



SPINAL
CORD
INJURY
RESEARCH
BOARD

NEW YORK STATE
DEPARTMENT OF HEALTH

Annual Report

January 1, 2013 to December 31, 2013

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NEW YORK STATE SPINAL CORD INJURY RESEARCH BOARD
Roster of Members
As of December 31, 2013

Lorne Mendell, PhD, Chair

Stony Brook University, State University of New York

Donald S. Faber, PhD, Vice Chair

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Blair Calancie, PhD

Upstate Medical University

Jeffrey D. Ehmann

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The Brooke Ellison Project

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College of Physicians and Surgeons

Jason H. Huang, MD

University of Rochester Medical Center

Gary D. Paige, MD, PhD

University of Rochester Medical Center

Paul Richter

Spinal Cord Society

Adam B. Stein, MD

The North Shore-Long Island Jewish
Health System

Robert D. Trotta, Esq.

Davis and Trotta, Attorneys-at-Law

Jonathan R. Wolpaw, MD

Wadsworth Center
New York State Department of Health

**New York State Department of Health Staff
Wadsworth Center
Extramural Grants Administration**

Bonnie Jo Brautigam

Executive Secretary to the Board and Director

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Mary Rogers

Health Program Administrator

Nora Prall

Administrative Aide

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State of New York Spinal Cord Injury Research Board Annual Report January 1, 2013 to December 31, 2013

I. INTRODUCTION

Spinal cord injury (SCI) was once thought of as incurable. Significantly, the basic science carried out by researchers in this field, much of it accomplished in New York State, has served as an important stimulus for the clinical trials now underway in fields as diverse as neuro-rehabilitation, axon growth, cell biology and robotics. Although it is not yet possible to reliably repair the human spinal cord, there are new treatments that improve the lives of SCI patients, and continued scientific explorations offer hope for doing more.

The Board appreciates the opportunity to serve the citizens of New York State by focusing on this important public health problem while stimulating economic growth through investigation and discovery. The Board looks forward to providing additional financial support for such highly meritorious SCI research in the coming years.

II. BACKGROUND

SCI is the second most common cause of paralysis.¹ Each year, approximately 1,000 New York residents suffer traumatic spinal cord injuries (SCI),² joining the nearly 1 in 50 people living in the United States with paralysis – approximately 6 million people.¹ The personal and economic costs to these persons, their families and society are immense.

SCI results in an abrupt change in the quality of life for those affected. Most frequently, these injuries can be caused by falls, vehicle accidents, diving or sports accidents, or acts of violence. Injuries to the spine near the head can result in quadriplegia, with the loss of motor control, sensation and function of the arms, legs, bowel, bladder, chest, abdomen and diaphragm. Injuries to the lower spine can result in loss of sensation and movement in the lower body, and loss of bowel and bladder control. Both types of injuries can result in constant pain.

The economic costs of SCI are great. In addition to societal and individual costs incurred for medical care and through loss of productivity, there are significant costs for home and vehicle modifications, equipment purchase, medications and personal assistance services. The National Spinal Cord Injury Statistical Center reported that first-year costs for an individual with SCI range from approximately \$341,000 to more than \$1,000,000, with annual costs thereafter ranging from approximately \$41,000 to \$182,000.³ These expenses are borne by the individuals, their families, and by society at large.

¹ Christopher and Dana Reeve Foundation Survey, funded by a Cooperative Agreement with the Centers for Disease Control and Prevention, 2011

² New York State Department of Health, Bureau of Occupational Health and Injury Prevention, 2006-2008 data

³ National Spinal Cord Injury Statistical Center, Facts and Figures at a Glance. Birmingham, AL: University of Alabama at Birmingham, March 2013.

The New York State Spinal Cord Injury Research Board (SCIRB or Board) was created in 1998 to solicit, review and support proposals from leading New York State researchers in their efforts to find a cure for SCI. The Spinal Cord Injury Research Trust Fund (Trust Fund) was established to fund this research. It is financed primarily by a portion of surcharges on moving traffic violations, because automobile accidents are the second leading cause of SCI in New York,² after falls. The Board and Trust Fund were authorized by Title IV (Sections 250 through 251) to Article 2 of the Public Health Law and Section 99-f to Article 6 of the State Finance Law. The Board's enabling legislation can be found at www.wadsworth.org/extramural/spinalcord and in Appendix I of this report.

The Board was first convened in August 1999. It is responsible for advising the Commissioner of Health regarding the oversight of a program to support research proposals from leading New York State researchers in their efforts to find a cure for SCI, financed by the Trust Fund. The Board is required to report annually to the Governor and Legislature on its grant-related activities, the status of supported research and on the Trust Fund.

New York's investment in SCI research has stimulated millions of dollars in additional funding for New York State researchers from sources such as the National Institutes of Health, the Department of Veterans' Affairs, the Craig H. Neilsen Foundation, the Christopher and Dana Reeve Foundation and the Department of Defense, among others.⁴ The number of National Institutes of Health (NIH)-funded SCI research awards made to New York State researchers grew from 9 in 1998 to 37 in 2013.⁵ At least 22 spinal cord injury-related patent applications have been filed by New York State researchers since 2001.⁶ The scientific advancements of New York State's research community lead to a better quality of life for its injured residents and their families.

III. BOARD ORGANIZATION AND MEMBERSHIP

The Board's membership is comprised of 13 members appointed by the Governor and legislative leaders (see page iii and Appendix IV). The composition of the Board's current 12 members is approximately 40 percent basic science researchers, 20 percent clinicians and surgeons and 40 percent spinal cord-injured persons or advocates. Members serve four-year terms. As the Board enters 2014, there is one vacant Board seat to be filled.

IV. BOARD OPERATIONS

Meetings

Meetings are announced at least two weeks in advance whenever possible and are open to the public. A recording of each meeting is available via the Department of Health's public web site <http://www.health.state.ny.us/events/webcasts/archive/> for 30 days after a meeting, opening the proceedings to a wide audience.

⁴ As reported by SCIRB-funded contractors to the Chair of the Board in 2010.

⁵ National Institutes of Health, Research Portfolio Online Reporting Tools, search limited to "spinal cord injury."

⁶ United States Trade and Patent Office on-line search, search limited to "spinal cord injury."

All Board meeting agendas and approved minutes are available by request from the Board's Executive Secretary. Meeting agendas are also posted on the Wadsworth Center's web site at: <http://www.wadsworth.org/extramural/spinalcord/>.

Three board meetings were held in 2013. The first was held April 10 to discuss options in response to an appropriation of \$2 million from the state budget. A second meeting was held April 30 to consider and authorize an RFA for distribution of those funds. Lastly, at the meeting of September 27, the Board approved nine applications, recommending a total \$1,117,296 in funding for SCI research.

Bylaws

No changes were made to the Board's bylaws in 2013. The bylaws can be found at <http://www.wadsworth.org/extramural/spinalcord> and in Appendix II of this report.

V. PROGRAM FUNDS

Through December 31, 2013, deposits to the Trust Fund totaled \$78.96 million. Interest on unexpended funds rose to \$5.3 million, for a total of \$84.26 million since the inception of the Trust Fund.

Total cash disbursements from the Trust Fund include: research contracts (\$62.8 million); peer-review and strategic planning contracts (\$2.6 million); and administrative costs (\$4.5 million). In addition, in 2002 there was a cash reduction of \$13.5 million from the Trust Fund.

VI. MAJOR ACTIVITIES OF THE BOARD AND PROGRAM

The 2013-14 state budget provided funding to complete contracts executed prior to April 1, 2010 and an additional \$2 million for spinal cord injury research that was required to be disbursed prior to March 31, 2014. The remainder of this report addresses those activities.

Presentations, Publications and Patents Resulting From SCIRB-Funded Research

During 2013, investigators reported their findings in six scientific journal articles (Appendix III, citations and abstracts).

Institutional Support for Spinal Cord Injury Research

The \$2 million appropriated for SCI research in the 2013-14 state budget was made available through a targeted letter of solicitation in July 2013. The SCIRB intended these funds to provide a rapid influx of flexible funding to re-invigorate the spinal cord injury research efforts of research organizations throughout New York State.

A funding formula was established to allow organizations to apply that had:

- (1) received spinal cord injury research funding from SCIRB and/or the National Institutes of Health since the beginning of federal fiscal year 2010, and
- (2) an employee that held a current notice of funding for any peer-reviewed spinal cord injury research.

The formula provided funds for the top 20 organizations, ranked according to total spinal cord injury research funding received, and allowed additional organizations to apply in rank order if one of the top 20 organizations did not apply or was otherwise ineligible. Eligible organizations were able to apply for funding to support the purchase of shared equipment/instrumentation, and/or for funding to support the initiation or continuation of any peer-reviewed spinal cord injury research project that received a Priority Score (or fundable score, as appropriate to the funder's scoring method) dated no earlier than July 1, 2012, for which funds were not available to support the research project at that time.

As a result, SCIRB recommended support for nine projects totaling \$1,117,296 in funding. A tenth application is scheduled to be considered by SCIRB in January 2014. Due to limitations on the funds, the contract term is October 1, 2013 through February 28, 2014 (and all funds must be disbursed before March 31, 2014).

Award Recommendations Made During 2013

Institution	Total Amount Funded
City College of New York	\$49,834
Mount Sinai School of Medicine	\$166,054
Stony Brook University	\$149,367
Burke Medical Research Institute	\$99,936
Health Research, Inc.	\$174,895
SUNY Downstate Medical Center	\$31,250
University of Rochester	\$196,783
Columbia University	\$199,361
College of Staten Island	\$49,636

Research Projects and Accomplishments

Highlights of research accomplishments related to the ongoing SCIRB-funded grant contract are presented here.

Program Projects Award

C023832 Samie Jaffrey, Ph.D., Principal Investigator (PI)

Weill Medical College of Cornell University, \$2,409,665.

“Synthesis and Evaluation of NAD-Augmenting Agents for Spinal Cord Injury”

Contract term January 1, 2009 – December 31, 2013

The overall goal of the project is to evaluate the efficacy of NAD precursors derived from or related to nicotinamide riboside as an intervention for treating spinal cord injury. These studies are coordinated between several laboratories and combine the skills of an organic synthetic and biochemical laboratory (Co-PI Sauve), a basic neuroscience laboratory (Jaffrey), and a neuroscience laboratory with translational focus (Co-PI Langley). The goal is to execute animal studies to evaluate these compounds in spinal cord injury models.

The project has reached a mature phase, wherein early synthetic improvements and pharmacodynamic studies of NR and derivatives (Sauve and Langley) enabled selection of a lead compound for evaluation in a rat spine-crush injury model. Preliminary data suggests low toxicity for nicotinamide riboside, with some evidence of improved functional performance in injured animals (Langley). Studies to evaluate the effects of NR (250mg/kg) in raising tissue NAD in the study animals are ongoing (Sauve). The work is currently focused on immediate preparation for an increased dosage study (Langley and Sauve). The Jaffrey work has yielded impressive neuroprotective effects for NAD in axonopathies.

Future directions include completion of an additional NR treatment of rats at a higher dose (at least 500 mg/kg). This level has been well tolerated in trial studies, and raises NAD level above the effect provided by 250 mg/kg dosing. These studies will attempt to provide larger improvements in outcomes than were noted in the preliminary study.

The study is reaching crucial endpoints for evaluating NR as a possible therapeutic for treating spinal cord injury. With commercial supplements of NR becoming recently available to human populations (July 2013, via Cornell synthetic method), demonstrated efficacy of NR therapy in animals could accelerate clinical trials to evaluate NR in human spinal cord injury.

VII. CONCLUSION

This very successful SCI research program continues to enable highly qualified New York State researchers to develop treatments, alleviate pain associated with SCI, restore function and to search for a cure for spinal cord injuries.

Appendix I

Laws of New York State

Public Health Law, Title IV, § 250 Spinal Cord Injury Research Board.

1. A spinal cord injury research board is hereby created within the department for the purpose of administering spinal cord injury research projects and administering the spinal cord injury research trust fund created pursuant to section ninety-nine-f of the state finance law. The purpose of research projects administered by the board shall be neurological research towards a cure for such injuries and their effects. The members of the spinal cord injury research board shall include but not be limited to representatives of the following fields: neuroscience, neurology, neuro-surgery, neuro-pharmacology, and spinal cord rehabilitative medicine. The board shall be composed of thirteen members, seven of whom shall be appointed by the governor, two of whom shall be appointed by the temporary president of the senate, two of whom shall be appointed by the speaker of the assembly, one of whom shall be appointed by the minority leader of the senate, and one of whom shall be appointed by the minority leader of the assembly.
2. Board members shall be reimbursed for ordinary travel expenses, including meals and lodging, incurred in the performance of duties pursuant to section two hundred fifty-one of this title.
3. The terms of board members shall be four years commencing January first, nineteen hundred ninety-nine.
4. At the end of a term, a member shall continue to serve until a successor is appointed. A member who is appointed after a term has begun shall serve the rest of the term and until a successor is appointed. A member who serves two consecutive full four year terms shall not be eligible for reappointment for four years after completion of those terms.
5. A majority of the full authorized membership of the board shall constitute a quorum.
6. One member of the board shall be chosen by the governor to serve as chairperson.
7. Meetings of the board shall be held at least twice a year but may be held more frequently as deemed necessary, subject to call by the chairman or by request of a majority of the board members. Board meetings shall concern, among other things, policy matters relating to spinal cord injury research projects and programs, research progress reports, and other matters necessary to carry out the intent of this title.
8. Members of the board shall be indemnified pursuant to section seventeen of the public officers law.

Title IV, § 251. Powers and Duties.

The spinal cord injury research board created pursuant to section two hundred fifty of this title shall:

1. Formulate policies and procedures necessary to carry out the provisions of this title;
2. Solicit, receive, and review applications from public and private agencies and organizations and qualified research institutions for grants from the spinal cord injury research trust fund, created pursuant to section ninety-nine-f of the state finance law, to conduct research programs which focus on the treatment and cure of spinal cord injury. The board shall make recommendations to the commissioner, and the commissioner shall, in his or her discretion, grant approval of applications for grants from those applications recommended by the board.
3. Ensure that state funds, appropriated for spinal cord injury research are not diverted to any other use; and
4. Provide the governor and the legislature an annual report by January thirty-first of each year succeeding the year in which this title shall take effect setting forth the status of funds appropriated for spinal cord injury research and the progress of the Board in terms of the results of its spinal cord injury research efforts.

State Finance Law, Article 6 § 99-f. Spinal cord injury research trust fund.

1. There is hereby established in the joint custody of the state comptroller and the commissioner of taxation and finance a special revenue fund to be known as the "spinal cord injury research trust fund."
2. The fund shall consist of all monies appropriated for its purpose, all monies required by this section or any other provision of law to be paid into or credited to such fund, and monies in an amount not to exceed eight million five hundred thousand dollars collected by the mandatory surcharges imposed pursuant to subdivision one of section eighteen hundred nine of the vehicle and traffic law. Nothing contained herein shall prevent the department of health from receiving grants, gifts or bequests for the purposes of the fund as defined in this section and depositing them into the fund according to law.
3. Monies of the fund, when allocated, shall be available for administrative costs of the spinal cord injury research board established pursuant to title four of article two of the public health law and for funding spinal cord injury research projects administered by such board.
4. Monies shall be payable from the fund on the audit and warrant of the state comptroller on vouchers approved and certified by the commissioner of health.

Appendix II

Bylaws of the Spinal Cord Injury Research Board

I. OFFICERS

1. The officers of the Spinal Cord Injury Research Board (“Board”) shall be the Chair and Vice-Chair. The Chair is designated by the Governor. The Vice-Chair shall be selected by the Chair and shall serve for one year or until his or her successor has been selected.
2. The Chair may appoint a Board member to preside during the absence of the Chair and Vice-Chair from any meeting.

II. DUTIES

1. The officers of the Board shall perform the duties ordinarily associated with their respective offices.
2. The Chair shall be responsible for the general supervision of the work of the Board. The Chair shall represent the Board before the Governor, committees of the Legislature, or other public authorities, and may request any member or members to appear with him or her in his or her stead. The Chair shall preside at Board meetings.
3. The Vice-Chair, in the absence of the Chair, shall perform the duties of the Chair.

III. CODE OF ETHICS AND CONFLICT OF INTEREST

Section 1. Code of Ethics.

Members of the Board shall comply with Section 74 (Code of Ethics) of the Public Officers Law. No member of the Board should have any interest, financial or otherwise, direct or indirect, or engage in any business, transaction, or professional activity, or incur any obligation of any nature, which is in substantial conflict with the proper discharge of his or her duties as a Board member. Members should exercise their duties and responsibilities as Board members in the public interest of the inhabitants of the State, regardless of their affiliation with, or relationship to, any institution, organization, facility, agency, program, activity, category of provider, or interest group. The principles that should guide the conduct of Board members include, but are not limited to, the following:

- a) A Board member should endeavor to pursue a course of conduct that shall not raise suspicion among the public that he or she is likely to be engaged in acts that are in violation of his or her trust as a Board member.
- b) No Board member should permit his or her employment to impair his or her independence of judgment in the exercise of his or her duties as a Board member.

- c) No Board member should disclose confidential information acquired by him or her in the course of his or her duties as a Board member, or by reason of his or her position as a Board member, nor use such information to further his or her personal interests.
- d) No Board member should use, or attempt to use, his or her position as a Board member to secure unwarranted privileges or exemptions for himself or herself or others.
- e) No Board member should engage in any transaction as a representative or agent of the State with any business entity in which he or she has a direct or indirect financial interest that might reasonably tend to conflict with the proper discharge of his or her duties as a Board member.
- f) A Board member should not make personal investments in enterprises which may be directly involved in decisions to be made by him or her as a Board member or which shall otherwise create substantial conflict between his or her duty as a Board member to act in the public interest and his or her private interest.
- g) To preserve the public trust, Board members are prohibited during the tenure of their appointment from applying for or receiving support from the Spinal Cord Injury Research Trust Fund under Section 251 of the Public Health Law, or from having any role or interest (other than routine professional and collegial interest in the success of their institution or department) in proposals submitted for consideration by, or in research or proposals supported by, the Spinal Cord Injury Research Trust Fund.

Section 2. Conflict of Interest – Applications and other Pending Matters.

This section applies both to activities of the full Board and its committees.

- a) **Absolute Disqualifications.**
When a Board or committee member, or his or her family has an interest, financial or otherwise, whether as owner, officer, director, fiduciary, employee, colleague, consultant, or supplier of goods or services, in an entity, institution, organization, facility, agency or program (hereafter collectively referred to as “entity”) whose application is before the Board or a committee of the Board for consideration or determination for a grant from the Spinal Cord Injury Research Trust Fund under Section 251 of the Public Health Law, that member shall (i) identify such interest to the Board or committee at any meeting when the application or request is to be considered, (ii) absent himself or herself from any portion of any meeting when such application is considered, and (iii) not participate in any vote of the Board or committee on such application. For purposes of this Article, “family” shall include a spouse, children, sibling, and any relative living in the member’s household.
- b) **Disclosure and Possible Disqualification.**
When a Board or committee member, or his or her family member has (i) any of the above-noted interests in an entity the status of which might reasonably be affected by another entity whose grant application is before the Board or a committee of the Board, or (ii) when a member has any other interest or association which might reasonably be construed as tending to embarrass the Board or elicit public suspicion that he or she might be engaged in acts in violation of his or her trust as a Board member, the member shall disclose such interest or association at the time the application or other matter is formally considered by the Board or committee, so that the Chair and, if necessary, the Board or committee can then determine

whether the member's participation in the discussion or the vote on the application by the Board or by the committee or on the other matter would be proper.

- c) Procedure.
Prior to the discussion of a grant application, the Chair of the Board and the Chair of the Committee shall request that Board members and committee members disclose all actual or potential conflicts and, when appropriate, explain the conflicts. In the case of conflicts constituting Absolute Disqualifications, the members with such conflicts shall immediately leave the meeting and remain absent during the period when the application is under consideration. In the case of conflicts constituting possible disqualifications, the Chair of the Board or Committee shall rule upon such conflicts subject to appeal by motion to the Board or committee that may override the Chair's decision by the affirmative vote of a majority of those present, excluding those members who are the subject of the vote.
- d) Disclosure of Committee Interests to Board Meetings.
When the Chair of any committee reports the Committee's deliberations and recommendations on a matter to the Board, the Committee Chair shall indicate in the report all interests or associations disclosed by the committee members and state how such members voted with respect to the committee's recommendations.
- e) Compliance with Public Officers Law.
Members of the Board shall comply with Sections 74 and 78 of the Public Officers Law as amended and the following rules governing conflicts of interest:
 - i) No member shall receive compensation in return for services rendered in relation to matters before any State agency if compensation is contingent upon action or failure to act by such State agency.
 - ii) No member of the Board who is also associated with any firm or association in which he/she has a specific interest shall sell any goods or services valued in excess of \$25 to any State agency unless pursuant to competitive bid.
 - iii) No member of the Board shall accept any gift (in excess of \$75) under circumstances in which it could reasonably be inferred that the gift was intended to influence him/her as a member of the Board.
 - iv) Members of the Board shall avoid any action which might result in or create the appearance of a conflict of interest.
- f) Violation of Provisions.
If any member knowingly and intentionally violates these provisions, the Board or its Chair shall refer the matter to the Commissioner of Health for appropriate action.

IV. EXECUTIVE SECRETARY

The Board shall request the Department of Health to designate a Department employee as the Board's Secretary.

The Secretary shall prepare and send official notices of actions of the Board and shall administer the daily business of the Board under the general direction of the Chair. The Secretary shall send a copy of the minutes of each meeting of the Board to each member of the Board ten business days prior to the next Board meeting. The minutes, as approved or corrected, shall serve as the official record of a meeting of the Board. Minutes shall be distributed or made available to the public after they have been approved by the Board. The Secretary shall make available records requested under the Freedom of Information Law and make announcements to the media and public of scheduled meetings as required by the Open Meetings Law.

V. MEETINGS OF THE BOARD

- a) **Regular Meetings.**
The regular meetings of the Board shall be held at least two times per year but may be held more frequently as deemed necessary, subject to a call by the Chair or by request of a majority of the Board members, at a date, time and place approved by a majority of members, unless otherwise determined by the Board or by the Chair, who shall notify the Secretary at least ten business days in advance of the meeting.
- b) **Meeting Notification.**
The Secretary shall notify each Board member of Board meetings and shall send an agenda to his or her usual address not less than ten business days before the meeting.
- c) **Quorum.**
A majority (seven members) of the members of the Board (13 members) shall constitute a quorum for the transaction of any business or the exercise of any power or function of the Board and all matters requiring action shall be passed by a vote of a majority of the voting members of the Board. (A voting member abstaining from a vote shall be counted as present for the purpose of establishing a quorum.) Except as provided below, all meetings shall be conducted in accordance with Robert's Rules of Order Newly Revised, and a record of each vote shall be maintained. The normal method of voting shall be by roll call. A roll call vote on any question shall be taken by ayes and noes, abstentions noted, and a record of how each member voted entered in the Minutes.
- d) **Open Meetings.**
Meetings of the Board shall be noticed and conducted in accordance with the requirements of Article 7 (Open Meetings Law) of the Public Officers Law. Such meetings shall be open to the public except when otherwise provided by law. Guidelines for observers shall be adopted by the Board.
- e) **Public Comment Period.**
At least some portion of every regular Board meeting shall be set aside for public comment.
- f) **Order of Business.**
The order of business may be altered at the Chair's discretion or upon the request of a Board member. A portion of each Board meeting shall be set aside for the development of an agenda for the next Board meeting.

- g) Absences.
Any member, who fails to attend three consecutive meetings of the Board, unless excused by formal vote of the Board, shall be deemed to have vacated his or her position.

VI. COMMITTEES

- a) Standing Committees
There shall be the following Standing Committee:

A Scientific Review Committee for the scientific and technical merit review of requests for proposals (grant applications).

The Chair of the Board shall appoint the members of Standing Committee and designate its Chair. In appointing members to the Standing Committee, the Chair will, to the extent practicable, ensure that the Committee comprises national or international experts of the highest scientific and technical caliber appropriate to spinal cord injury-related research while minimizing the potential for real or apparent conflict of interest. The term of committee membership shall be three years from the date of appointment. The Chair of the Board shall prescribe duties of the Standing Committee with approval by a majority of Board members.

- b) Ad hoc Committees
The Board may, at any time, appoint a special committee on any subject. All such special committees not previously discharged by the Board shall be considered discharged one year following their appointment, unless the Board shall move to continue them.
- c) Committee Actions
All committee matters requiring action or a formal recommendation shall be passed by a vote of a majority of the members appointed to serve on the committee.

When making a report to the Board, a committee should, in addition to reporting any recommendations of the majority of the committee, summarize any significant deliberations leading to such recommendations as well as opinions or recommendations of committee members who did not support the majority recommendations.

VII. PROPOSAL REVIEW PROCESS

The Board shall establish merit review procedures to be used by the Scientific Advisory Committee which are modeled after the National Institutes of Health or the National Science Foundation as appropriate to the granting mechanisms the Board establishes.

VIII. OFFICE OF THE BOARD

The official headquarters of the Board (at which the official copies of its Minutes, records, documents and other papers shall be kept) shall be at the offices of the Commissioner of Health at Albany, New York. The Secretary shall be responsible for the safekeeping of all Minutes, records, documents, correspondence and other items

belonging to the Board. Every member of the Board and any other person duly authorized by a member shall have access at all times during the ordinary office hours of the Department of Health to all such Minutes, records, documents, correspondence and other items belonging to the Board; provided, however, that persons authorized by members shall not have access to records, documents, correspondence or other items that are exempt from disclosure or confidential under the Freedom of Information Law, the Personal Privacy Protection Law, or any other state or federal law. The Secretary shall designate some person to be in charge of all such Minutes, records, documents, correspondence and other items belonging to the Board during his or her absence from the office.

IX. AMENDMENT OF BYLAWS

These Bylaws may be amended by the affirmative vote of the majority of the voting members of the Board at any regular or special meeting, provided that notice of the proposed amendment has been given at a prior meeting and that a copy of the proposed amendment has been sent by the Secretary to each member of the Board at least ten business days prior to the vote.

Appendix III

2013 Publications Resulting from Funded Projects

C023832 Samie Jaffrey, Ph.D., Principal Investigator

Weill Medical College of Cornell University, \$2,409,665.

“Synthesis and Evaluation of NAD-Augmenting Agents for Spinal Cord Injury”

Contract term January 1, 2009 – December 31, 2013

1) Brochier C, Dennis G, Riviaccio MA, McLaughlin K, Coppola G, Ratan RR, **Langley B.** "Specific acetylation of p53 by HDAC inhibition prevents DNA damage-induced apoptosis in neurons." *J Neurosci* 2013, 33:8621-8632.

Abstract

Histone deacetylase (HDAC) inhibitors have been used to promote neuronal survival and ameliorate neurological dysfunction in a host of neurodegenerative disease models. The precise molecular mechanisms whereby HDAC inhibitors prevent neuronal death are currently the focus of intensive research. Here we demonstrate that HDAC inhibition prevents DNA damage-induced neurodegeneration by modifying the acetylation pattern of the tumor suppressor p53, which decreases its DNA-binding and transcriptional activation of target genes. Specifically, we identify that acetylation at K382 and K381 prevents p53 from associating with the pro-apoptotic PUMA gene promoter, activating transcription, and inducing apoptosis in mouse primary cortical neurons. Paradoxically, acetylation of p53 at the same lysines in various cancer cell lines leads to the induction of PUMA expression and death. Together, our data provide a molecular understanding of the specific outcomes of HDAC inhibition and suggest that strategies aimed at enhancing p53 acetylation at K381 and K382 might be therapeutically viable for capturing the beneficial effects in the CNS, without compromising tumor suppression.

2) Walker BA, Ji SJ, **Jaffrey SR.** “Intra-axonal translation of RhoA promotes axon growth inhibition by CSPG.” *J Neurosci* 2012, 32:14442-14447.

Abstract

Chondroitin sulfate proteoglycans (CSPGs) are a major component of the glial scar that contributes to the limited regeneration of the CNS after axonal injury. However, the intracellular mechanisms that mediate the effects of CSPGs are not fully understood. Here we show that axonal growth inhibition mediated by CSPGs requires intra-axonal protein synthesis. Application of CSPGs to postnatal rat dorsal root ganglia axons results in an increase in the axonal levels of phosphorylated 4E-BP1, a marker of increased protein translation. Axons grown in media containing CSPGs exhibit markedly reduced growth rates, which can be restored by the selective application of protein synthesis inhibitors to distal axons. We show that these axons contain transcripts encoding RhoA, a regulator of the cytoskeleton that is commonly used by the signaling pathways activated by many inhibitors of axon growth. We also show that selective application of CSPGs to axons results in increased intra-axonal synthesis of RhoA and that depletion of RhoA transcripts from axons results in enhanced growth of axons in the presence of CSPGs. These data identify local translation as an effector pathway of CSPGs and demonstrate that local translation of RhoA contributes to the axon growth inhibitory effect of CSPGs.

C023690 Maria Knikou, PhD, Principal Investigator

College of Staten Island, CUNY, \$1,422,066

“Mechanisms Underlying Locomotor Recovery after Step Training in SCI”

Contract term October 1, 2008 – September 30, 2012

- 1) **Knikou M**, Hajela N, Mummidisetty CK. “Corticospinal excitability during walking in humans with absent and partial body weight support.” *Clin Neurophysiol* 2013, 124(12): 2431-8.

Abstract

OBJECTIVE: To establish changes in corticospinal excitability with absent and partial body weight support (BWS), and determine test-retest reliability of motor evoked potentials (MEPs) recordings during stepping in healthy humans. **METHODS:** The tibialis anterior (TA) and soleus MEPs during stepping at 0 and at 25 BWS were recorded in two experimental sessions in the same subjects. Transcranial magnetic stimulation was delivered randomly across the step cycle at 1.2xTA MEP resting threshold. The non-stimulated associated electromyogram (EMG) was subtracted from the TA and soleus MEPs at identical time windows and bins of the step cycle, and the resultant values were normalized to the maximal homologous EMG activity during stepping. The relationship between MEPs and background EMG activity was determined for each BWS level and session tested. **RESULTS:** The TA MEPs were facilitated at heel contact, progressively decreased during the stance phase, and facilitated throughout the swing phase of the step cycle. In contrast, the soleus MEPs were progressively increased at early-stance, depressed at the stance-to-swing transition, and remained depressed throughout the swing phase. The TA and soleus MEPs were modulated in a similar pattern across sessions at 0 and at 25 BWS, and were linearly related to the associated background EMG activity. **CONCLUSIONS:** These results provide evidence that reduced body weight loading does not alter the strength of corticospinal excitability, and that MEPs can be reliably recorded at different sessions during stepping in healthy humans. **SIGNIFICANCE:** A rehabilitation strategy to restore gait in neurological disorders utilizes BWS during stepping on a motorized treadmill. Based on our findings, the strength of corticospinal drive will not be affected negatively during stepping under conditions of partial body loading.

- 2) Smith AC, Muumidisetty CK, Rymer WZ, **Knikou M**. “Effects of mechanical vibration of the foot sole and ankle tendons on cutaneomuscular responses in man.” *Neuroscience Lett* 2013 545:123-6.

Abstract

The modulation of cutaneomuscular responses in response to mechanical vibration applied to the foot sole and to the ankle tendons was established in ten healthy subjects. The effects of mechanical vibration applied to the skin adjacent to the tibialis anterior (TA) and Achilles tendons were examined in two subjects. With the subjects seated, mechanical vibration applied to the TA and/or Achilles tendons significantly depressed the cutaneomuscular responses in all subjects, regardless of the frequency (50, 150, 250Hz) of vibration. Mechanical vibration applied either to the foot sole or to the skin adjacent to the tendons induced no significant effects. The demonstration that mechanical vibration applied to muscle tendons exerts an inhibitory effect on cutaneomuscular responses supports the hypothesis that receptors that mediate body kinesthesia can be used as a vehicle to alter the spinal

excitability state. The data suggests that tendon vibration could be utilized in neurological disorders to induce exogenous-mediated potentiation of presynaptic inhibition.

3) **Knikou M.** "Functional reorganization of soleus H-reflex modulation during stepping after robotic-assisted step training in people with complete and incomplete spinal cord injury." *Exp Brain Res* 228(3):279-96.

Abstract

Body weight-supported (BWS) robotic-assisted step training on a motorized treadmill is utilized with the aim to improve walking ability in people after damage to the spinal cord. However, the potential for reorganization of the injured human spinal neuronal circuitry with this intervention is not known. The objectives of this study were to determine changes in the soleus H-reflex modulation pattern and activation profiles of leg muscles during stepping after BWS robotic-assisted step training in people with chronic spinal cord injury (SCI). Fourteen people who had chronic clinically complete, motor complete, and motor incomplete SCI received an average of 45 training sessions, 5 days per week, 1 h per day. The soleus H-reflex was evoked and recorded via conventional methods at similar BWS levels and treadmill speeds before and after training. After BWS robotic-assisted step training, the soleus H-reflex was depressed at late stance, stance-to-swing transition, and swing phase initiation, allowing a smooth transition from stance to swing. The soleus H-reflex remained depressed at early and mid-swing phases of the step cycle promoting a reciprocal activation of ankle flexors and extensors. The spinal reflex circuitry reorganization was, however, more complex, with the soleus H-reflex from the right leg being modulated either in a similar or in an opposite manner to that observed in the left leg at a given phase of the step cycle after training. Last, BWS robotic-assisted step training changed the amplitude and onset of muscle activity during stepping, decreased the step duration, and improved the gait speed. BWS robotic-assisted step training reorganized spinal locomotor neuronal networks promoting a functional amplitude modulation of the soleus H-reflex and thus step progression. These findings support that spinal neuronal networks of persons with clinically complete, motor complete, or motor incomplete SCI have the potential to undergo an endogenous-mediated reorganization, and improve spinal reflex function and walking function with BWS robotic-assisted step training.

4) Jessop T, DePaola A, Casaletto L, Englard C, **Knikou M.** "Short-term plasticity of human spinal inhibitory circuits after isometric and isotonic ankle training." *Eur J Appl Physiol* 2013, 113(2):273-84.

Abstract

The purpose of this study was to determine to what extent one session of isotonic and isometric ankle dorsi and plantar flexion training induces changes in the frequency-dependent depression of the soleus H-reflex. Further, adaptation of reciprocal Ia inhibition exerted from tibialis anterior flexor group I afferents on soleus motoneurons, and presynaptic inhibition of Ia afferent terminals induced by a conditioning afferent volley following stimulation of the antagonist nerve were established with subjects seated before and after training. The soleus H-reflexes evoked at the inter-stimulus intervals of 1, 2, 3, 5, and 8 s were normalized to the mean amplitude of the H-reflex evoked every 10 s. Conditioned H-reflexes were normalized to the associated control H-reflex evoked with subjects seated before and after training. Twenty-six subjects were randomly assigned to one or more of the 4 exercise groups. Isometric ankle

dorsi flexion training decreased the reciprocal and presynaptic inhibition, while isotonic ankle dorsi flexion had no significant effects. Isotonic plantar flexion training decreased only the reciprocal inhibition, whilst isometric plantar flexion had no significant effects on the reciprocal or presynaptic inhibition. None of the training exercise protocols affected the amount of homosynaptic depression of the soleus H-reflex. Our findings support the notion that plastic changes of reciprocal and presynaptic inhibition due to exercise are transferrable to a resting state, and that homosynaptic depression remains unaltered after a single session of ankle training. Further research is needed to outline the time-course of plastic changes of spinal inhibitory mechanisms in humans.

Appendix IV

Spinal Cord Injury Research Board Members

Lorne Mendell, Ph.D., Chair

Stony Brook University, State University of New York

Dr. Mendell is a Distinguished Professor at SUNY-Stony Brook, and his laboratory focuses on the functional effects of neurotrophins in pain and segmental reflex pathways. Specifically, his research centers on the physiology of neurotrophins, and their action in modifying well-delineated circuits in the intact and injured spinal cord, including sensory input and motor output. His group is investigating the effects of neurotrophins on nociceptors and nociception in rats. In previous work, the team determined that administration of the neurotrophin nerve growth factor (NGF), known to be normally upregulated in skin during inflammation, produces hyperalgesia, and now is studying the basis for the peripheral component of this hyperalgesia. Another focus in his research is the action of neurotrophins such as NT-3 and BDNF on spinal reflexes and pathways in the neonatal rat. Dr. Mendell is the author of numerous journal articles and a past president of the Society of Neuroscience.

Donald S. Faber, Ph.D., Vice Chair

Albert Einstein College of Medicine at Yeshiva University

Dr. Faber has served as chair of the Department of Neuroscience and director of the Rose F. Kennedy Center at the Albert Einstein College of Medicine in the Bronx since 1999. He is a world-renowned neuroscientist who has made major contributions to understanding of both the regulation and plasticity of synaptic transmission, the role of intrinsic membrane properties in both normal and abnormal operation of neural networks, as well as the physiological consequences of nerve cell responses to injury.

Dr. Faber earned his Ph.D. in physiology in 1968 from SUNY at Buffalo. After completing a postdoctoral fellowship with Nobel Laureate John Eccles, he worked as a research associate at the Max Planck Institute for Brain Research in Frankfurt and at the Hospital Salpetriere in Paris, before returning to the U.S. to join the faculty of the University of Cincinnati in 1972. He moved to the Department of Physiology at Buffalo in 1974, where he was named an associate professor and director, Division of Neurobiology in 1978 and rose to professor in 1981. In 1992, he moved to MCP-Hahnemann School of Medicine as chair of the Department of Neurobiology and Anatomy and a member of the School's Spinal Cord Injury Program, until he moved to Albert Einstein in 1999. Dr. Faber has served as a consultant to the National Institutes of Health (NIH) and the National Science Foundation (NSF), as well as on the editorial boards of three major journals. His extensive professional recognition includes appointment as a Javits Investigator of the NIH National Institute of Neurological Diseases and Stroke and election as a Fellow of the American Association for the Advancement of Science.

Blair Calancie, Ph.D.

Upstate Medical University

Jeffrey D. Ehmann

Gannett Co. Inc.

Mr. Ehmann is a survivor of a 2005 climbing accident that left him a paraplegic. Mr. Ehmann continues to work full time for the media conglomerate Gannett, parent company of USA Today and six New York state newspapers. Gannett is based in McLean, Virginia; Mr. Ehmann telecommutes from his home in Kingston, NY. Mr. Ehmann performs household chores, drives and exercises, hoping to reach his pre-accident fitness level. Mr. Ehmann is married to wife Meg and has three college-aged children.

Brooke M. Ellison, M.A.

The Brooke Ellison Project

Brooke Ellison has worked as an advocate for stem cell research for nearly a decade. In 1990, at the age of 11, Brooke was stricken in an accident that left her paralyzed from the neck down and dependent on a ventilator to breathe. However, Brooke never let her physical condition stand in the way of what she could achieve, and she graduated with honors from Harvard University in 2000 and from Harvard's Kennedy School of Government in 2004. In 2002, Brooke published an autobiography, *Miracles Happen*, which was later made into a movie directed by Christopher Reeve.

For more than a decade, Brooke has worked across the country as a public speaker, delivering her message of hope, optimism and strength in the face of obstacles, with her own experiences as a vehicle to convey the message. In 2006, Brooke ran as a candidate for the New York State Senate, focusing on the need for New York State to commit funding to stem cell research. Brooke has continued her work in the field of stem cell research, and in July 2007 formed a non-profit organization, The Brooke Ellison Project, to educate and mobilize the public on behalf of stem cell research. Moreover, working with leading scientists and advocates in the field, Brooke is now working on a documentary to disseminate the necessary information to advance stem cell research.

Michael E. Goldberg, M.D.

Columbia University College of Physicians and Surgeons

Dr. Goldberg is the David Mahoney Professor of Brain and Behavior in the Departments of Neuroscience, Neurology, Psychiatry and Ophthalmology at Columbia University College of Physicians and Surgeons, and Director of the Mahoney Center for Mind and Brain. He is also a member of the Kavli Institute for Brain Science at the Columbia University. He is a Research Scientist at the New York State Psychiatric Institute, and Senior Attending Neurologist at New York Presbyterian Hospital. Dr. Goldberg served as President of the Society for Neuroscience from 2009 through 2010.

In 1963, Dr. Goldberg received an A.B. degree, *magna cum laude*, from Harvard College. From 1963 to 1964, he was a graduate fellow at Rockefeller University, and earned a medical degree from Harvard Medical School, *cum laude*, in 1968. He was Medical House Officer at Peter Bent Brigham Hospital from 1968-1969, Research Associate in the Laboratory of Neurobiology and the National Institute of Mental Health from 1969-1972, and Resident in Neurology in the Harvard Longwood Program from 1972-1975.

Dr. Goldberg's research on cognitive systems and neuroscience focuses on the psychophysics and physiology of cognitive processes in the monkey, using single unit

recording, iontophoresis, and careful behavioral measurements. Current projects include elucidation of the cortical representation of oculomotor proprioception, using saccadic adaptation to understand the coordinate system of neurons in the lateral intraparietal area (LIP), the role of prestriate cortex in visual search, and the role of inhibition in the response of parietal neurons. Recent discoveries in Dr. Goldberg's laboratory include the demonstration of a predictive relationship of parietal activity to both saccadic reaction time and visual attention; the demonstration that the lateral parietal area acts as a linear summing junction for at least three independent signals: a saccadic signal, and undifferentiated visual signal, and a cognitive signal; and the proprioceptive representation of eye position in monkey area 3a of primary somatosensory cortex.

Keith Gurgui

Resource Center for Accessible Living

Two weeks before he planned to start college, Keith Gurgui sustained a spinal cord injury while diving, leaving him permanently paralyzed below the neck. After leaving the hospital, he underwent six months of rigorous physical therapy to maintain muscular, orthopedic, respiratory and cardiovascular health as well as to learn how to use assistive technology and a wheelchair.

With Mr. Gurgui's accident and rehabilitation came an understanding of disability and rehabilitation, and a personal desire to advocate for issues, knowledge, concerns, needs and rights of people with disabilities. As the System Advocate for the New York Statewide Systems Advocacy Network at the Resource Center for Accessible Living (RCAL) in Kingston, New York, he works with a network of community members who advocate for the needs of the disability community. He is also very interested in stem cell research and the field of regenerative medicine and attended the 2010 World Stem Cell Summit in Detroit, Michigan, hosted by the Genetics Policy Institute. Currently, Mr. Gurgui is pursuing a communications and political science degree online at the State University of New York's Empire State College.

Jason H. Huang, M.D.

University of Rochester Medical Center

Dr. Huang is assistant professor of neurosurgery at the University of Rochester Medical Center and attending neurosurgeon at Strong Memorial Hospital and Unity Hospital at Rochester, where he directs the neurotrauma and peripheral nerve surgery programs. He is author or co-author of 75 peer-reviewed papers, abstracts, editorial reviews and book chapters. He received a Bachelor of Arts degree in neurosciences in 1994, *magna cum laude*, from Amherst College. Dr. Huang earned his medical degree in 1999 from Johns Hopkins University School of Medicine. He underwent neurosurgery residency training at the University of Pennsylvania from 1999 to 2006 and was the recipient of numerous awards and NIH grants during his training. Dr. Huang's main research interest lies in the field of central nervous system injury and repair. He is a faculty member at the Center for Neural Development and Disease at URMC and leads an active extramurally-funded research laboratory.

Dr. Huang is also a lieutenant colonel in the United States Army Reserves and was recently deployed to Iraq to treat injured soldiers with brain and spinal trauma during Operation Iraqi Freedom.

Dr. Huang resigned from SCIRB effective December 31st 2013. He has accepted a position in the state of Texas.

Gary D. Paige, M.D., Ph.D.

University of Rochester Medical Center

Dr. Paige received his undergraduate education in 1970 at the University of California at Irvine in biological sciences. He then moved to the University of Chicago's Medical Scientist Training Program, where he completed medical school (M.D., 1980) and graduate training in physiological and pharmacological sciences (Ph.D., 1981) on vestibular neurophysiology with Jay M. Goldberg. He followed with an internship at Michael Reese Hospital in Chicago and an ophthalmology residency at the University of California at San Francisco in 1985. Dr. Paige then joined the faculty of Washington University in St. Louis in the Department of Otolaryngology, where he established and directed the Vestibular and Oculomotor Laboratory. In 1990, he was recruited by the University of Rochester in the Department of Neurology as chief of the Sensory-Motor Neurology Unit, as well as director of the Balance and Eye Movement Laboratory and the Balance Disorders Clinic. In 1998, he was appointed Kilian J. and Caroline F. Schmitt Professor and chair of the Neurobiology and Anatomy Department at the University of Rochester Medical Center, while concurrently holding joint appointments in the Medical Center's Departments of Neurology, Ophthalmology, Biomedical Engineering, and Brain and Cognitive Science.

Dr. Paige's research on multisensory interactions underlying spatial orientation focuses on how the brain integrates visual and auditory sensory inputs from the outside world with the internal senses (vestibular and somatosensory) to depict accurately humans' orientation, motion and behavior. Equally important to this topic is how plastic mechanisms register errors and adaptively adjust or restore performance in response to the challenges of development, disease and natural aging. In addition to research and clinical responsibilities, his academic activities include various levels of medical and graduate instruction. Peer review assignments include NIH (and other) panels, as well as a range of journal review responsibilities and editorial duties. Dr. Paige has served on the governing boards of professional organizations, among others, as president of the Association of Medical School Neuroscience Department Chairs and vice president of the Society for the Neural Control of Movement.

Paul Richter

Spinal Cord Society

Mr. Richter is responsible for the 1998 legislation that created the Spinal Cord Injury Research Board. He was serving as a State Trooper Zone Sergeant 34 years ago when he was shot three times and was left with a spinal cord injury.

Adam B. Stein, M.D.

The North Shore-Long Island Jewish Health System

Adam B. Stein, MD, is Chairman of the Department of Physical Medicine and Rehabilitation for North Shore-Long Island Jewish Health System. Since 2008, he has been responsible for the delivery of rehabilitation services for the system's many hospitals and outpatient therapy centers. He oversees the system's residency training program in physical medicine and rehabilitation as well.

Prior to this, Dr. Stein was on faculty at Mount Sinai School of Medicine in the Department of Rehabilitation Medicine. He directed the Spinal Cord Injury Unit and developed a program for ventilator-dependent individuals, while developing a national reputation in the area of spinal

cord injury medicine. He was a co-investigator and key component of the Mount Sinai Spinal Cord Injury Model System. He participated in multiple clinical trials in SCI including those evaluating GM-1 ganglioside, 4-aminopyridine and autologous activated macrophages. Additionally, he served as the Program Director for the Residency Training Programs in Physical Medicine and Rehabilitation and Spinal Cord Injury Medicine, respectively.

Dr. Stein is a member of both the American Spinal Injury Association (ASIA) and the American Paraplegia Society. He has served on numerous committees of ASIA. He has written on many clinical topics in spinal cord injury.

Dr. Stein completed his medical degree at the New York University School of Medicine in 1987 and residency training in physical medicine and rehabilitation at New York University-Rusk Institute in 1991.

Robert D. Trotta, Esq.

Davis and Trotta, Attorneys-at-Law

Mr. Trotta is a graduate of Hobart College in Geneva, New York and Syracuse University College of Law. He is admitted to the New York State Bar and has worked with Davis and Trotta since 1966. He served in the Dutchess County Public Defender's Office from 1968 to 1981, and worked as Town Attorney for the Town of Northeast for 16 years and School Attorney for the Webutuck (New York) Central School District for three years. He became interested in finding a cure for spinal cord injury after his son, David, was paralyzed from the neck down as the result of a motorcycle accident.

Jonathan R. Wolpaw, M.D.

Wadsworth Center, New York State Department of Health

Dr. Wolpaw is a board-certified neurologist who has worked at the Wadsworth Center for more than 25 years. He received a medical degree from Case Western Reserve University in 1970, and then completed a residency in neurology at the University of Vermont and a fellowship in neurophysiological research at the NIH. He is chief of Wadsworth's Laboratory of Neural Injury and Repair and a professor in the Department of Biomedical Sciences, SUNY University at Albany's School of Public Health.

Dr. Wolpaw's major research interest is developing and using operant conditioning of spinal reflexes as a new model for studying learning and memory in the vertebrate nervous system. These methods are now being applied to the study of spinal cord injury and to development of new treatment methods. Dr. Wolpaw is also designing electro-encephalograph-based brain-computer interface technology as a new communication and control channel for those with severe motor disabilities. He is the author of numerous journal articles and holds several NIH grants.

Abbreviations Key

CUNY	City University of New York
NAD	nicotinamide adenine dinucleotide
NIH	National Institutes of Health
NR	nicotinamide riboside
PI	Principal Investigator
SCI	spinal cord injury
SCIRB	Spinal Cord Injury Research Board
SUNY	State University of New York