



**LEGISLATIVE UPDATE:**

*Overview of Public Laws, Appropriations, and Pending Legislation from the 112<sup>th</sup> Congress*

**September 2012**

**OFFICE OF SCIENCE POLICY & PLANNING**

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**\*Note:** Highlighted sections are new or updated since the last Legislative Update (May 2012).

## **Public Laws**

### ***P.L. 112-32: The Combating Autism Reauthorization Act of 2011***

The Combating Autism Act of 2006 (P.L. 109-416) established an Interagency Autism Coordinating Committee (IACC) that includes representatives from HHS agencies, the Department of Education, and public members. The IACC was mandated to develop and annually update a strategic plan for the conduct of, and support for, autism spectrum disorder research. The provision of the Combating Autism Act of 2006 that establishes the IACC was scheduled to sunset on September 30, 2011. On September 30, 2011, President Obama signed P.L. 112-32, the Combating Autism Reauthorization Act of 2011. The bill reauthorizes autism programs for another three years through FY 2014. These programs include surveillance and research activities, education programs, and the Interagency Autism Coordinating Committee.

### ***P.L. 112-81: National Defense Authorization Act for Fiscal Year 2012 [includes SBIR/STTR reauthorization]***

The Small Business Innovation Research (SBIR) and Small Business Technology Transfer (STTR) grant programs at the NIH and similar programs at other Federal agencies provide a funding source for U.S. small businesses. For the past few years, Congress has been trying to reauthorize the SBIR/STTR program, which expired on September 30, 2008. Since that date, Congress has not been able to agree on the provisions of legislation to reauthorize the programs, and although different bills were passed independently in the House and the Senate during the 111<sup>th</sup> Congress, both chambers were not able to agree on a final version of the reauthorization. In the absence of a reauthorization, Congress instead passed a series of temporary extensions to keep the programs active. On December 31, 2011, President Obama signed into law the National Defense Authorization Act for Fiscal Year 2012, which includes provisions reauthorizing the SBIR/STTR programs. The SBIR/STTR provisions reauthorize the programs for 6 years and increase SBIR/STTR awards to \$150,000 for Phase I and \$1 million for Phase II awards. Provisions of particular significance to NIH increase the SBIR set aside to 3.2 percent over six years and increase the STTR set aside to 0.45 percent over six years; allow small business concerns majority-owned and controlled by venture capital firms to be eligible for up to 25 percent of the SBIR funds; allow agencies to apply for waivers to exceed the hard cap on awards under the guidelines for Phase I and Phase II awards; and grant NIH a one-year exception to the rule shortening the time span for final decisions to not more than 90 days after the date a solicitation closes.

## Appropriations Update

### **FY 2013**

The President's FY 2013 budget was released on February 13, 2012. The budget would allocate \$30.6 billion to NIH, which is the same funding level as FY 2012. NINDS would receive \$1.625 billion under the FY 2013 President's budget, which is a decrease of 0.1% from the FY 2012 funding level.

On June 14, 2012, the Senate Committee on Appropriations marked up and reported out S. 3295, the FY2013 Senate Labor-HHS-Education Appropriations bill. The bill would provide \$30.7 billion for NIH and \$1.630 billion for NINDS, which is similar to the FY 2012 funding level. The full Senate has not yet voted on this bill or any other appropriations bill. Although the House Labor-HHS-Education Appropriations Subcommittee approved a spending bill July 19, 2012, it has not been taken up by the full House Appropriations Committee. Under the House draft spending bill, NIH would receive \$30.6 billion, and the NINDS budget would be \$1.624 billion. The bill also contained language that would reduce the salary cap for grantees and prohibit economic and patient-centered outcomes research. Additionally, 90% of the aggregate amount of funds appropriated to the NIH would need to be allocated to extramural activities, 10 percent for intramural activities, and at least 55 percent toward basic science activities.

Although the House has passed six of twelve appropriations bills, the Senate has not yet voted on any FY 2013 spending bills. On September 10<sup>th</sup>, a six-month continuing resolution (CR) was introduced in the House, and the House was scheduled to vote on the measure September 13<sup>th</sup>. The CR reflects the \$1.047 trillion cap on discretionary spending set in the Budget Control Act of 2011 (P.L. 112-25) and keeps the government funded through March 27<sup>th</sup>. The CR, as introduced, includes only a handful of policy riders -- most of them related to defense, nuclear, wildfire and border security programs. House leaders were hopeful that the Senate would pass the bill quickly without adding additional provisions.

As a result of the Budget Control Act of 2011 (P.L. 112-25), which became law on August 2, 2011, and the inability of a bipartisan "supercommittee" to make recommendations about how to achieve deficit reduction levels specified in the Act, automatic cuts to both defense and non-defense discretionary spending (a process known as "sequestration") are scheduled to begin in January 2013. On August 7, 2012, the President signed the Sequestration Transparency Act of 2012 into law (P.L. 112-155). This act required the President to submit to Congress within 30 days a detailed report on how sequestration would be implemented. This report had not yet been publicly released by the time this Legislative Update was printed but was expected to be released by the White House the week of September 10<sup>th</sup>. A number of organizations that advocate for NIH funding have put together information about the potential impact of spending cuts on NIH. Examples can be found at:

<http://www.faseb.org/Portals/0/PDFs/opa/4.16.12%20Sequestration%20and%20the%20NIH%20pdf.pdf> and <http://www.unitedformedicalresearch.com/wp-content/uploads/2012/03/UMR-Sequestration-Impact-on-NIH-2012.pdf> .

**House Energy and Commerce Committee Hearing**  
***The National Institutes of Health — A Review of Its Reforms, Priorities, and Progress***

On June 21, 2012, at the request of Representative Joe Pitts (R-PA), Chairman of the House Energy and Commerce Subcommittee on Health, Dr. Collins testified before the Subcommittee at a hearing on “The National Institutes of Health—A Review of Its Reforms, Priorities, and Progress.” In his opening statement Dr. Collins provided an overview of NIH, discussed NCATS, and gave an update on implementation of the NIH Reform Act of 2006. The Committee questioned him on various aspects of NIH operations, including the potential impact of sequestration and funding cuts, prioritization of diseases, study section and the review process, indirect costs, NIH employee salaries, commercialization of medical products, interactions with the FDA, NCATS, and the merger of NIDA and NIAAA. Other topics included the Common Fund, pancreatic cancer, genomics, diabetes, Down Syndrome, asthma, and Alzheimer’s disease.

The full webcast of the hearing can be found at:

<http://energycommerce.house.gov/hearing/national-institutes-health-%E2%80%93-review-its-reforms-priorities-and-progress>

## **Federal Neuroscience Initiative through the Office of Science and Technology Policy (OSTP)**

**Background:** The conference report of the Consolidated and Further Continuing Appropriations Act of 2012 (P.L. 112-55; providing funds for Agriculture; Commerce, Justice, Science (includes the National Science Foundation); and Transportation-HUD) included language, introduced by Rep. Chaka Fattah (D-PA), to establish an interagency working group to coordinate Federal investments in neuroscience research:

*Neuroscience.-The conferees believe there is a potential in the near future for significant, transformative advances in our fundamental understanding of learning, brain development, and brain health and recovery. Such advances will require enhanced tools to better understand the working of the brain, enhanced data and data infrastructure, and expanded interdisciplinary and large-scale research efforts. Neuroscience research is supported by the National Institutes of Health, the National Science Foundation (NSF), the Department of Veterans Affairs, the Department of Defense and other Federal agencies. The conferees encourage OSTP to establish, through the National Science and Technology Council (NSTC), an interagency working group to coordinate Federal investments in neuroscience research. The interagency working group should help focus and enhance Federal efforts toward: developing future clinical treatments for traumatic and acquired brain injuries; better understanding cognition and learning, and applying that understanding to improving education and learning; and improving our understanding of and developing better therapies for Alzheimer's disease, childhood developmental disorders and other neurological conditions.*

Similar language was part of the report accompanying the FY 2013 Commerce, Justice, Science, and Related Agencies Appropriations Bill which was reported from the full House Appropriations Committee on April 26, 2012.

*Neuroscience Working Group.—The Committee understands that OSTP, through the National Science and Technology Council (NSTC), is establishing an interagency Neuroscience Working Group, consistent with language encouraging such an effort in the statement accompanying Public Law 112–55. The Committee continues to believe there is a potential in the near future for significant, transformative advances in our fundamental understanding of learning, brain development, and brain health and recovery, requiring enhanced tools to better understand the working of the brain, enhanced data and data infrastructure, and expanded interdisciplinary and large-scale research efforts. The interagency working group is intended to help coordinate, focus and enhance Federal efforts related to neuroscience, including efforts to develop future clinical treatments for traumatic and acquired brain injuries; increase our understanding of cognition and apply that knowledge to the improvement of education and learning; and improve our understanding of, and develop better therapies for, neurodegenerative diseases, childhood developmental disorders, and other neurological conditions.*

In addition, on April 16, 2012, Rep. Fattah introduced *H. Res. 613: Supporting the Office of Science and Technology Policy interagency working group to coordinate Federal investments in neuroscience research*. The resolution 1) applauds the establishment of the Office of Science and Technology Policy interagency working group to coordinate Federal investments in neuroscience research; 2) commends President Obama for the expeditious appointment of Dr. Philip Rubin to lead the group; 3) encourages the efficient and effective use of Federal research dollars; and 4) acknowledges the need for increased investment in the neurosciences. The resolution was referred to the House Energy and Commerce Committee, Subcommittee on Health.

**Status and Future Directions:** Dr. Philip Rubin of Yale University has been appointed as the coordinator of this initiative and will chair the working group. A charter is being drafted for the group and there are ongoing discussions with leadership from the relevant Federal agencies and other partners about the scope and direction for this group.

## **Pending Legislation from the 112<sup>th</sup> Congress (calendar years 2011-2012) of interest to NINDS**

### **Alzheimer's Disease**

**Background:** In the past three Congresses, the House and Senate introduced several bills related to Alzheimer's disease (AD) research, prevention, and education. The National Alzheimer's Project Act was signed into law (P.L. 111-375) on January 4, 2011, and was the only AD research bill to be passed by the 111<sup>th</sup> Congress. This legislation requires the HHS Secretary to develop an annually updated plan for overcoming AD and to evaluate annually all federally funded efforts in AD research, care and services. It also creates the Advisory Council on Alzheimer's Research, Care, and Services consisting of both non-federal members and members representing federal agencies, including NIH, to coordinate and oversee federal agencies conducting AD-related activities and the development of the national plan.

The final version of the National Plan to Address Alzheimer's Disease was released on May 15, 2012 and is available at <http://aspe.hhs.gov/daltcp/napa/NatlPlan.shtml>.

On April 24, 2012, Rep. Edward Markey (D-MA) introduced H Con Res 120, a resolution expressing support for the goals of the draft National Plan to Address Alzheimer's Disease, which was referred to the House Energy and Commerce Committee. That same day, Senator Mark Warner (D-VA) introduced an identical resolution in the Senate, S Res 434, which was referred to the Senate Health, Education, Labor and Pensions Committee. No further action has occurred on either resolution.

On February 7<sup>th</sup>, 2012, the Obama Administration announced new efforts to fight AD, including \$50 million in new AD projects at NIH and \$80 million in funding for AD research in FY 2013, utilizing funds in the Affordable Care Act's Prevention and Public Health Trust Fund. During the Senate Appropriations hearing for NIH, Subcommittee Chairman Senator Tom Harkin (D-IA) along with Senator Barbara Mikulski (D-MD) questioned the use of this fund for AD research and made clear that the Administration should look elsewhere for additional AD research funds.

### **H.R. 1897: *Alzheimer's Breakthrough Act of 2011***

**Provisions of the Legislation/Impact on NIH:** Unlike the National Alzheimer's Project Act, which involves HHS and other federal agencies, this legislation is focused exclusively on NIH funded research on AD. This bill would direct NIH to establish an annually updated strategic plan for AD research. Additionally, NIH would report to Congress budget estimates of the amounts required to carry out the strategic plan, and funds in the existing NIH budget available to be used for AD activities. The bill also encourages the establishment of public-private partnerships.

**Status:** On May 13, 2011, Representative Christopher Smith (R-NJ) introduced H.R. 1897, which was referred to the House Committee on Energy and Commerce. No further action has occurred.

**H.R. 610:** Making Investments Now for Dementia (MIND) Act of 2011

**Provisions of the Legislation/Impact on NIH:** This bill would authorize the Secretary of the Treasury to issue bonds to aid in the funding of Alzheimer's disease research. The bill would require the Secretary of the Treasury in consultation with the Secretary of Health and Human Services and the NIH Director to submit an annual report describing the implementation of the program, including a description of the use of funds and status of the program.

**Status:** H.R. 601 was introduced by Rep Michael Burgess (R-TX) on February 10, 2011 and referred to the Committee on Ways and Means, and to the Committee on Energy and Commerce. No further action has occurred.

## **Autism**

**Background:** P.L. 112-32, The Combating Autism Reauthorization Act of 2011, reauthorizes autism programs, including the Interagency Autism Coordinating Committee, for another three years through FY 2014. Other pending bills in the 112<sup>th</sup> Congress have also focused on autism spectrum disorders, including those described below.

**H.R. 2006/S.1128:** *National Autism Spectrum Disorders Initiative Act of 2011*

**Provisions of the Legislation/Impact on NIH:** The bill would establish a National Autism Spectrum Disorders Initiative within HHS for research on prevention, treatment, services, and cures for people with Autism Spectrum Disorders (ASD). The Secretary (or designee) would oversee ASD research conducted at NIH, approve the strategic plan for ASD, allocate funds within NIH for ASD research, plan and evaluate NIH research on ASD, communicate information concerning ASD to relevant government agencies, and consult with the IACC, advisory councils, and the heads of the agencies of the NIH. These provisions would sunset 7 years after the date of enactment.

**Status:** On May 26, 2011, Representative Christopher Smith (R-NJ) introduced H.R. 2006, which was referred to the House Committee on Energy and Commerce, and Senator Robert Menendez (D-NJ) introduced S. 1128, which was referred to the Senate Committee on Health, Education, Labor, and Pensions. No further action has occurred.

## **Down Syndrome**

**Background:** In 2007, the NIH Down Syndrome Working Group, with input from the outside scientific and family communities, developed a 10-year research plan setting research goals to advance understanding of Down syndrome and speed development of new treatments for the condition. The report is available at:

[http://www.nichd.nih.gov/publications/pubs/upload/NIH\\_Downsyntaxrome\\_plan.pdf](http://www.nichd.nih.gov/publications/pubs/upload/NIH_Downsyntaxrome_plan.pdf). In the 111<sup>th</sup> Congress, bills were introduced in both the House and Senate to expand and coordinate translational research on Down syndrome. These bills would 1) establish Centers of Excellence to conduct Down syndrome research; 2) establish a Down Syndrome Coordinating Committee to develop a plan for Down syndrome research; 3) create a National Down Syndrome Patient Registry and Biobank through operative agreements at the Centers for Disease Control and Prevention (CDC). These bills did not pass out of committee. In the 112<sup>th</sup> Congress, two bills related to Down syndrome have been introduced in both the House and Senate.

### **H.R. 2695/ S. 1840: *Trisomy 21 Research Centers of Excellence Act of 2011***

**Provisions of the Legislation/Impact on NIH:** This legislation would require the NIH Director acting through the NICHD, to expand and intensify research activities of the NIH related to Down syndrome, including a research plan to be updated every five years. The bill would also require NIH to establish at least six centers of excellence that would conduct basic, translational and clinical research, building upon the recommendations set forth in the NIH Research Plan on Down Syndrome. The bill would also authorize the NIH Director to establish a Down Syndrome Consortium to facilitate the exchange of information, and require the Secretary of HHS to prepare and submit an annual report to Congress.

**Status:** On July 29, 2011, Representative Cathy McMorris Rodgers (R-WA) introduced H.R. 2695, which was referred to the House Committee on Energy and Commerce. On November 10, 2011, Senator Sherrod Brown (D-OH) introduced S. 1840, which was referred to the Senate HELP Committee. No further action has occurred on either bill.

### **H.R. 2696 / S. 1841: *Trisomy 21 Research Resource Act of 2011***

**Provisions of the Legislation/Impact on NIH:** Research provisions would direct NICHD to expand and intensify research and related activities concerning Down syndrome, in coordination with an NIH working group comprising representatives of the relevant institutes, centers, and offices. A Down syndrome research plan would be updated every five years. In support of basic, translational and clinical research, the NIH Director would be authorized to establish several research resources, including a contact registry, a research database, and a biobank for Down syndrome. The bill would also authorize a Down syndrome consortium to facilitate the exchange of information and to make the research effort on Down syndrome more efficient and effective. CDC activities would also be authorized, and an annual report to Congress would be required.

**Status:** On July 29, 2011, Representative Cathy McMorris Rodgers (R-WA) introduced H.R. 2696, which was referred to the House Committee on Energy and Commerce. On November 10, 2011, Senator Sherrod Brown (D-OH) introduced S. 1841, which was referred to the Senate HELP Committee. No further action has occurred on either bill.

## **Great Ape Research**

**Background:** Versions of the Great Ape Protection Act have been introduced in the 110<sup>th</sup>, 111<sup>th</sup>, and 112<sup>th</sup> Congresses. No significant progress was made on any of the bills. Although some of the specific wording in the bill changed with each new Congress, the substance has remained essentially the same.

**H.R. 1513/S. 810:** *Great Ape Protection and Cost Savings Act of 2011*

**Provisions of the Legislation/Impact on NIH:** Within 3 years of enactment, the bill would end all invasive research on great apes (chimpanzees, gorillas, bonobos, orangutans, and gibbons). All great apes currently housed in laboratories would be moved to sanctuaries. During the Committee mark-up, the bill was amended to provide a contingency exemption for research if an emerging or reemerging disease or condition should arise in the future. The amendment would also create a Task Force to review funding proposals once the Secretary determines that there is such a research need that might require the chimp model for research.

**Status:** On April 13, 2011, Representative Roscoe Bartlett (R-MD) introduced H.R.1513, which was referred to the House Energy and Commerce Committee, and Senator Maria Cantwell (D-WA) introduced S. 810, which was referred to the Committee on Environment and Public Works. On April 24, 2012, Dr. James Anderson, Director, NIH Division of Program Coordination, Planning and Strategic Initiatives (DPCPSI), testified before the Senate Environment and Public Works Subcommittee on Water and Wildlife during a hearing which included this legislation as well as other bills of interest to the committee. Dr. Anderson's testimony was focused on NIH's efforts to implement recommendations from the 2011 Institute of Medicine report on the use of chimpanzees in research. On July 25, 2012, the Senate Environment and Public Works Committee favorably reported S. 810, as amended, out of Committee by voice vote. Senator James Inhofe (R-OK) voiced his concern that the bill went further than the IOM report and voted against the bill.

## **Neurological Diseases Surveillance System**

**Background:** Legislation to create patient registries has been introduced in the past few Congresses. Most recently, in the 111<sup>th</sup> Congress, the House passed the “National Neurological Diseases Surveillance System Act of 2010” (H.R. 1362), which was initially introduced as the “National MS and Parkinson’s Disease Registries Act” and subsequently amended to include all neurological diseases. The bill did not pass the Senate.

**H.R. 2595/S. 425** *National Neurological Diseases Surveillance System Act of 2011*

**Provisions of the Legislation/Impact on NIH:** This bill would authorize the Secretary of HHS, acting through the CDC, to enhance and expand infrastructure and activities to track the epidemiology of neurological diseases, such as multiple sclerosis and Parkinson's disease. This information would be incorporated into an integrated surveillance system, the “National Neurological Diseases Surveillance System.” As part of this effort, the bill directs the Secretary to provide for the collection and storage of information on the incidence and prevalence of neurological diseases in the US, and to collect other relevant information to the extent practicable, including: demographics associated with neurological disease; risk factors, including genetic and environmental risk factors; and diagnosis and disease progression markers. The bill directs the CDC to coordinate with other agencies, including NIH.

**Status:** On March 1, 2011, Senator Mark Udall (D-CO) introduced S. 425, which was referred to the Senate Committee on Health, Education, Labor, and Pensions, and on July 20, 2011 Representative Chris Van Hollen (D-MD) introduced H.R. 2595, which was referred to the House Committee on Energy and Commerce. No further action has occurred.

## **Pediatric Brain Injury**

**Background:** In January 2009, the Sarah Jane Brain Foundation hosted a meeting of over 60 physicians, health care professionals, educators, researchers, and families of children with brain injuries. Based on this meeting, they developed the National Pediatric Acquired Brain Injury Plan, whose purpose is to develop a “seamless, standardized, evidence-based system of care universally accessible for all children.” To carry out this plan, a total of 52 Sarah Jane Brain Family Centers of Excellence would be funded across the country, with the goals of these Centers being: 1) to develop and implement a pediatric brain injury plan specific to their state; 2) to develop specialized case management system for each family that remains with the family unless they move to another state; 3) to be responsible for leading prevention, recovery, rehabilitative and research efforts in their state. Data from these Centers would be incorporated into a centralized registry to allow for the efficient evaluation of best practices.

**H.R. 2600:** *National Pediatric Acquired Brain Injury Plan Act of 2011*

**Provisions of the Legislation/Impact on NIH:** This bill would authorize the Secretary of HHS to make payments to each State Lead Center of Excellence (as defined and designated under the National Pediatric Acquired brain Injury Plan) for the implementation of the plan. The Secretary would also submit an annual report containing an evaluation of federally funded pediatric acquired brain injury research and clinical care. This bill would sunset in 2018.

**Status:** On July 20, 2011, Representative Leonard Lance (R-NJ) introduced H.R. 2600, which was referred to the House Committee on Energy and Commerce. No further action has occurred on this bill.

## **Pediatric Research Network**

**Background:** Legislation introduced in the House by Representative Diana DeGette (D-CO) in the 110<sup>th</sup> and 111<sup>th</sup> Congresses would have required NIH to establish up to 20 pediatric research consortia. In the 112<sup>th</sup> Congress similar bills have been introduced; however, the new bills contain language that would require awards be made to consortia focused on pediatric rare diseases and conditions. The previous bills were not as specific in their language.

**H.R. 6163/S. 3461:** National Pediatric Research Network Act of 2012

**Provisions of the Legislation/Impact on NIH:** This bill would authorize the NIH Director, acting through the Director of NICHD and in collaboration with other institutes, to establish a National Pediatric Research Network, consisting of up to 20 pediatric research consortia that conduct basic, clinical, behavioral, and translational research and train researchers in pediatric research techniques. The Director would be required to “ensure that an appropriate number of such awards are awarded to consortia that agree to (A) focus primarily on pediatric rare diseases or conditions (including any such diseases or conditions that are genetic disorders (such as spinal muscular atrophy and Duchenne muscular dystrophy) or are related to birth defects (such as Down syndrome and fragile X)) (B) conduct or coordinate one or more multisite clinical trials ... (C) rapidly and efficiently disseminate scientific findings resulting from such trials.” Additionally the bill would require the Director to establish a data coordinating center to distribute scientific findings, to provide assistance in the design of collaborative research projects and the management, analysis and storage of data, to organize and conduct multisite monitoring activities, and to provide assistance to the CDC in the establishment of patient registries. The data coordinating center would also be required to provide regular reports to the Director of NIH and the Commissioner of the FDA on research conducted by consortia, including information on enrollment in clinical trials and the allocation of resources.

**Status:** On July 19, 2012, Representative Cathy McMorris Rodgers (R-WA) introduced H.R. 6163, which was referred to the House Committee on Energy and Commerce. On September 11, 2012, the Health Subcommittee of the House Energy and Commerce Committee approved HR 6163 by voice vote. A companion measure was introduced in the Senate on July 31, 2012 by Senator Sherrod Brown (D-OH), and the Senate bill was referred to the Committee on Health, Education, Labor, and Pensions.

## **Traumatic Brain Injury**

**Background:** The first version of the Traumatic Brain Injury (TBI) Act became law in 1996. The TBI Act of 1996 amended the Public Health Service Act to provide for the conduct of expanded studies and the establishment of innovative programs with respect to traumatic brain injury. The law authorized funding for prevention, surveillance, research and State grant programs to improve service delivery and access for individuals with TBI. It was reauthorized in 2000 as an amendment to the Children's Health Act of 2000, and was reauthorized a second time as the TBI Act of 2008 (Public Law 110-206).

### **H.R. 4238:** *Traumatic Brain Injury Act of 2012*

**Provisions of the Legislation/Impact on NIH:** This bill would reauthorize the TBI Act through 2017. In addition to research activities that are currently authorized (including conducting research on acute care, rehabilitation, diagnosing, and treating TBI), the TBI Act of 2012 would also authorize NIH to conduct studies specific to the needs of children and youth with TBI. It also calls for the Secretary of HHS to coordinate with other Federal agencies as appropriate and to establish and implement a national plan for TBI activities described in the Act in consultation with Federal, State, and local agencies and professional and patient stakeholders.

**Status:** On March 21, 2012, Representative Bill Pascrell (D-NJ) introduced H.R. 4238, which was referred to the House Committee on Energy and Commerce. No further action has occurred on this bill.

## **Tourette Syndrome**

**Background:** Tourette Syndrome (TS) is a neurological disorder characterized by repetitive, stereotyped involuntary movements and vocalizations called tics. TS can be a chronic condition with symptoms lasting a lifetime; however, in many individuals, the condition may improve in their late teens and early 20s.

**H.R. 3760/S. 2321** *Collaborative Academic Research Efforts for Tourette Syndrome Act of 2011.*

**Provisions of the Legislation/Impact on NIH:** These bills direct the Secretary of HHS, acting through the Director of NIH, to expand, intensify and coordinate activities of the NIH related to Tourette syndrome. Specifically, the bills would require the Secretary to develop a system to collect epidemiologic data on Tourette syndrome, fund 4 to 6 Centers of Excellence for Tourette Syndrome, and conduct research on symptomology and treatment options for Tourette patients.

**Status:** H.R. 3760 was introduced by Rep. Albio Sires (D-NJ) on December 20, 2011, and referred to the House Committee on Energy and Commerce. S. 2321 was introduced by Senator Robert Menendez (D-NJ) on March 19, 2012 and referred to the Senate Committee on Health, Education, Labor, and Pensions. No further action has occurred on either bill.