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JOINT LEGISLATIVE FISCAL COMMITTEE HEARING EXECUTIVE BUDGET HEALTH CARE AND MEDICAID 30 JANUARY 2013 STATEMENT OF TERRY O'NEILL, DIRECTOR THE CONSTANTINE INSTITUTE, INC.

The Constantine Institute, Inc. has been organized to promote the highest constitutional, legal, ethical and professional standards in law enforcement; to encourage innovation in public safety strategy, tactics, training and education and to foster a seamless continuum of cooperation, support and mutual respect among public safety agencies and organizations.

High on any list of progressive and positive concepts in the field of public safety is that of **Restorative Justice**. Simply stated, restorative justice is an approach to community public safety that emphasizes undoing the harm caused by crime. It often takes the form of restitution or reconciliation between victim and offender. With vision and imagination, far more sweeping measures can be taken to address the damage caused by misconduct we normally rely on retributive justice to address. As the issue of dangerous firearms has been much in the news and on the agenda of these Honorable Bodies in recent days, I'd remind you that many progressive thinkers in the field of public protection see gun violence as a medical pathology. This Legislature recently took dramatic and courageous action toward curing that disease. Another pioneering and imaginative response to a public safety hazard was taken by the state of New York in 1998.

In January, 1998, former New York State Police **Zone Sergeant Paul Richter** went to the state Legislature with a proposal to get a law enacted creating a research program with the goal of

discovering a cure for spinal cord injury paralysis. On September 30, 1973, Paul had been shot and paralyzed on the job near Lake Placid. Ironically, the two characters who shot him had just stolen a quantity of handguns from a nearby sporting goods store.

This was an extraordinary moment of possibility in tackling a medical problem that since the days of the pharaohs doctors have told patients and families there is simply no hope. **Dr. Wise Young** of Rutgers University was telling the national media that we were on the verge of major breakthroughs. The late **Christopher Reeve**, himself a victim of spinal cord injury paralysis, helped get the attention this issue demanded. Former **Assemblyman Edward Griffith**, who for nearly three decades represented Brooklyn's East New York, known as "the murder capital of New York City," sponsored the bill. His 40th Assembly District was home to an appalling number of paralyzed victims of gunshot wounds – victims of the "crack wars" of the 1980s and 90s.

In April that year, a bill was introduced in both Houses of the Legislature. Governor George E. Pataki signed it into law on July 13 as **Chapter 338 of the Laws of 1998**. In the years since, the landmark **Spinal Cord Injury Research Program (SCIRP)** has, through a small surcharge on fines for moving violations of the Vehicle and Traffic Law, raised and invested nearly \$70 million toward research on paralysis and other medical issues affecting the central nervous system, including the traumatic brain injury that is at epidemic levels among our service members coming home from the Iraq and Afghanistan wars. New York has, as a result, taken a national, if not international, leadership role in this area of medical research and innovation. The surcharge has also generated new revenue to the state's general fund in the neighborhood of \$150 million a year – money that would not be coming in without the hard work that Mr. Richter and his supporters put into getting Chapter 338 enacted.

At the outset, let me just say that the leading cause of spinal cord injury in the nation is motor vehicle accidents, all too often caused by reckless and drunken driving. With Chapter 338, we effectively put New York's first responders to work generating the revenue that will advance research toward a cure for paralysis. That is a stunning example of restorative justice.

Governor David Paterson, in his first budget proposal (2010-11) to the Legislature, proposed terminating SCIRP and appropriating the program's tiny fraction of the revenue derived from the surcharge to paying the state's ordinary bills. Since that time, the portion of the revenue from this program that by law should be going to SCIRP has not been forthcoming. The budget proposal that Governor Andrew Cuomo has sent to the Legislature continues this neglect. This is most unfortunate and undercuts a decision the state and people of New York made in 1998 to make a long-term and sustained investment in advanced neurological research, not only toward a cure, but to the generation of valuable patents, advances in pharmaceutical science, leveraging of research dollars from the National Institutes of Health and private sources, and our state's prestige and leadership in this field -- an investment in jobs and prosperity that will benefit all New Yorkers. It is also blatantly insulting to all the people who worked so hard to create a program that not only funds this research, but brings in a great deal of general fund revenue that the state would not have were it not for their imagination and hard work.

Please do the right thing and ensure that SCIRP continues to receive its share of the revenue the state has been receiving for all these years as the result of the work we all did to create this extraordinary and far-reaching program in 1998.

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January 30, 2013

Joint Legislative Fiscal Committees
Legislative Office Building
181 State Street, Hearing Room B
Albany, NY 12247

Chairman DiFrancesco, Chairman Farrel, distinguished members of the Joint Legislative Fiscal Committees, thank you for the opportunity to submit testimony today in regards to New York States 2013-2014 budget proposal. I am very grateful for the devoted efforts of the legislature in seeing that it pass a timely and balanced budget as the Constitution requires. While I realize due diligence is necessary I also recognize the reality and the grand scope of government. There are simply too many issues for one small group of individuals to keep track of and it is the responsibility of the people to make their representatives aware of what programs are successful and beneficial and those that are draining and detrimental to the progress of society.

To that end, I have been involved in an ongoing effort for the past three years to address the states research policies in respect to the lucrative regenerative medicine field. I am extremely pleased to see our state investing in the renowned NYSTEM program and fully support the continuation of this effort. At the same time, there has been negligence on the part of government in addressing a crucial and powerful arm of the health department's research platform. Since 1998 New York State has had the Spinal Cord Injury Research Program (SCIRP) which invests up to \$8.5 million annually to regenerative medicine research into the advancement of this specific neurological trauma. Since 2010 no monies have been appropriated to the research program for any clear stated reason other than to fill the general fund revenue gap.

Unfortunately, I feel the government does not recognize a crucial flaw in letting this program go idle. Because the state has its stem cell program, SCIRP is able to focus on all things non-stem cell in regenerative medicine field that the NYSTEM program cannot cover, including: molecular enzyme growth factors & scarring deterrents, electrical stimulation, robotics, pharmaceutical, and chemical therapies that will play an essential role in improving function in neurodegenerative illnesses that are being severely neglected in the research field to date.

SCIRP is an essential partner to New York's STEM program and retrieves its revenue from moving traffic violation surcharges and is not a drain to New York taxpayers. The surcharge imposed in the 1998 law created to fund SCIRP has grown to collect \$150 million in 2010 alone, NONE of which is being directed to its initial purpose. At the very least a revenue stream that was initially created for research should have at least 5% of its funds go to that specific cause. I urge the members of the committee to look into this issue and to analyze the potential of Sen. John Bonacic bill S. 1883 to see that this program receives the small portion of the revenue stream it has sown into New York law.

Sincerely,
Keith Gurgui

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January 30, 2013

Joint Legislative Fiscal Committees
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Dear Chairmen DeFrancisco and Farrell:

I am writing this testimony in support of the NY State's Spinal Cord Injury Research Program.

My name is Linda Gurgui and my son is 21 years old and suffered a SCI 3 ½ years ago. He is a C4 Quadriplegic and is unable to move anything below his shoulders. While I won't go into the long term hospitalization, rehabilitation, home modifications, and extreme financial cost necessary to get him home, I will say that within my terrible grief I found solace in the knowing that SCIRP existed and there were people in NY - Scientists, Doctors, and Therapists working hard to find actual real life treatments for this abominable condition.

My research into cures and treatments began when my son returned home 9 months after his injury. The technology of the computer age lead me to current research, names of people and advocates for the SCI community and ultimately to a summit in Detroit, Michigan in 2010 which focused on the advances in this field. There I met scientists and advocates from all over the world. Amongst this community it was well known that NYS had a progressive and well funded program called the Spinal Cord Injury Research Program, (SCIRP) known throughout the US and afar. NY was considered a leader in research in the area of therapies, and research for SCI. It was there that I met the people who form the team that is advocating for continuance of this valuable, crucial and progressive program, clearly respected and a model for other efforts throughout the US. In a period of 10 years, SCIRP earned and granted 70 million dollars towards scientific research and therapies in SCI and created high tech jobs in NYS. It also leveraged additional funding from other sources including the National Institutes of Health (NIH). Scientists moved with their families to NY to be among the best and the brightest.

As a mother trying to understand all of the life changes, and struggles that had befallen my son and family, it was of some comfort and source of great hope that I lived in the state of NY that placed SCI at the forefront of efforts for change. It was of great interest to me as a nurse as well, to see the actual research brought to the bedside and have real time results that benefited human kind that I hoped would reach my son. You will find in other testimony the mention of therapies and treatments used today because of this program as well the crossover benefits for other related neurological disease processes.

A Spinal Cord Injury happens in a flash of a second to anyone at anytime and halts the trajectory of life that was once planned. The hardships and cost to the community and families are immense. Please support reinstatement of funds to this essential program that will benefit mankind amongst which we all are members.

Sincerely,
Linda Gurgui RN, BSN