related injuries but not with their seizures. Most of the inpatients we identified with epilepsy were admitted with severe burns or fractures experienced during a seizure, but they had failed to mention the seizure or their epileptic condition to the admitting healthcare

provider. Less than 10% of the people with epilepsy we saw as inpatients had ever been treated for the disorder and even among those who had been identified and treated, the prescribing healthcare worker, usually a clinical officer or nurse, had provided doses of antiepileptic drugs (AEDs) for seizure prevention in doses so low as to be essentially useless. Clearly, the healthcare workers required additional training in epilepsy care. At this time we also noted that the hospital, which routinely registered patients with chronic conditions to assure sufficient medications were kept in stock, had only 32 people with epilepsy in their registry. This was a very low number given the catchment area of 65,000 and led us to conclude that there were many cases of epilepsy in the community which are unrecognized and untreated. Indeed, our subsequent population based prevalence study identified almost 2,000 people with epilepsy in the catchment area.

Our findings are congruent with what has subsequently become evident globally. Approximately 80% of the 50 million people with epilepsy worldwide live in resource poor regions¹. Epilepsy represents 0.49% of the global burden of disease and among neurologic disorders it ranks third after dementia and cerebrovascular disease in terms of its contribution to global disease and disability¹. Epilepsy is the most common chronic neurologic disorder in sub-Saharan Africa (SSA)^{2,3}. The WHO estimates that a years supply of phenobarbitone could cost as little as \$5 per person⁴ yet the treatment gap, meaning the proportion of people with active epilepsy who warrant treatment but who are not receiving it, remains >90% in most SSA countries⁵. The avertable burden of death and disability due to epilepsy in SSA is particularly disturbing. WHO estimates indicate that 41% of all lives lost and disabilities due to epilepsy could be regained if drug availability could be scaled up.

The early initial hospital-based studies of seizures and epilepsy at Chikankata involved collaboration with several clinical officers and nurses who shared my concerns that we were missing something when it came to epilepsy in the community. When our investigations began to provide insights into the local burden of disease, hospital administrators gained an interest. The busy (and expensive to run)

burns unit was filled mostly with people with epilepsy and seizures accounted for a substantial proportion of the ICU admissions. In 2000, with support from hospital administration and seed money from Michigan State University, the Chikankata Epilepsy Care Team (ECT) was founded. The initial Chikankata ECT Coordinator was, Mrs. Ellie Kalichi. Prior to accepting the position of ECT coordinator, Mrs. Kalichi was Head of Nursing at Chikankata Hospital. Having completed additional training in leprosy diagnosis and control in Tanzania, she also served as the hospital's Leprosy Control Officer. Her work with leprosy had given her great social insights into the burden of stigmatized conditions in the community. These insights proved critical for guiding the direction of the ECT teams work and the development of additional partnerships within the broader community.

The Chikankata ECT provides clinical services, conducts research and supports local capacity building and medical education in Zambia. I spend 4-6 months a year on site annually and when I am absent the ECT team remains in weekly contact with me by email and Skype. Specific activities related to our work are detailed in Table 1. Over the past 11 years, the Community partners involved in ECT activities has expanded to include collaborative partners from other Zambian healthcare institutions, faculty from the University of Zambia and Chainama Hills College, and officials from the Zambian Ministry of Health. The ECT work is predicated upon its grassroots partners from the community including teachers, clerics and traditional healers. As Director of the ECT, I work with my Zambian academic colleagues on grant preparation and research dissemination. As a healthcare worker at Chikankata, I provide inpatient, outpatient and community-based care.

The agenda for the ECT, is guided by the priorities determined within the community of grassroots stakeholders and as well as the Zambian academic community. All activities (teaching, community education, healthcare service delivery) are undertaken in such a way to allow an academic evaluation of the circumstances in the community and impact of the activity. As such, the academic productivity associated with the various activities has been substantial. Importantly, findings from these scholarly

activities are relayed back to the community for their interpretation and feedback. The process of developing by consensus the agenda for the ECT activities includes ongoing, regular informal communications as well as formal meetings with community representatives and ~ biannual retreats with academic and professional partners.

Numerous MSU students, staff and faculty are closely involved in the partnership. Graduate and medical students have participated in clinical and research rotations including six students whose thesis dissertations have been based upon work in Zambia. Two Fulbright scholarships and two Fogarty Student Fellowships have been awarded. Senior MSU grants administrators have traveled to Zambia and led training courses for Zambian grants administrators. US neurology residents who have worked with me in Zambia have gone on to develop similar projects in other African countries.

The Chikankata ECT is an entity jointly supported by Chikankata Mission and Michigan State University (MSU). The Epilepsy Care Team obtained its initial funding from MSU and is supported further through my leadership role and the regular stream of MSU visiting scholars and students. This unique partnership is fully congruent with MSU's mission to *advance knowledge and transform lives* by (mission statement in italics); (1) *Providing outstanding undergraduate, graduate, and professional education to promising, qualified students in order to prepare them to contribute fully to society as globally engaged citizen leaders. The Epilepsy Care Team's work has offered numerous MSU students opportunities for direct global engagement in a community-based, international academic endeavor,* (2) *Conducting research of the highest caliber that seeks to answer questions and create solutions in order to expand human understanding and make a positive difference, both locally and globally. The Epilepsy Care Team's work has resulted in more than 40, full-length, peer reviewed publications. Individuals involved in this partnership now regularly serve as advisors to the World Health Organization, the US National Institute of Health, and the World Bank. Healthcare policy at the local, national and international level has been directly*

impacted by the Epilepsy Care Team's work, (3) *Advancing outreach, engagement, and economic development activities that are innovative, research-driven, and lead to a better quality of life for individuals and communities, at home and around the world.* More than 2 million dollars in extramural research funding has been obtained for activities that include direct service delivery and outcomes assessments related to services. The number of people with epilepsy in the Chikankata catchment area receiving regular care has improved substantially—the burns unit closed in 2005!

The Impact on the Community Partners

As noted above, the initial funding for the Epilepsy Care Team's work was seed money from Michigan State University. Subsequently, funding has been acquired from the Lancet International Fellowship, the Rockefeller Brothers Fund, Doris Duke Charitable Foundation, the US National Institute of Health, the World Federation of Neurology, and several private donors. In kind contributions have been made (staff, space, etc.) by Chikankata Mission Hospital, the Zambian Ministry of Health, and the University of Zambia. These resources as well as the healthcare policy and clinical care guidelines improvements made possible through the work have substantially impacted the community and specifically the lives of people with epilepsy and those affected by epilepsy.

The Impact on the University Partner

The positive impact of this work on the University is evident through the activities the directly concur with the University's mission statement and those detailed in Table 1. MSU has long valued global partnerships and recognized itself as a "world grant" university. In 2005, MSU's commitment to the Epilepsy Care Team's work was further demonstrated when it committed over \$900,000 to the establishment of the International Neurologic & Psychiatric Epidemiology Program (INPEP). I serve as Director for this relatively new academic unit. Two additional full-time faculty members have been recruited and an INPEP fellowship is sponsored. INPEP's mission is to undertake research on neurologic or psychiatric conditions that impact public health in developing regions of the world.

Multidisciplinary training and collaborations involving MSU experts in neurology, psychiatry, epidemiology, and radiology are central to this effort. Additional expertise includes those found in the social sciences, anthropology, political science, health services research, and the basic biomedical sciences. The research undertaken by INPEP strives to place the diseases under study in the appropriate social and geopolitical context.

Lessons Learned and Best Practices

The most critical challenges faced initially in this collaboration related to the inclusion of research endeavors within the structure of service delivery. Challenges primarily related to issues of trust. Most of our Zambian partners had witnessed “research mercenaries” in action—US academics who parachute in, collect their data and fly away never to be heard from again. Our long-term commitment to the project has been an essential part of developing trust. As our Zambian grassroots partners came to appreciate their central role in determining research priorities, their concerns have dissipated. Findings and best practices from epilepsy Care Team work are being incorporated into programs in other regions of Zambia and several other African countries.

Future

The Chikankata Epilepsy Care Team activities continue in full force. We are presently in the 3rd year of a 5 year NIH-funded project to evaluate the impact of a series of multifaceted community-based interventions aimed at improving healthcare services and decreasing epilepsy associated stigma. In February 2011, we were awarded an NIH grant to conduct a cohort study of HIV-associated seizures and epilepsy. We continue our community-based outreach activities with school-based interventions planned for 2011 and work with traditional healers planned for 2012. If awarded, funds would be used to support ongoing, community-based activities that are unassociated with an active research project. This includes Epilepsy Care Team visits to Rural Health Centers to provide direct patient services and assure the medication supply chain remains intact.

Table 1: Examples of Activities of the Chikankata Epilepsy Care Team

<i>Improving Healthcare Services</i>
<p>Improved clinical service provision to people with epilepsy in the community. In addition to epilepsy care provision at the Epilepsy Care Team office adjacent to the hospital, the Epilepsy Care Team mobile clinic makes weekly visits to the rural health centers serving our district to assure drugs are available and provide more advanced services to people with epilepsy closer to their own homes. Training of primary healthcare workers through a grant from the Lancet. Healthcare workers who underwent this training lobbied for its incorporation into the basic curriculum for clinical officers in Zambia. With funding from the World Federation of Neurology formal training materials were developed and an ongoing visiting professorship was funded to assure that experts return annual to train and re-train the trainers.</p>
<p>With faculty from the University of Zambia, we co-founded the Neurologic & Psychiatric Society of Zambia (NPSZ), which is a professional organization of healthcare workers who focus upon neurologic and psychiatric disorders. NPSZ has been an important organization for providing expert advice to the Ministry of Health and for offering continuing medical education opportunities for physicians in Zambia. NPSZ was awarded funds from the World Federation of Neurology to begin development of a Center of Excellence which will focus on epilepsy care</p>
<i>Advocacy</i>
<p>Co-founders of the Epilepsy Associate of Zambia led by a past graduate of the Lancet-funded training program. This is a grassroots organization affiliated with the World Health Organizations International League against Epilepsy and is focused upon the “Out of the Shadow Campaign” aimed at bringing epilepsy out of the shadows.</p>
<p>Ongoing peer support group activities are supported by the Chikankata epilepsy Care Team. As research endeavors have expanded to include other Provinces, such opportunities for people with epilepsy have also expanded. We are aware of at least 20 such groups now meeting in 3 provinces.</p>

First to notify the World Health Organization and then publish reports describing

- Antiepileptic drug toxicity related to extreme weight loss in famine (8)
- The lack of appropriate medications for treatment of co-morbid HIV and epilepsy(9). As a result of our work, the World Health Organization and the American Academy of Neurology has developed a joint committee to develop formal guidelines and recommendations for the treatment of co-morbid epilepsy and HIV. I serve as the Chair of the committee.
- Unintended consequences of World Health Organization programs to improve pharmaceutical regulations that have resulted in a global decrease in treatment availability (publication pending in the American Journal of Tropical Medicine & Hygiene). A World Health Organization Task Force has been formed to evaluate and address this new problem.

Teaching/Capacity Building

- Neurologic rotations are available to Zambian medical students. No other neurology rotations are available in country. MSU medical students have also taken advantage of this opportunity.
- Several Master's level students in Zambia have worked with the Epilepsy Care Team as part of their training. I have served as the primary advisor for 2 such students and am presently the primary advisor and mentor for Zambian PhD and one Masters students studying issues related to epilepsy, stigma and co-morbid social and medical problems in Zambia.
- Additional training for grants administrators in Zambia has been provided in Zambia by MSU administrators funded through my NIH R01 award.

Research

Over 2 million dollars in research funds, mostly through NIH, have been awarded to support the research related to this work and over 40 peer-reviewed publications have resulted from the research findings.

Appendix

I. Excerpts from letters of support from community partners

The following are direct excerpts from letters of support from Zambian partners, which were often quite lengthy. Full letters are available for review.

Richard Bradbury-previously Chikankata Hospital Manager Administration. Presently Director of Research and Development for the Salvation Army.

"Through its research, education and outreach programme, coupled with the dedication and commitment of Dr. Birbeck, the Chikankata ECT has broken down barriers and made seeking advice and treatment more accessible and acceptable for those who require it. The results speak for themselves. This has been achieved by working through the existing community groups and the local health care system, led by Chieftainess Mwenda. The effective partnership and innovative ways of working has attracted great interest across Africa and as a result this good practice has been transferred to other areas of Zambia.

Central to the success of this programme is that Dr. Birbeck and staff that the Chikankata ECT have worked extremely closely with local community leaders and developed an excellent relationship with local tribal leader, Chieftainess Mwenda. Without the support and partnership, it is difficult to see how this programme would have succeeded. The staff and students, under the guidance of Dr. Birbeck, have worked with a cultural sensitivity not often seen by partners from outside of Zambia. They became accepted as trustworthy and respected medical practitioners and researchers, and people were prepared to listen to their advice. This privilege has to be earned in rural Zambia.

Finally, I want to add that there have been a number of additional indirect benefits to the hospital and wider Chikankata community due to this partnership. The hospital, College of Nursing, and College of Biomedical Sciences were often able to draw on the expertise of the visiting staff and students. The research and data of the Chikankata ECT also assisted in the wider health planning of the Hospital and particularly its primary health care wing. The outreach activities also helped to reduce the expensive inpatient care within the struggling hospital.

I cannot speak highly enough of the collaboration between Michigan State University and the local Chikankata community through the work of Dr. Birbeck and Chieftainess Mwenda. It has been a partnership in the true sense of the word and an outstanding success in many different ways"

Professor Elwyn Chomba, MD-Consultant Pediatrician for the University of Zambia

"Gretchen Birbeck works tirelessly to raise funds from donors and with support from the hospital they continue to provide not only health care to the community but also help to alleviate the suffering arising from acute disasters. The best example was in 2003 when famine hit the community; she spearheaded a plan to have food donated to people with epilepsy who were hit most hard by lack of food."

Edward K. Mbewe-Principal Lecturer, Chainama hills College Hospital

"What is outstanding about Dr. Birbeck is the ability to work not only with fellow professionals but with the community as well. For instance, she managed to train a team of Clinical Officers and nurses specifically on neurological conditions and built a formidable team that has since been conducting community support visits, taking antiepileptic drugs into the villages, visiting families of people with epilepsy and continuously engaging the team in research activities.

To this effect, Dr. Birbeck's Chikankata work has not only become something to talk about, but the only example in Zambia demonstrating what a community can do when given the right direction and support by expertise from the outside with no ulterior objectives. While many outsiders have come to initiate projects in Zambia, the issue of sustainability has always eluded them as soon as they left the country. This is not the case with Chikankata Epilepsy Care Team.

I would be failing myself if I do not mention the special qualities of Dr. Birbeck, especially in the area of identification of negative or positive potential in people, and the ability to form lasting formidable teams at both the professional and community levels. Another quality is her ability not to easily lose friends whether highly or lowly educated something that makes it very easy to work with her. Because of this, Dr. Birbeck has contributed a great deal in supporting the policy of the 'Girl Child' in rural and urban settings, as seen in her balanced engagement of female colleagues in every community activity she undertakes. It is clear that on her contribution to the country's development, Dr. Birbeck's role cannot be overlooked as her services go beyond the borders of Chikankata when it comes to teams she has built and research works she has conducted in Zambia. For instance, she has been identified with work in HIV and AIDS, febrile convulsions, and population study of epilepsy..."

Fridah Kabwenda-Epilepsy Care Team Coordinator

With Dr. Birbeck's knowledge, experience and ideas management of this once feared disease has been eased as many patients come to receive medical attention, reducing the risk of complications which result from receiving treatment from traditional healers. Dr. Birbeck has made sure that epileptic drugs are always available and are accessible by providing them to all Rural Health Centers in the catchment area. This has allowed epilepsy care delivery closer to patients and patients are testifying how these drugs have managed to reduce seizures considerably giving young epileptic patients a chance to attend school and hope for a better life which without Dr. Birbeck's efforts these children would have been condemned to a life time of poverty and marginalization because of lack of education and stigma.

Medical staffs of Chikankata Mission Hospital including clinical officers, nurses and pharmacists have benefited from the interaction with Dr. Birbeck such that even in her absence they continue providing primary health care to epileptic patients and their acquired knowledge has earned the confidence of patients and their families alike such that they are adhering to treatment which has helped most of these patients live a normal life."

Roy Baskind, MD FRCP ABPN—North York General Hospital, University of Toronto (Previous neurology fellow serving Chikankata)

"Finally, Dr. Birbeck's scholarship and research arising out of this partnership has been phenomenal. Dr. Birbeck has become a world leader and expert in international and tropical neurology and this particular partnership has served as a model for effective collaborative healthcare in underserved areas of the world. Indeed, this has been included in a publication of the Institute of Medicine of the National Academy of Sciences—Mental, Neurological, and Substance Use Disorders in Sub-Saharan: Reducing the Treatment Gap, Increasing Quality of Care.

I cannot emphasize enough the incredible healthcare, education, research and community building value of this project and Dr. Birbeck's involvement in it."

II. Key Publications

Books

Eds. J Engel, GL Birbeck, AG Diop, S Jain & A Palimini. *Epilepsy: Global issues for the practicing neurologist*. 2005 Demos, New York.

GL Birbeck. *Where There is No Neurologist*. 2002 World Federation of Neurology
http://neurology.msu.edu/downloads/where%20there%20is%20no%20neurologist_whole%20book.pdf
Peer-Reviewed Full Length Original Research:

EK Mbewe, LR Uys, GL Birbeck. Detection and Management of Depression and Anxiety as Comorbidities of Epilepsy in Primary Health Care Settings in Zambia. (Submitted to *Curationis* 5 March 2011).

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GL Birbeck. The healthcare workforce for epilepsy in resource-poor settings: What will work? What is realistic? *Epilepsia* 2008;49(9):1642-1643. PMID: 18782215.

GL Birbeck. Epilepsy, AIDS pose medical dilemma in developing world. *Detroit Free Press*, December 11, 2007.

GL Birbeck & K Rockwell. Social inequities worsened by stigma: The experience of women with epilepsy in Zambia. *Medical Humanities Report* 2007;28(4):1-3.

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Letters to the Editor:

T Munsat, J Aarli, Weiss, GL Birbeck. Educational Programs of the World Federation of Neurology. *Neurology* 2009;72(10):e46-9. PMID: 19273819.

GL Birbeck, E Chomba, E Ddumba, F Kauye, J Mielke. Lack of appropriate treatment for people with comorbid HIV/AIDS and epilepsy in sub-Saharan Africa. *Epilepsia* 2007;48(7):1424-5. PMID: 17635568.

GL Birbeck, EMN Kalichi. Famine-associated AED toxicity in rural Zambia. *Epilepsia* 2003;44(8):1127. PMID: 12887449.

Book Chapters:

GL Birbeck. Medical treatment of epilepsy in situations with limited resources. In: S Shorvon, E Perucca and J Engel eds. *Treatment of Epilepsy 3rd edition*. Oxford University Press. ISBN-13: 9781405133833.

GL Birbeck & TE Taylor. Malaria. In: Jose Biller, editor. *Neurology & Internal Medicine*, Lippencott, Williams & Wilkin Publishing. 2007 Chapter 101, pages 616-620.

AC Meyer & GL Birbeck. Parasitic Infections of the CNS. In: Sid Gilman, editor. *Neurobiology of Disease*. Elsevier Publishing 2007. Chapter 41, pages 453-472.

GL Birbeck. HIV Neurology in the Developing World. In: Aminoff, Boller, & Swaab editors. *HIV/AIDS and the Nervous System* 2007:33-44.

GL Birbeck. Childhood malaria as a risk factor for epilepsy in the tropics. In: Sinha KK and Chandra P (editors). *Advances in Clinical Neurosciences*. Catholic Press, Jharkhand, India. 2003:155-173.

Extramural Grants

Past Funding:

2006-2007	Rural Antiretroviral Adherence in Zambia (RAAZ) Doris Duke Charitable Foundation ORACTA Program (\$200,000)
2003-2006	Epilepsy-Associated Stigma in Zambia (EASZ) US National Institute of Health NINDS R21 NS48060 (\$340,547)
2002-2005	Chikankata Epilepsy and Fever-associated Seizure Study (ChEAFS). Rockefeller Bros/Charles E. Culpeper Medical Scholars Program (\$324,000)
2001	Neurology Where You Need It The Lancet International Fellowship Grant (£25,000)
2000	Where There is No Neurologist World Federation of Neurology Education Grant (\$5,000)

Ongoing Funded Projects:

Epilepsy Associated Stigma in Zambia: Evidence-Based Interventions & Outcomes
US National Institute of Health 1R01NS061693 (\$1,456,095)

Evaluating the Impact of EEG and Neuroimaging Technologies on Quality of Care and Clinical Outcomes for People with Seizures in Zambia
US National Institute of Health 1R01NS061693-03S1 (\$62,029)

A Cohort Study of Seizures and Epilepsy in HIV+ Zambian Adults
US National Institute of Health 1R21NS0735091(\$244,750)

III. Select News Releases

Feature Interview announcement online for Zambian Blogtalk
Feature Article: Greater Lansing Woman January 2008
Nature Reviews Neurology, Volume 7, January 2011.
Lancet Neurology, Volume 6, January 2007
JAMA Feb 3, 2010
The Hill, May 22, 2008
Yahoo News-India

IV. Letter of Support from MSU's President Simon

Elizabeth Arden

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FEATURED

EPISODE NOTES

Host Name: [ZambiaBlogTalkRadio](#) Follow

Show Name: [Dr. Gretchen Birbeck- Epilepsy Care in Zambia](#)

Date / Length: 1/22/2011 12:00 PM - 57 min

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Description: Dr. Gretchen Birbeck, is an [Associate Professor](#) at Michigan State University, and also serves as Director, International Neurologic & Psychiatric Epidemiology Program. Dr. Birbeck spends several months in Zambia, serving as Director for Epilepsy Care Team in Mazabuka and Honorary Lecturer at the University of Zambia's Department of Internal Medicine. She will discuss her Epilepsy Care work among rural communities in Zambia. Join us for another exciting

collapse

Category: News

Tags: [Dr. Gretchen Birbeck](#) [Epilepsy Care](#) [Chikankata Mission Hospital](#) [Michigan State](#) [International neurology](#)

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Epilepsy Experts Focus on Treatment Gaps

Tracy Hampton, PhD

BOSTON—Although the diagnosis and treatment of epilepsy have advanced substantially in recent years, this progress has not reached most of the 50 million people around the world who have the seizure disorder, including many of the nearly 3 million in the United States. This treatment gap was a focus of attention at the 63rd Annual Meeting of the American Epilepsy Society, held here in December.

"Many patients do not receive state-of-the-art care, and in some regions of the world, 90% of patients with epilepsy are not on any medication," said Steven Schachter, MD, professor of neurology at Harvard Medical School, in Boston, and president of the American Epilepsy Society. The heavy toll imposed by undiagnosed, untreated, and suboptimally treated epilepsy is significant, diminishing quality of life and raising risk of disability and death for many individuals, he said.

DEVELOPING NATIONS STRUGGLE

Zambia, Africa, Gretchen Birbeck, MD, MPH, has witnessed barriers to epilepsy care at every level—individual, family, community, health care system, and national policy. Most prevalent are



Gretchen Birbeck, MD, MPH (second from right), and her epilepsy care team treat patients in Zambia with epilepsy and work to expand neurological care in the community.

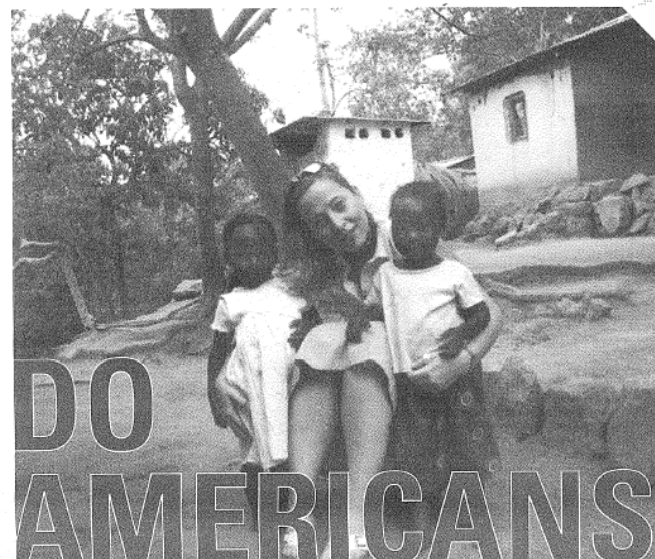
advocates for improving individuals' and families' socioeconomic status and education to reduce stigma and misconceptions, collaborating with village leaders and traditional healers to provide appropriate epilepsy care, improving access to affordable medications, and promoting legislation against discrimination.

Altruistic incentives are not the only reasons to attempt to improve epilepsy care in developing countries, Engel noted. "The world is smaller, and our health depends on global health," he said. In addition, because an increasing number of patients in the United States come from developing nations, physicians must become familiar with cross-cultural issues. Engel also stressed that improving health care in countries with limited resources could provide insights into how to make health care more cost-effective at home. "Developing world conditions are not limited to developing countries; they exist here too," he said.

Birbeck agreed. "Are the issues and challenges facing persons with epilepsy in the US vs Zambia so very different?"

THE HILL THURSDAY, MAY 22, 2008

PAUL G. ROGERS SOCIETY AMBASSADOR Gretchen Birbeck, MD, MPH, DTMH, Michigan State University
LOCATION A small village outside of Blantyre, Malawi
HER PLEDGE Create interventions to reduce the development of epilepsy in survivors of severe malaria.



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Gretchen Birbeck: a Zambian experience



For more on Birbeck's work in Zambia see *Lancet Neurol* 2002; 1: 58-61

Not many western neurologists choose to devote their career to helping people living in a far-flung country. But Gretchen Birbeck, who grew up in a small town in southern Indiana in the American mid west, has been working on and off as a neurologist in Zambia for over 10 years now. In that time she has managed to create two lives for herself: she spends 6 months of the year working in Zambia and 6 months back home in Michigan, where she is director of the International Neurological and Psychiatric Epidemiology Program at Michigan State University.

In her early years as a doctor in the mid 1990s, not many

the less-developed world. Their study shows that people living with epilepsy in Zambia are likely to be poorer and of lower social status than people living with other non-stigmatising chronic disorders. Importantly, poverty has direct implications for the health of people living with epilepsy: obtaining water from rivers or cooking over open fires can have devastating consequences for someone prone to unpredictable seizures.

For behind the statistics are startling stories of people struggling to cope with a life devastated by uncontrolled seizures. Birbeck recalls one 36-year-old male patient who travelled 16 hours by bus to attend her clinic in

A SPARTAN CAN SAVE LIVES IN ZAMBIA



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Cerebral malaria linked to epilepsy, behavior disorders: Study

ANI

Wed, Nov 17 04:30 PM

EPILEPSY

Preventing epilepsy in malaria survivors

Nearly one-third of cerebral malaria survivors develop epilepsy or other neurological conditions soon after recovery. A new study has demonstrated that improved seizure control and management of aggressive fever caused by malaria could provide the key to decreasing the risk of developing epilepsy.

"A prospective study was needed to identify potential opportunities for interventions that might prevent epilepsy," explains lead investigator Gretchen Birbeck. To determine whether the seizures and fevers experienced by patients with

plight of patients with epilepsy who must endure the social stigmas that accompany their condition, which prevents some individuals from seeking medical attention for seizure-related injuries.

In resource-limited areas, the drugs typically used to treat seizures—including benzodiazepines and phenobarbital—often cause respiratory suppression, and ventilation support is frequently not accessible. Finding suitable, inexpensive drugs that can be administered within basic clinical environments is, therefore, an important challenge in improving the



The Blantyre Malaria Project Epilepsy Study team making home-based visits to ascertain outcomes in cerebral malaria survivors. Photograph by Michael J. Pritchard.

MICHIGAN STATE UNIVERSITY

March 15, 2011

Selection Committee
C. Peter Magrath/W.K. Kellogg Foundation Engagement Award
Association of Public and Land-grant Universities
1307 New York Avenue, NW, Suite 400
Washington DC 20005

Dear Selection Committee:

Michigan State University faculty, staff, students, and alumni work to advance the common good in uncommon ways. For more than 150 years we have worked to democratize higher education and help bring academic innovation into everyday life. Foremost among our values are quality, inclusiveness, and connectivity.

At MSU, engagement is defined as “a form of scholarship that cuts across teaching, research, and service. It involves generating, transmitting, applying, and preserving knowledge for the direct benefit of external audiences in ways that are consistent with university and unit missions.” MSU’s dedicated scholars create and apply knowledge as they work to provide sustainable solutions to the world’s most pressing problems.



OFFICE OF THE PRESIDENT

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It is an honor to provide a letter of endorsement to the Selection Committee for the C. Peter Magrath/W.K. Kellogg Foundation Engagement Award nomination representing Michigan State University. The **Working Together to Improve the Lives of People Affected by Epilepsy in Zambia** project is led by Dr. Gretchen L. Birbeck, Associate Professor and Program Director of the International Neurologic & Psychiatric Epidemiology Program. This project is an exemplary international effort that demonstrates MSU’s commitment to collaborative, participatory, empowering, systemic, and transformative work anchored in scholarship.

Dr. Birbeck began a working collaboration in Zambia in 1994 when she arrived as a medical student. For 16 years she has worked closely with the Chikankata community in the rural southern province to improve the lives of people with epilepsy and their families. Since 2000 the epilepsy care team has provided clinical services, conducted research, and supported local capacity building and medical education in Zambia. Results include: tireless advocacy efforts such as co-founding the Neurologic & Psychiatric Society of Zambia (NPSZ), teaching and training opportunities for physicians in Zambia, over two million dollars in research funding, and scholarly output in more than 30 peer-reviewed publications. We are most proud that the efforts undertaken by Dr. Birbeck have resulted in a direct impact on global health policy to the World Health Organization, and other key stakeholders. The **Working Together to Improve the Lives of People Affected by Epilepsy in**

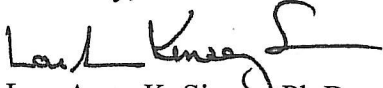
Zambia project is an outstanding example of scholarship applied to community-based needs in a global context, designed to demonstrate the disciplinary impact of university-community collaboration.

The longevity of the project, the support and involvement by community participants, the Zambia academic community, the Zambia government, and the World Health Organization make this an extraordinary recommendation on behalf of Michigan State University. We value the longstanding collaboration between Dr. Birbeck and Chieftainess Mwenda of the Basanje Royal Establishment, and the Chikankata community, and commend the research and advocacy that have led to substantive and positive impacts for epilepsy patients and their families.

I invite you to contemplate the breadth, depth, and impact of the work associated with Dr. Birbeck's project. It is an honor to endorse this application for the 2011 C. Peter Magrath/W.K. Kellogg Foundation Engagement Award.

Thank you for your consideration.

Sincerely,


Lou Anna K. Simon, Ph.D.
President