Commonwealth Neurotrauma Initiative Trust Fund

Meeting Minutes June 1, 2007

Members Present

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 Neurocare, Roanoke

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

Michael Zuckerman Wintergreen Adaptive Skiing (WAS)

Eric Messick Joint Legislative Audit Review Commission (JLARC)
Jamie Bitz Joint Legislative Audit Review Commission (JLARC)

Juan Carlos Arango, Ph.D. Virginia Commonwealth University (VCU)
Kelli Williams Virginia Commonwealth University (VCU)
Vanessa Rakestraw Department of Rehabilitative Services

The Commonwealth Neurotrauma Initiative (CNI) Advisory Board met for a regular quarterly business meeting at 8004 Franklin Farms Drive in Richmond, Virginia. Dr. David Reid, Chair, convened the meeting at 10:09 a.m.

Public Comment Period

A public comment period was held. Juan Carlos Arango, Ph.D. and Kelli Williams, Research Fellow from Virginia Commonwealth University (VCU) provided information to the Board on 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. VCU is looking for donations upwards of \$50,000 to plan and organize a conference of this magnitude. VCU asked CNI to contribute to the conference with a stipend to support it. 70% of the speakers will be from VCU so VCU will be contributing in-kind with speakers. The conference will happen within the next year, by the end of calendar '08.

The Board discussed its interest in funding such a conference because it is cutting edge research. Dr. Arango and Ms. Williams were asked about other supporters of the conference, financial and otherwise. Commissioner Rothrock requested that it be put on the agenda at the September 21 Board meeting. The 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. Commissioner Rothrock offer some support – though he could not commit to how much and what kind – from the Department of Rehabilitative Services. In the meantime, Dr. Arango and Ms. Williams will meet with Patti Goodall of DRS Brain Injury & Spinal Cord Injury Services to discuss possible co-presenters and how to make the conference more relevant for DRS Counselors direct service providers. The CNI Board will review its ability to support the conference again in September.

Introductions of Guests:

Eric Messick and Jamie Bitz from the Joint Legislative Audit and Review Commission (JLARC) attended the meeting to observe the workings of the CNI Advisory Board workings and the award process for new grants. Mr. Messick and Mr. Bitz are a part of a three-person study team assigned to review access to brain injury services in the Commonwealth, per Item 21F, 2006 Appropriation Act:

"F. The Joint Legislative Audit and Review Commissioner (JLARC) shall report on access to brain injury services in the Commonwealth. The report shall include, but not be limited to, the causes and prevalence of brain injuries, the array of community-based medical and/or rehabilitative services available in Virginia for treating individuals with brain injuries, the extent to which private insurance pays for brain injury services, and how other states have addressed the needs of individuals with brain injuries for community services. The report shall also examine funding provided through the Department of Rehabilitative Services to provide a continuum of community-based brain injury services across the Commonwealth, including how efficiently and effectively funding is allocated and expended to meet service needs. JLARC shall submit a final report by October 1, 2007."

Approval of December 8, 2006 Minutes

Commissioner Rothrock made a motion to approve the minutes of the December 8, 2006 meeting; Terry Glenn seconded; motion passed unanimously.

Approval of June 1, 2007 Agenda

Gregory Helm, MD, Ph.D. made a motion to approve the agenda of the June 1, 2007 meeting; Doug Harris seconded; motion passed unanimously.

Michael Zuckerman, Executive Director of Wintergreen Adaptive Skiing (WAS), presented on the status of the WAS CNI Grant (#07-061), as they wrap up year 1 (July 1, 2006-June 30, 2007) of their grant award. WAS provides specialized "adaptive" ski lessons to people with virtually any level of injury. WAS trains mentors in adaptive skiing who in turn work with individuals with disabilities who want to learn adaptive skiing. Mr. Zuckerman showed a video of one of the participants in the program who was learning to ski using adaptive equipment. Mr. Zuckerman requested an additional \$5,800 for Year Two (original amount awarded \$17,765) and \$11,600 for Year Three (original amount awarded \$22,165) due to unanticipated costs associated with the national disabled sports mentor training (Hartford Ski Spectacular) held in Breckenridge, Colorado in December each year. In addition, they requested a change in scope of services to send two additional participants and their caregivers to the national disabled sports training.

Commissioner Rothrock made a motion to accept the proposal for additional funds (\$5800) as suggested by Mr. Zuckerman for year two. Doug Harris seconded, the motion passed unanimously. The board will request that Mr. Zuckerman come back and update the Board on Year Two, prior to requesting additional funds for Year Three.

CNI Trust Fund Regulations

Pursuant to Executive Order 36(2006), the Virginia Department of Rehabilitative Services (DRS) conducted a periodic review inviting public comment on the following regulation: "22VAC 30-50 Policies and Procedures for Administering the Commonwealth Neurotrauma Initiative Trust Fund". As part of the review, the Department will consider whether this existing regulation is essential to protecting the health, safety and welfare of the public while administering the Commonwealth Neurotrauma Initiative Trust Fund to improve the treatment and care of persons with traumatic spinal cord injuries and brain injuries. Public comment ended April 30, 2007. Staff to the Board reviewed the regulations with the assistance of DRS Policy Analyst, Vanessa Rakestraw, and proposed changes to the Board. Board member Doug Harris, J.D., who had worked on establishing the initial written regulations for the Board, agreed with the proposed changes.

Doug Harris made motion to present the Board's recommended changes of the CNI Regulations, 22VAC 30-50, to the Commissioner of the Department of Rehabilitative Services, asking him to consider revising the regulations in conjunction with the periodic review under way. Mr. Harris also suggested an amended change to remove the word "clinical" under section 22VAC30-50-80-86. Dr. Bendall seconded, the motion passed unanimously.

Financial Report

Kristie chamberlain, staff to the Advisory Board, provided a comprehensive overview of the CNI Trust Fund finances. Since its inception in 1998 through April 30, 2007, the Trust Fund has awarded \$12,020,987.63 in grant awards, and has expended \$345,092.18 on administrative services (beginning in FY '03). The Fund currently has an obligated balance of \$652,521. The current monthly average in fees and interest into the Trust Fund is \$117,000 per month. When

new grant awards under Option-A RFP are funded, the Fund will continue to carry an "obligated" balance.

Requests for Carryover

Staff to the Board described requests for carryover from Option-B grants that are ending their first year of funding on June 30th. One request in particular from Woodrow Wilson Rehabilitation Center (CNI 07-062—PI: Capps) is for more than 75% of the first year of funds (\$113,525), so staff felt it necessary to request formal Board approval. Staff saw no reason not to fulfill the request of \$113,525 to WWRC from Year 1 to Year 2 of the grant and the Board agreed.

Site Visits by CNI Board Chair

David B. Reid, Psy.D., CNI Advisory Board Chair, reported on three site visits he had conducted to Option-B "Community-Based Rehabilitative Service" grantees to learn more about their programs. To date, Dr. Reid had visited Wintergreen Adaptive Skiing, the Woodrow Wilson Rehabilitation grant focusing on the ERGYS2 Electrical Stimulation lower extremity cycle ergometry, and the specialized nursing home unit for young adults with brain injury operated by Brain Injury Services, Inc. in Northern Virginia. Dr. Reid stated that he hopes to visit one grantee every few months. Dr. Reid provided the Board with a written summary of his visits to each site (site visit summaries are provided as a separate document following the minutes).

Future Meeting Dates

The next two meeting dates in 2007 for the Board are Friday, September 21, 2007 and Friday, December 7, 2007.

Old Business

CNI received 21 applications of interest for funds through the Option-A RFP 07-302. The applications were reviewed by four to eight external national reviewers (neuropsychologists and neuroscientists).

The Board reviewed the recommendations of the reviewers who commented on the 20 applications under RFP #07-302: "Research on the Mechanisms and Treatment of Neurotrauma". The Board examined the purpose of each grant application in light of the intent of the Option A research awards, as well as strengths and weaknesses identified by the review panel and as determined by the Advisory Board.

Note: Board members Teresa Poole and Terry Glenn abstained from final comments in the discussion on the Virginia Commonwealth University (PI-Kreutzer) application due to personal affiliations.

Following an in-depth discussion of the scores, comments and purposes of all of the proposals received, Teresa Poole moved to award funding in the amount of \$2,329,617 over a three

year period to six applicants, two pending negotiation as noted by staff. Dr. Helm seconded; the motion passed unanimously.

The slate of applicants awarded funding:

- 1. University of Virginia (PI-Peter Patrick, Ph.D.)

 "Growth Hormone and Insulin Growth Factor 1: Deficiencies in Children/Adolescents Following
 TBI: The impact on growth/development and neuropsychological recovery" \$450,000 over three
 - TBI: The impact on growth/development and neuropsychological recovery \$450,000 over three years (Fund first two years; third year contingent on presentation to the Advisory Board at close of year two.)
- 2. Virginia Commonwealth University (PI-Dong Sun, Ph.D.)

 "Human Neuronal Progenitor Cells Isolated from Neurosurgical Resection Tissue as a Cell Source for Brain Repair Following Trauma" \$434,408
- 3. Virginia Commonwealth University (PI-Christina Marmarou, Ph.D.) "Sodium Channel Sequestration in Traumatic Axonal Injury" \$443,507
- 4. Virginia Commonwealth University (PI-Robert Hamm, Ph.D.) *"Lithium as a Treatment for Traumatic Brain Injury"* \$192,126 (two years with negotiations see below)
- 5. Virginia Commonwealth University (PI-Severn Churn, Ph.D.) "Cellular and Molecular Mechanisms of Trauma-induced Epilepsy" \$360,928
- 6. Virginia Commonwealth University (PI-Thomas Reeves, Ph.D.) "Unmyelinated Axons. A Role in Injury and a Target for Therapy" \$448,648

Dr. Reid, Chair adjourned the meeting at 2:38 p.m.

CNI Trust Fund Advisory Board: Chair's Report of Grantee Site Visits

February 22, 2007 – ERGYS2 Electrical Stimulation lower extremity cycle ergometry, Woodrow Wilson Rehabilitation Center. I met with physical therapists Kate Baxter and Joe Fangman who introduced me to the ERGYS2 cycle. While there, a client from WWRC demonstrated the machine and, for the first time since his spinal cord injury, began to experience sensation in his hips and upper thighs while riding. He informed me that using the ERGYS2 3 to 4 times weekly helps control his spasms. There are five ERGYS2 strategically situated throughout the Commonwealth to allow survivors of spinal cord injury and opportunity to utilize this machine on a regular basis.

February 23, 2007 – Wintergreen Adapted Skiing Program. I met with Director Michael Zuckerman and his staff who provided a tour of the facility and overview of the history of the program. CNI provided funds to allow SCI survivors and ski instructors/mentors the opportunity to attend a national conference on adaptive skiing. Through CNI funds, the SAP has also purchased ski equipment that permits individuals with disabilities an opportunity to expand their leisure and sport activities through skiing. This is a very exciting program whose energy and enthusiasm is quite contagious. I encourage all CNI board members to take the time to visit this wonderful program and see it in action.

April 12, 2007 - Younger Adults with Brain Injuries in Nursing Homes: A Model Project for Appropriate Care and Successful Outcomes. I met with Karen Brown and a number of staff members involved in this project. While touring the facility at INOVA I had the opportunity to observe individuals involved in some of the therapeutic recreation and other activities that are available. The services offered through this program clearly provide therapeutic interventions that unfortunately are unavailable to brain injury survivors residing in nursing homes. As a consultant to nursing homes that care for younger adults with brain injuries, it is apparent that a program such as that offered at INOVA is needed. Unfortunately nursing homes are not equipped or staffed with trained personnel to manage and assist the emotional and behavioral challenges of individuals with brain injuries.

June 8, 2007 – Planned visit to the Roanoke Clubhouse for People with Brain Injuries