



## **2008 Portfolio Analysis of Autism Spectrum Disorder (ASD) Research Portfolio**

## Introduction

After the release of the Interagency Autism Coordinating Committee (IACC) Strategic Plan for Autism Spectrum Disorder Research (ASD) in January 2009, the IACC created a subcommittee assist in its Congressionally-mandated (P.L. 109-416) responsibility to both monitor Federal activities related to ASD and to annually update the Strategic Plan.

In April 2009, the Subcommittee for Planning the Annual Strategic Plan Updating Process sent a request to Federal and private funders of ASD research soliciting the total dollars their organization spent on 2008 ASD research categorized by which question and objective of the Strategic Plan they correspond to. 13 Federal organizations and 6 private organizations were solicited. The information they provided was assembled to address several questions, including;

- What is the total dollar investment in ASD research?
- What is the total Federal investment in ASD research?
- Is the Strategic Plan from ASD Research comprehensive enough to encompass all the areas of currently funded ASD research?
- What areas of the Strategic Plan from ASD Research are underfunded?

Presented at the July 15, 2009 IACC meeting, the 2008 Portfolio Analysis will now be used to inform the annual updating of the Strategic Plan by providing information on the strengths and weaknesses of the current ASD research portfolio, the gaps in funding, and opportunities for future investment.

## **ASD Research Funders Solicited**

### **Federal Funders of ASD Research**

Administration for Children and Families (ACF)  
Agency for Healthcare and Research Quality (AHRQ)  
Centers for Disease Control and Prevention (CDC)  
Centers for Medicare and Medicaid Services (CMS)  
Department of Defense (DoD)  
Department of Education (ED)  
Department of Housing and Urban Development (HUD)  
Health Resources and Services Administration (HRSA)  
National Institutes of Health (NIH)  
Social Security Administration (SSA)  
Substance Abuse & Mental Health Services Administration  
(SAMHSA)

### **Private Funders of ASD Research**

Autism Consortium  
Autism Speaks  
Autism Research Institute (ARI)  
Center for Autism and Related Disabilities (CARD)  
Organization for Autism Research (OAR)  
Southwest Autism Research and Resource Center (SARRC)  
Doug Flutie Jr. Foundation for Autism  
The Simons Foundation (Simons)

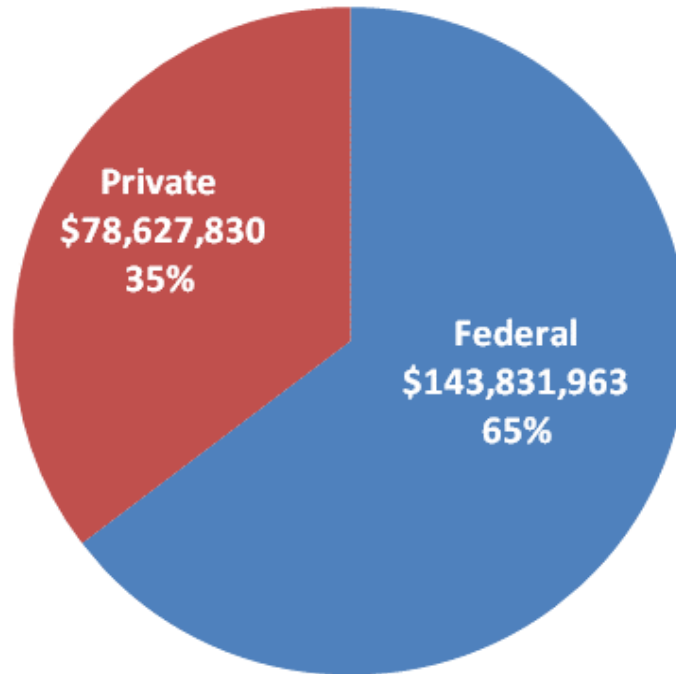
## 2008 Autism Spectrum Disorder (ASD) Research Funding by Funding Agency/Organization

Funding Agency/Organization*	Number of Projects	Average Funding Per Project	Total Funding
National Institutes of Health	422	\$279,803	\$118,076,888
Simons Foundation	77	\$558,256	\$42,985,684
Autism Speaks	203	\$152,539	\$30,965,449
Centers for Disease Control and Prevention	27	\$682,855	\$15,022,812
Health Resources and Services Administration	3	\$2,030,264	\$6,090,792
Department of Education	7	\$491,292	\$3,439,047
Autism Consortium	22	\$100,683	\$2,215,017
Department of Defense	8	\$147,223	\$1,177,781
Center for Autism and Related Disorders	26	\$31,369	\$815,581
Organization for Autism Research	16	\$45,625	\$730,000
Autism Research Institute	13	\$40,085	\$521,099
Southwest Autism Research & Resource Center	5	\$79,000	\$395,000
Centers for Medicare and Medicaid Services	1	\$24,643	\$24,643
<b>Grand Total</b>	<b>830</b>	<b>\$269,648</b>	<b>\$222,459,793</b>

\*Includes Federal and private funders who responded to an April 2009 request from the IACC to provide a comprehensive listing of autism spectrum disorder (ASD) research projects funded (i.e., paid) in the most recent 12 months for which data were available. The IACC received responses from all of the 19 agencies/organizations contacted. Thirteen provided data and six reported that they did not fund ASD research in 2008 (the Administration for Children and Families, the Agency for Healthcare Research and Quality, the Doug Flutie Jr. Foundation for Autism, the Substance Abuse and Mental Health Services Administration, the U.S. Department of Housing and Urban Development, and the U.S. Social Security Administration.)

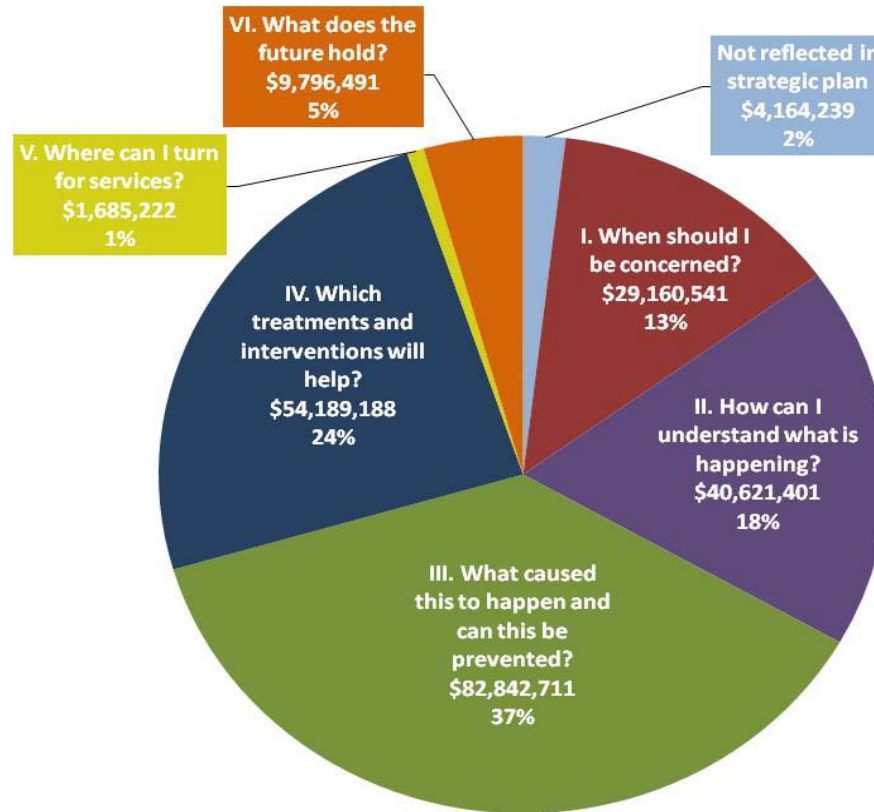
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**2008 Autism Spectrum Disorder (ASD) Research Funding\* by Type of Agency/Organization: Federal versus Private (Total = \$222,459,793)**



\* Reported by the Autism Consortium, the Autism Research Institute, Autism Speaks, the Center for Autism and Related Disorders, the Centers for Disease Control and Prevention, the Centers for Medicare and Medicaid Services, the Health Resources and Services Administration, the National Institutes of Health, the Organization for Autism Research, the Simons Foundation, the Southwest Autism Research & Resource Center, and the U.S. Departments of Defense and Education.

## 2008 Autism Spectrum Disorder (ASD) Research Funding\* by Strategic Plan Question\*\* (Total = \$222,459,793)

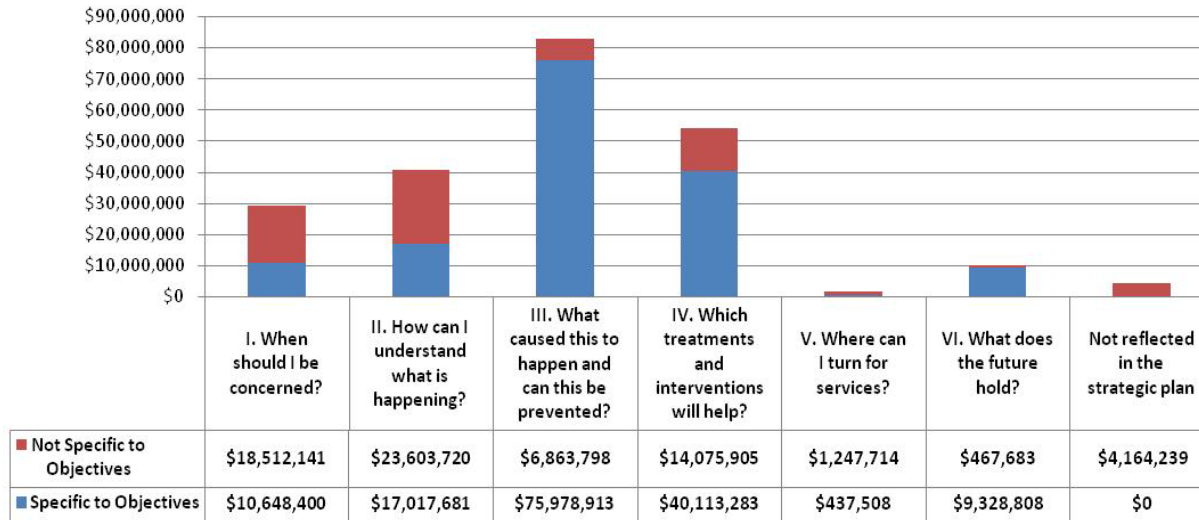


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\*\* At the request of the IACC Planning Subcommittee, the NIMH Office of Autism Research Coordination (OARC) assigned projects reported as not reflected in the strategic plan to a strategic plan question whenever possible.

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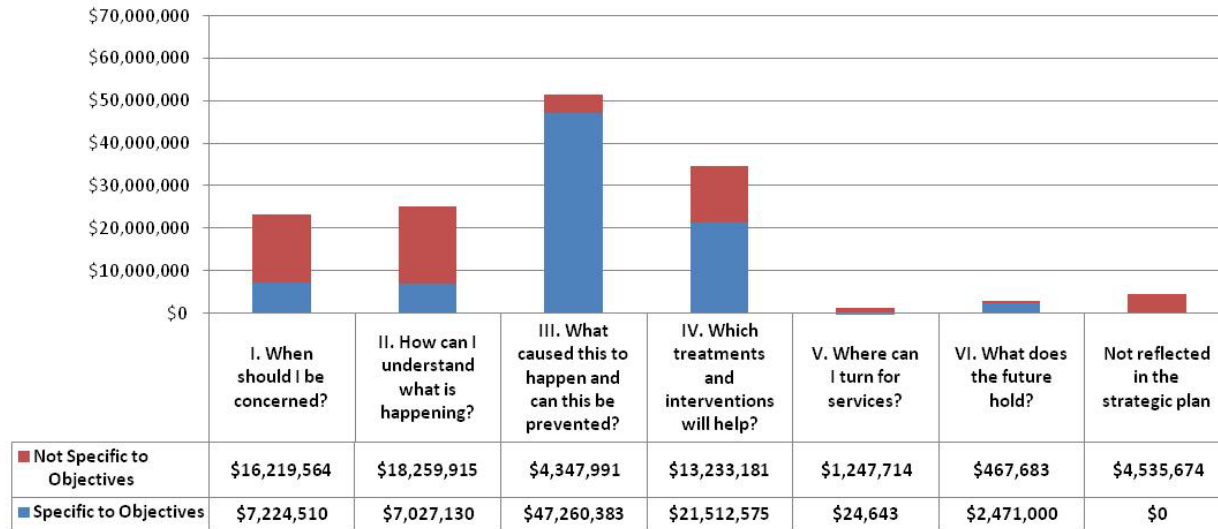
**2008 Autism Spectrum Disorder (ASD) Research Funding\* by Strategic Plan Question\*\*: Specific versus Not Specific to Research Objectives (Total = \$222,459,793)**



\* Reported by the Autism Consortium, the Autism Research Institute, Autism Speaks, the Center for Autism Related Disorders, the Centers for Disease Control and Prevention, the Centers for Medicare and Medicaid Services, the Health Resources and Services Administration, the National Institutes of Health, the Organization for Autism Research, the Simons Foundation, the Southwest Autism Research & Resource Center, and the U.S. Departments of Defense and Education.

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**2008 Autism Spectrum Disorder (ASD) Research Federal Funding\* by Strategic Plan Question\*\*: Specific versus Not Specific to Research Objectives (Total = \$143,831,963)**



\* Reported by the Centers for Disease Control and Prevention, the Centers for Medicare and Medicaid Services, the Health Resources and Services Administration, the National Institutes of Health, the U.S. Departments of Defense and Education.

\*\* At the request of the IACC Planning Subcommittee, the NIMH Office of Autism Research Coordination (OARC) assigned projects reported as not reflected in the strategic plan to a strategic plan question whenever possible.



## **Question 1: When Should I Be Concerned?**

1.1 Develop, with existing tools, at least one efficient diagnostic instrument (e.g., briefer, less time intensive) that is valid in diverse populations for use in large-scale studies by 2011. IACC Recommended Budget: \$5,300,000 over 2 years. **2008 research funding \$75,000.**

1.2 Validate and improve the sensitivity and specificity of new or existing screening tools for detecting ASD through studies of the following community populations that are diverse in terms of age, socio-economic status, race, ethnicity and level of functioning by 2012.

- School aged children
- General population (vs. clinical population)

IACC Recommended Budget: \$5,400,000 over 3 years. **2008 research funding \$1,247,915.**

1.3 Identify a panel of biomarkers that separately, or in combination with behavioral measures, accurately identify, before age 2, one or more subtypes of children at risk for developing ASD by 2014. IACC Recommended Budget: \$33,300,000 over 5 years. **2008 research funding \$2,922,280**

1.4 Develop at least five measures of behavioral and/or biological heterogeneity in children or adults with ASD, beyond variation in intellectual disability, that clearly relate to etiology and risk, treatment response and/or outcome by 2015. IACC Recommended Budget: \$71,100,000 over 5 years. **2008 research funding \$5,491,046**

1.5 Identify and develop measures to assess at least three continuous dimensions of ASD symptoms and severity that can be used by practitioners and/or parents to assess response to intervention for people with ASD across the lifespan by 2016. IACC Recommended Budget: \$18,500,000 over 5 years. **2008 research funding \$912,159**

Not specific to objectives - **2008 research funding \$18,512,141**

**Total 2008 research funding for Question 1. - \$29,160,541**

## **Question 2. How Can I Understand What is Happening?**

2.1 Establish an international network of biobanks for the collection of brain and other tissue (e.g., skin fibroblasts) with acquisition sites that use standardized protocols for phenotyping, collection and distribution of tissue by 2011. IACC Recommended Budget: \$10,500,000 over 2 years. **2008 research funding \$4,318,579**

2.2 Support at least four research projects to identify mechanisms of metabolic and/or immune system interactions with the central nervous system that may underlie the development of ASD during prenatal-postnatal life by 2010. IACC Recommended Budget: \$9,800,000 over 4 years. **2008 research funding \$3,377,568**

2.3 Launch three studies that specifically focus on the neurodevelopment of females with ASD by 2011. IACC Recommended Budget: \$8,900,000 over 5 years. **2008 research funding \$0**

2.4 Identify ways to increase awareness among the autism spectrum community of the potential value of brain and tissue donation to further basic research. IACC Recommended Budget: \$1,400,000 over 2 years. **2008 research funding \$0**

2.5 Complete a large-scale, multi-disciplinary, collaborative project that longitudinally and comprehensively examines how the biological, clinical, and developmental profiles of children, with a special emphasis on females, youths, and adults with ASD change over time as compared to typically developing people by 2020. IACC Recommended Budget: \$126,200,000 over 12 years. **2008 research funding \$8,555,306**

2.6 Maintain an international network of biobanks and support continued collection of brain and other tissue. IACC Recommended Budget: \$22,200,000 over 5 years. **2008 research funding \$700,000**

Not specific to objectives - **2008 research funding \$23,669,948**

**Total 2008 research funding for Question 2. - \$40,621,401**

### **Question 3. What Caused This to Happen and Can This Be Prevented?**

3.1 Initiate studies on at least five environmental factors identified in the recommendations from the 2007 IOM report “Autism and the Environment: Challenges and Opportunities for Research” as potential causes of ASD by 2010. IACC Recommended Budget: \$23,600,000 over 2 years. **2008 research funding \$7,600,673**

3.2 Coordinate and implement the inclusion of approximately 20,000 subjects for genome-wide association studies, as well as a sample of 1,200 for sequencing studies to examine more than 50 candidate genes by 2011. IACC Recommended Budget: \$43,700,000 over 4 years. **2008 research funding \$4,065,392**

3.3 Within the highest priority categories of exposures for ASD, identify and standardize at least three measures for identifying markers of environmental exposure in biospecimens by 2011. IACC Recommended Budget: \$3,500,000 over 3 years. **2008 research funding \$713,227**

3.4 Initiate efforts to expand existing large case-control and other studies to enhance capabilities for targeted gene – environment research by 2011. IACC Recommended Budget: \$27,800,000 over 5 years. **2008 research funding \$4,603,867**

3.5 Enhance existing case-control studies to enroll broad ethnically diverse populations affected by ASD by 2011. IACC Recommended Budget: \$3,300,000 over 5 years. **2008 research funding \$184,628**

3.6 Determine the effect of at least five environmental factors on the risk for subtypes of ASD in the pre- and early postnatal period of development by 2015. IACC Recommended Budget: \$25,100,000 over 7 years. **2008 research funding \$1,803,628**

3.7 Conduct a multi-site study of the subsequent pregnancies of 1,000 women with a child with ASD to assess the impact of environmental factors in a period most relevant to the progression of ASD by 2014. IACC Recommended Budget: \$11,100,000 over 5 years. **2008 research funding \$2,742,999**

3.8 Identify genetic risk factors in at least 50% of people with ASD by 2014. IACC Recommended Budget: \$33,900,000 over 6 years. **2008 research funding \$36,966,711**

3.9 Support ancillary studies within one or more large-scale, population-based surveillance and epidemiological studies, including U.S. populations, to collect nested, case-control data on environmental factors during preconception, and during prenatal and early postnatal development, as well as genetic data, that could be pooled (as needed), to analyze targets for potential gene/environment interactions by 2015. IACC Recommended Budget: \$44,400,000 over 5 years. **2008 research funding \$17,297,788**

Not specific to objectives - **2008 research funding \$6,863,798**

**Total 2008 research funding for Question 3. - \$82,842,711**

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#### **Question 4. Which Treatments and Interventions Will Help?**

4.1 Launch at least four research projects that seek to identify biological signatures that measure significant changes in ASD core symptoms across the lifespan by 2010. IACC Recommended Budget: \$12,700,000 over 4 years. **2008 research funding \$1,045,768**

4.2 Support at least three randomized controlled trials that address co-occurring medical conditions associated with ASD by 2010. IACC Recommended Budget: \$13,400,000 over 3 years. **2008 research funding \$4,583,171**

4.3 Conduct five randomized controlled trials of early intervention for infants and toddlers by 2011. IACC Recommended Budget: \$16,700,000 over 5 years. **2008 research funding \$8,071,787**

4.4 Launch three randomized controlled trials of interventions for school-aged and/or adolescents by 2012. IACC Recommended Budget: \$15,600,000 over 5 years. **2008 research funding \$4,137,729**

4.5 Standardize and validate at least 20 model systems (e.g. cellular and/or animal) that replicate features of ASD and will allow identification of specific molecular targets or neural circuits amenable to existing or new interventions by 2012. IACC Recommended Budget: \$75,000,000 over 5 years. **2008 research funding \$16,002,042**

4.6 Test safety and efficacy of at least five widely used interventions (e.g., nutrition, medications, medical procedures) that have not been rigorously studied for use in ASD by 2012. IACC Recommended Budget: \$27,800,000 over 5 years. **2008 research funding \$641,285**

4.7 Complete two multi-site randomized controlled trials of comprehensive early intervention that address core symptoms, family functioning and community involvement by 2013. IACC Recommended Budget: \$16,700,000 over 5 years. **2008 research funding \$4,236,869**

4.8 Complete at least three randomized controlled trials on medications targeting core symptoms in people with ASD of all ages by 2014. IACC Recommended Budget: \$22,200,000 over 5 years. **2008 research funding \$1,380,376**

4.9 Develop interventions for siblings of people with ASD with the goal of reducing risk recurrence by at least 30% by 2014. IACC Recommended Budget: \$6,700,000 over 5 years. **2008 research funding \$14,256**

Not specific to objectives - **2008 research funding \$14,075,905**

**Total 2008 research funding for Question 4. - \$54,189,188**

## **Question 5. Where Can I Turn for Services?**

5.1 Initiate a “State of the States” assessment of existing state programs and supports for people and families living with ASD by 2009. IACC Recommended Budget: \$630,000 over 2 years. **2008 research funding \$311,670**

5.2 Support two studies that assess how variations and access to services affect family functioning in diverse populations by 2012. IACC Recommended Budget: \$1,000,000 over 3 years. **2008 research funding \$0**

5.3 Test the efficacy and cost-effectiveness of at least four evidence-based services for people with ASD of all ages in community settings by 2015. IACC Recommended Budget: \$16,700,000 over 5 years. **2008 research funding \$0**

5.4 Test four methods to improve dissemination of effective interventions in diverse community settings by 2013. IACC Recommended Budget: \$7,000,000 over 5 years. **2008 research funding \$125,838**

Not specific to objectives - **2008 research funding \$1,247,714**

**Total 2008 research funding for Question 5. - \$1,685,222**

## **Question 6. What Does the Future Hold?**

6.1 Develop and have available to the research community means by which to merge or link databases that allow for tracking the involvement of people in ASD research by 2010. IACC Recommended Budget: \$1,300,000 over 2 years. **2008 research funding \$6,767,808**

6.2 Launch at least two studies to assess and characterize variation in adults living with ASD (e.g., social and daily functioning, demographic, medical and legal status) by 2011. IACC Recommended Budget: \$5,000,000 over 3 years. **2008 research funding \$0**

6.3 Conduct at least two clinical trials to test the efficacy and cost-effectiveness of interventions, services and supports to optimize daily functioning (e.g., educational, vocational, recreational, and social experiences) for adolescents, adults, or seniors living with ASD by 2012. IACC Recommended Budget: \$8,000,000 over 5 years. **2008 research funding \$90,000**

6.4 Conduct a needs assessment to determine how to merge or link administrative and/or surveillance databases that allow for tracking the involvement of people living with ASD in health care, education, and social services by 2009. IACC Recommended Budget: \$520,000 over 1 year. **2008 research funding \$0**

6.5 Develop at least two community-based interventions with individual specificity that improves outcomes, as measured by educational, occupational, and social achievements by 2015. IACC Recommended Budget: \$12,900,000 over 5 years. **2008 research funding \$2,471,000**

6.6 Develop and have available to the research community means by which to merge or link administrative databases that allow for tracking the involvement of people living with ASD research in health care, education, and social services by 2018. IACC Recommended Budget and Time Frame: To Be Determined. **2008 research funding \$0**

6.7 Conduct a cost/benefit analysis on provision of services and interventions over the lifespan with regard to long-term benefits including employment, productivity, and the need for federal/state assistance. IACC Recommended Budget: \$2,300,000 over 3 years. **2008 research funding \$0**

Not specific to objectives - **2008 research funding \$467,683**

**Total 2008 research funding for Question 6. - \$9,796,491**

**Not Reflected in the Strategic Plan - 2008 research funding \$4,164,239**

**Grand Total Strategic Plan 2008 research funding - \$222,459,793**

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