

Summary of meeting of the North American Clinical Research Consortium (NACC)
November 4, 2010, Atlanta, Georgia

A brief meeting of the NACC was held on November 4, 2010 between 7:00 PM and 8:00 PM at the Atlanta Hilton. Members who were attending the annual meeting of the American Society of Tropical Medicine and Hygiene in Atlanta, Georgia participated.

The NACC holds monthly audio meetings to further the goals of the consortium. The Atlanta meeting was similar in format and replaced the audio meeting for the month of November 2010.

The goals of the NACC at this meeting were to discuss the steps required to perform a retrospective review of patients with subarachnoid neurocysticercosis and to comment upon the contents of a position paper prior to submission. The position paper provides support for the importance of neurocysticercosis worldwide and the goals of NACC.

The participants were:

- 1 Christina Coyle Albert Einstein College of Medicine
Bronx, NY
christina.coyle@einstein.yu.edu
- 2 Siddhartha Mahanty National Institutes of Allergy and
Infectious Diseases
Bethesda, MD
smahanty@niaid.nih.gov
- 3 Theodore Nash National Institutes of Allergy and
Infectious Diseases
Bethesda, Maryland
tnash@niaid.nih.gov
- 4 Jose Serpa-Alvarez Baylor College of Medicine
Houston, Texas
jaserpaa@bcm.tmc.edu
- 5 Paul Southern UT Southwestern Medical Center
Dallas, TX
paul.southern@utsouthwestern.edu
- 6 Mitch Wallin VA Medical Center & Georgetown
VA Medical Center
Washington, DC

mitchell.wallin@va.gov

7 A. Clinton White University of Texas Medical Branch
Galveston, TX
acwhite@utmb.edu

8 Joe Zunt University of Washington
Seattle, WA
jzunt@u.washington.edu

The immediate goals of the NACC are to retrospectively review important aspects of the history, presentation and course of patients with subarachnoid neurocysticercosis evaluated and treated by participating members, develop standardized methods to test patients with neurocysticercosis for antibody and antigen levels and to publish a “position paper” stating the importance of neurocysticercosis globally and in the U.S., and to enlighten the North American practitioners about the goals of the NACC. The present meeting continued the ongoing discussions required to meet these goals. The operational steps required to achieve these goals were discussed. For the retrospective review these include the following steps: 1) create a data collection form to record important information for each patient 2) develop common radiological staging criteria that adequately reflects the extent and severity of the disease at presentation and over time, and 3) obtain IRB approval for chart review for each institution. Progress for each of the steps were discussed at the meeting similar to discussions held monthly.

1. Retrospective review of subarachnoid patients

- a. Radiological staging- Staging criteria and a data form were earlier presented to the group. Criteria were developed by a neuroradiology group at NIH and consist of assessments for each space around the brain and identification of other areas of involvement and complications. Descriptors include involvement for each subarachnoid space, presence of mass effect and parasite membrane and their appearance, and presence of enhancement, vasculitis, hydrocephalus as well as involvement of spine. There was some discussion about the importance of size measurements of the subarachnoid cysts. The NIH radiologist felt that measurements of size are highly variable and also very subjective. As an alternative, assessment of change in size of the involved spaces over time was suggested. Members are to go study the criteria and present it to other neuroradiologists for their comments on the staging criteria. Also the staging needs to be validated to determine if the changes recorded adequately represent changes that occur post treatment and/or over time.

- b. Data collection form - the form is essentially complete and awaits addition of the radiological staging criteria.
 - c. IRB approval - exemptions for consent from the IRB are required for each participant institution. Only a few of the members/institutions have IRB approval. These include Jose Serpa at Baylor/ Houston, Theodore Nash and Siddhartha Mahanty at NIH, possibly Christina Coyle at Albert Einstein.
 - d. Patricia Wilkins from the CDC did not attend the meeting. Post meeting, Dr. Wilkins received reagents to perform antigen testing of sera and CSF to diagnose and follow patients with neurocysticercosis. The literature and experience at NIH suggest that the level of cysticercal antigen is helpful in knowing whether treatment is successful and when to stop anthelmintic treatment.
2. Position paper - A manuscript is in the final stages of revision. Chris Colye heads the group writing the paper. The scope of the manuscript has gradually increased to include assessments of the importance of neurocysticercosis in areas of the world where the disease seems to be most prevalent. Although exact numbers of afflicted individuals are not known, similar to most other neglected diseases of resource poor countries, there are reasonable data to indicate that the prevalence of infection and disease are significant in many areas of the world where cysticercosis is not well studied, such as in Sub Saharan Africa. We argue that the numbers with epilepsy due to neurocysticercosis is massive with millions suffering from seizures due to this disease.

We anticipate completion of the position paper in the next month and final submission following approval of the NACC. The retrospective review should also be ready to begin pending finalization and approval of the radiological staging by the group and approval by the IRBs. The meeting was concluded about 8:00 PM. The monthly audio meeting is scheduled for the 3rd Wednesday of December as usual.