

# Making New York the Center for Alzheimer's Research

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November 1, 2013

More than 5 million people in this country have Alzheimer's disease, and more than 300,000 of those with Alzheimer's live in New York. By 2025, it is estimated that there will be 350,000 residents living with Alzheimer's in New York.<sup>1</sup> Congressman Steve Israel and New York Assemblyman Charles Lavine issued a joint proposal in June, 2013 suggesting that New York should become this country's center for Alzheimer's research. Noting that caring for people with Alzheimer's is already costing this nation more than \$200 billion a year ... costs expected to exceed \$1 trillion by 2050 ... and further noting that New York is home to some of the finest universities, health centers, and research facilities in the nation ... Israel and Lavine proposed a state bonding initiative. Their proposal would provide a dedicated funding stream to support research to find effective means to treat, cure, and eventually prevent Alzheimer's, as well as consider new programs to help people with Alzheimer's and their caregivers. According to Israel and Lavine, "Today's investment in Alzheimer's research could save millions of lives and billions of dollars for the nation's public health programs, as well as create jobs."<sup>2</sup>

New York ... the center for Alzheimer's research? Shouldn't we depend on the federal government to take the lead in such research? Unfortunately, we cannot depend on the National Institutes of Health (NIH) to take the lead in such research given their track record. Alzheimer's research continues to be underfunded when compared to NIH funding for other diseases. For example, in 2013-2014, NIH estimates it will spend slightly more than \$1 billion on Alzheimer's research. Yet, during this same two year period, NIH estimates it will spend \$6.2 billion on HIV/AIDS research.<sup>3</sup>

This is a large funding imbalance. HIV/AIDS has not been among the top 15 causes of death in this country since 1997. Alzheimer's, however, is the 6<sup>th</sup> leading cause of death in this country.<sup>4</sup> From 2000-2010, deaths due to HIV/AIDS decreased 42%, but during this same period deaths due to Alzheimer's increased 68%.<sup>5</sup> Alzheimer's is also the only disease among the top causes of death with no means of prevention, treatment, or cure.<sup>6</sup> And yet, HIV/AIDS research will receive \$6 for every \$1 going for Alzheimer's research.

So what do Congressman Israel and Assemblyman Lavine propose be done to come up with more funding Alzheimer's research? Obviously, they would both like to see increased federal funding, but they also know that we cannot count on that happening, especially now with federal sequestration budget limits in place. Their solution is a state bonding initiative, one similar to those that have made California this nation's center for stem cell research, and Texas this nation's center for cancer research.

The 2004 California initiative, known as Proposition 71, provided for \$3 billion in state general obligation bonds to fund stem cell research "and provide funding, through grants and loans, for such research and research facilities."<sup>7</sup> The 2007 Texas bond issue, known as Proposition 15,

was also for \$3 billion in general obligation bonds to finance research grants with the hope of finding cures, treatments, and preventative measures for cancer.<sup>8</sup> Both bonding initiatives hold the promise of attracting the best researchers in those fields to come to their states to conduct their research.

New York already has in place some of the major “ingredients” to make an Alzheimer’s bond initiative a success. Major research universities are based in New York, including 3 of our nation’s 29 Alzheimer’s Disease Research Centers ... at Columbia University, the Langone Medical Center at NYU, and at the Mount Sinai School of Medicine.<sup>9</sup> New York also has some of the finest research facilities in the nation, such as Long Island’s Cold Spring Harbor Laboratory, one of the world’s leading centers for genetic and neuroscience research. One can only imagine the synergy of having these world class institutions working on cooperative grants and projects with sufficient funding to attract even more world class researchers and scientists to find ways to prevent, treat, and cure Alzheimer’s.

Both the California and Texas models also involved “ordinary” citizens in committee leadership roles so their voices could be heard. With Alzheimer’s, too often doctors and researchers ignore caregivers’ observations about diagnosis and treatment, and their voices are not heard. The Advisory Committee for the National Alzheimer’s Project Act, signed into law in 2011 to set national priorities for Alzheimer’s research and programs, has only one member who is a full-time 24/7 caregiver.<sup>10</sup> More caregiver voices need to be heard.

A New York research model that involved caregivers to help set funding priorities would hear suggestions for grants that would make immediate positive differences both in their lives and in the lives of their loved ones. Caregivers could explain why grants to local non-profit organizations such as LIAF, the Long Island Alzheimer’s Foundation, are necessary. Caregivers could explain why more support groups for people with Alzheimer’s and their caregivers are needed, and why there is a need for more social day care model programs for those with early to moderate stage Alzheimer’s. Caregivers could explain why ongoing training is needed for those who work each day with Alzheimer’s residents living in assisted living facilities and nursing homes. Caregivers could offer many helpful suggestions for new program initiatives if given an opportunity to have their voices heard at the state level.

Research to find effective treatment protocols for those with Alzheimer’s, let alone an eventual cure or means of prevention, is desperately needed. But for those already dealing with moderate to severe stages of Alzheimer’s, and for their caregivers, any discoveries through such research may come too late. Therefore, in addition to research on prevention, treatment, and a cure for Alzheimer’s, we must also provide more effective programs to support those already dealing with Alzheimer’s, and their caregivers.

Hopefully, Congressman Israel and Assemblyman Lavine can make their proposal become a reality. A \$3 billion bond issue, spread out over 20-30 years, can make New York our nation’s center for Alzheimer’s research and innovation. A bond issue could create new jobs and over

time save the state money that would have been spent on Medicaid costs to care for people with Alzheimer's.

New York ... our country's center for Alzheimer's research. It's an idea whose time has come.

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