Commonwealth Neurotrauma Initiative Trust Fund

Meeting Minutes September 21, 2007

Members Present

Richard Bendall, Jr., MD Monelison Family Physician, Lynchburg Terry Glenn Department of Corrections, Richmond

Doug Harris, J.D. State Health Commissioner Designee, Richmond Gregory Helm, M.D., Ph.D. University of Virginia Medical Center, Charlottesville

Teresa Poole Lakeview Blue Ridge, Blacksburg

David Reid, Psy.D., Chair
Jim Rothrock
Comprehensive Health Systems, Fishersville
Department of Rehabilitative Services, Richmond

(*Ex-officio*)

Members Absent

Staff

Kristie Chamberlain Department of Rehabilitative Services, CNI Program

Administrator

Patti Goodall Department of Rehabilitative Services, Manager, BI/SCI

Services

Guests

Eric Messick Joint Legislative Audit Review Commission (JLARC)

Kelli Williams Virginia Commonwealth University (VCU)

David Gater, MD, Ph.D. McGuire Veterans Administration

The Commonwealth Neurotrauma Initiative (CNI) Advisory Board met for a regular quarterly business meeting in Conference Room 135 at 1606 Santa Rosa Drive in Richmond, Virginia. Dr. David Reid, Chair, convened the meeting at 10:08 a.m.

Public Comment Period

A public comment period was held. No public comment was taken.

Approval of June 1, 2007 Minutes

Dr. Bendall made a motion to approve the minutes with amended change [page four should read "December 7" not "December 8" for next meeting date]; Terry Glenn seconded the motion. The motion passed unanimously.

Approval of September 21, 2007 Agenda

Doug Harris made a motion to approve the agenda of the September 21, 2007 meeting; Terry Glenn seconded. The motion passed unanimously.

Presentation from Kelli Williams, Research Fellow, Virginia Commonwealth University Dr. Juan Carlos Arango and Ms. Kelli Williams came to the Board during public comment at the June 1, 2007 Board meeting marketing a multidisciplinary conference on cultural / ethnic issues affecting the treatment, care, and access to services for individuals with TBI. The conference would be the first of its kind in the nation to feature leading experts from across the country to present data, share strategies, and promote translational research on minorities with brain injury. Virginia Commonwealth University is looking for donations upwards of \$50,000 to plan and organize a conference of this magnitude and asked CNI to contribute to the conference with a stipend to support it. After the June meeting, the Advisory Board asked Dr. Arango and Ms. Williams to come back in September and give a status report of financial donations and other progress made to date.

Ms. Williams presented the Board with information on planning accomplishments to date for the conference projected to occur in October/November 2008. Ms. Williams presented information on total expenses for the conference averaging about \$56,950. Total Revenue to date is at \$16,000, so monies needed are \$41,000. Partners to date are: The Henry Kesler Foundation, the Center for Capacity Building for Minorities with Disabilities Research, National Institute on Disability and Rehabilitation Research, Virginia Commonwealth University, and the Traumatic Brain Injury Model Systems National Data and Statistical Center. Ms. Williams commented that next immediate steps to seek support would be with: the American Congress of Rehabilitation Medicine, the Brain Injury Association of America, the International Brain Injury Association, and the American Psychological Association. The Board recommended a few other options for funding through NAACP and the Urban League etc. Discussion ensued among Ms. Williams and the Advisory Board. When asked in an ideal world how much money Ms. Williams would ask CNI to contribute, she said \$41,000, but in a realistic world she was asking CNI for \$25,000 towards the conference. The Board thanked Ms. Williams for her presentation and said that they would be in touch.

Discussion ensued re-the CNI Trust Fund's purpose and intent in the code of Virginia. The Board unanimously agreed that the funding stream of CNI is not large enough to fund individual requests for support conferences while still allowing it to maintain its original intent to fund grant initiatives. **Dr. Bendall made a motion not to fund the National Multidisciplinary Conference on Ethnicity, Culture, and Brain Injury Rehabilitation proposed by Ms. Williams from Virginia Commonwealth University; Teresa Poole seconded. The motion passed unanimously.**

Presentation from David Gater, MD, Ph.D., McGuire Veterans Administration (affiliated with VCU).

Dr. David Gater from the McGuire Veterans Administration (affiliated with VCU) proposed an idea to the Board to fund a state-of-the-art lecture series that would bring in researchers from outside Virginia to speak at a monthly lecture series focused on traumatic brain injury and spinal cord injury research. Dr. Gater presented the Board with possible speakers and topics for the series. The speaker fees would be about \$1500/speaker or \$15,000/year. The audience for the

monthly lecture could be anyone from clinicians and investigators to consumers and families of consumers. Dr. Gater explained he worked on similar endeavors in Kentucky and Michigan. In Michigan, the Paralyzed Veterans of America funded the conference series.

Board members discussed options of partnering with Dr. Gater on the lecture series with the research colloquium tentatively scheduled for 2010, as well as the idea to offer the lecture series as a "stand alone," per Dr. Gater's proposal. The Board recognized and appreciated Dr. Gater's efforts to expand educational research opportunities in the Commonwealth, but agreed that the CNI funding stream is not large enough to fund requests for outside educational opportunities. There was also discussion that the Board should maintain focus on the original intent of the Fund. Doug Harris made a motion not to fund the proposal for a lecture series on traumatic brain injury and spinal cord injury presented by Dr. David Gater from McGuire Veterans Administration; Terry Glenn seconded the motion. The motion passed unanimously. The Commissioner requested that staff inform Dr. Gater that there is a possibility that the Department of Rehabilitative Services may be able to fund the initiative and to contact Commissioner Rothrock to discuss this further.

Presentation from Eric Messick, Principal Analyst, Joint Legislative Audit and Review Commission, on the report on "access to brain injury services in the Commonwealth." The Board invited Eric Messick to summarize the findings of the Joint Legislative Audit and Review Commission (JLARC) Report on "Access to Brain Injury Services in the Commonwealth" which was presented in draft form to the General Assembly on September 10 and to the Joint Commission on Healthcare on September 19. Mr. Messick specifically focused on the findings that could potentially impact the intent of the CNI Trust Fund which was a suggestion to use CNI funds for residential treatment services for persons with severe neurobehavioral issues; these critically needed services are currently unavailable in Virginia. According to the report, because the fund produces about \$1.4 million dollars in revenue annually, the annual proceeds deposited in the CNI grant fund could be used to treat an average of 8 persons per year (at a rate of \$172,000/person/year for neurobehavioral services).

The Board thanked Mr. Messick for his presentation, but informed Mr. Messick that they did not concur with using CNI Trust Fund dollars as a way to alleviate the need for neurobehavioral services in Virginia. The Advisory Board and staff endorsed the original intent of the Commonwealth Neurotrauma Initiative (CNI) Trust Fund that allows for the expansion and enhancement of services for individuals with brain injury and spinal cord injury in Virginia, as well as research, through funding grant proposals. Further, the Board maintained that failing to endorse the original intent of the Trust Fund would adversely impact citizens who have already suffered neurotrauma, but thousands more who could benefit from the cutting edge research and intervention programs/services funded through the CNI Trust Fund.

The Advisory Board Chair, Dr. Reid, thanked Mr. Messick for his time and thorough review and report on brain injury services. Dr. Reid stated that he will draft a letter on behalf of the Advisory Board responding to the report's findings. The Commissioner also informed the Advisory Board that he is assisting Secretary Marilyn Tavenner with a response to the Joint Commission on Healthcare to the JLARC findings, including the recommendation to use CNI Funds for neurobehavioral services.

Dr. Reid informed the Board of an e-mail request he received from Paul Aravich, Ph.D., chair of the Neurobehavioral Committee of the Virginia Brain Injury Council, requesting the CNI Trust Fund Advisory Board to issue a Request For Proposals (RFP) for a "pilot project" to implement and evaluate the effectiveness of a residential neurobehavioral treatment program for individuals with brain injury who have severely challenging behaviors. The VBIC Neurobehavioral Committee has developed a "white paper" describing the need for neurobehavioral services in the Commonwealth. Dr. Aravich sent an email to Dr. Reid prior to CNI meeting to request that the Board consider an RFP to implement a project that would generate outcome data which could be used for funding decisions in the future regarding this treatment approach (the requested RFP is included in the committee's "white paper" as a recommendation). The Board opted to table this discussion until a later date to see if a proposed Brain Injury Medicaid Waiver would be able to fund neurobehavioral services. The Board Chair will contact Dr. Aravich to inform him of the status of his request.

Comments from the Commissioner of DRS

The JLARC report cited the negative findings of the study regarding the Virginia Brain Injury Registry (reporting requirement for hospitals was enacted in 1984), particularly the low response rate to outreach efforts. Currently, the hospitals must complete a written form or submit electronic data containing the name, age, place of residence and cause of injury within 30 days to the Department of Rehabilitative Services. This information is then entered in the Central Registry database at DRS. The JLARC report found that the Brain Injury Registry is not collecting comprehensive follow-along information about brain injury survivors and that the outreach efforts are not producing desired results. Data compatibility problems have prevented at least two Level I Trauma hospitals in Virginia from reporting to DRS. The JLARC report found that fewer than 2% of outreach mailers result in direct contact for additional information.

As a result of JLARC finding the Registry faulty, the Commissioner reminded the Board of his authority in the 2004 budget amendment "Notwithstanding any other law to the contrary, the Commissioner may reallocate up to \$500,000 from unexpended balances in the Commonwealth Neurotrauma Initiative Trust Fund to fund new grant awards for research on traumatic brain and spinal cord injuries". The Commissioner stated that he would be re-allocating \$85,000 under this authority to fund a solicited proposal from the Brain Injury Association of Virginia to research alternative funding and improved outreach options.

Chair's DRAFT Letter to Katie Couric

Dr. Reid explained to the Board that he had drafted a letter to Katie Couric noting Virginia's accomplishments with the CNI Trust Fund which encouraged her to assist in establishing similar funds in every state in the country. Dr. Reid informed the Board that about only 10 states address SCI with their trust funds. Dr. Reid hopes to "get the word out" about the good work of Virginia's Trust Fund and to encourage other states to consider this source of funding for research and program development. The Board tabled further discussion until the December meeting.

Financial Report

Kristie Chamberlain, staff to the Advisory Board, provided an overview of the CNI Trust Fund finances. Since its inception in 1998 through August 31, 2007, total revenue into the Fund is

\$11,708,307.46. The Trust Fund has actually awarded \$14,473,441.63 in grant awards (including \$379,998.57 in administrative services since July 2003). The Fund currently has an obligated balance of \$2,765,134.17 (revenue minus grant awards), with an available balance of \$1,263,430.14 (revenue minus expenditures). The current monthly average in fees and interest into the Trust Fund in Fiscal Year (FY) 2008 (began July 1, 2007) is \$108,331.75 per month.

FY'07 Annual Report to the Governor

Kristie Chamberlain, staff to the Advisory Board, reminded the Board of the required annual report to the Governor due October 1. The report includes a comprehensive financial overview of FY '07 (July 1, 2006-June 30, 2007) as well as aggregate data on operations (grant awards, carryover requests, etc.). This year, the report will contain a list of grantee publications and presentations to focus on the state and national impact of the work that is being funded through CNI Trust Fund. In addition, many research grantees have been able to secure federal grant funding (such as National Institute of Health) as a result of the research conducted through CNI funding. The report goes to the Secretary of Health and Human Services, Marilyn Tavenner, for approval first and then to the Governor and General Assembly. The final report will be sent to Board members, and will also be available on the CNI website.

Future Meeting Dates

The next meeting date is Friday, December 7, 2007.

Dr. Reid, Chair adjourned the meeting at 1:18 p.m.