

QUESTION 2: HOW CAN I UNDERSTAND WHAT IS HAPPENING?

IACC Strategic Plan Objectives	Planning Group Summary	Funding 2008-2013
<p>2.S.A. Support at least four research projects to identify mechanisms of fever, metabolic and/or immune system interactions with the central nervous system that may influence ASD during prenatal-postnatal life by 2010 (Fever studies to be started by 2012).</p> <p><i>IACC Recommended Budget: \$9,800,000 over 4 years</i></p>	<p>The recommended budget for this objective was met and many projects were funded in this area, but the field is still developing and emphasis on this objective should continue in the future.</p>	\$16,997,853
<p>2.S.B. Launch three studies that specifically focus on the neurodevelopment of females with ASD, spanning basic to clinical research on sex differences by 2011.</p> <p><i>IACC Recommended Budget: \$8,900,000 over 5 years</i></p>	<p>The recommended budget for this objective was partially met, and more than 3 studies were launched, but further work is needed in this area.</p>	\$5,856,783
<p>2.S.C. Identify ways to increase awareness among the autism spectrum community of the potential value of brain and tissue donation to further basic research by 2011.</p> <p><i>IACC Recommended Budget: \$1,400,000 over 2 years</i></p>	<p>The recommended budget for this objective has been partially met as of 2012. In 2013, NIH launched the NIH Neurobiobank (\$5M), which includes samples for research on autism as well as other brain disorders, so this may not be reflected in the 2013 portfolio analysis figures. The NIH Neurobiobank has a web publication "Why Brain Donation? A Legacy of Hope." to increase awareness about brain donation. Loss of autism brain samples in 2012 due to a freezer malfunction has caused a loss of progress and there is a need for new samples to replace and build the amount of available brain tissue for ASD research. It was noted that some projects coded to this objective focus on tissue processing rather than specifically on donation. More funding and projects are needed to achieve this objective.</p>	\$856,031
<p>2.S.D. Launch three studies that target improved understanding of the underlying biological pathways of genetic conditions related to autism (e.g., Fragile X, Rett syndrome, tuberous sclerosis complex) and how these conditions inform risk assessment and individualized intervention by 2012.</p> <p><i>IACC Recommended Budget: 9,000,000 over 5 years</i></p>	<p>The recommended budget for this objective has been met and a large number of projects funded that address this objective. Investment in this area has doubled since 2009, and there is an ACE center focused on tuberous sclerosis. This objective is on track.</p>	\$53,147,645
<p>2.S.E. Launch three studies that target the underlying biological mechanisms of co-occurring conditions with autism, including seizures/epilepsy, sleep disorders, wandering/elopement behavior, and familial autoimmune disorders, by 2012.</p> <p><i>IACC Recommended Budget: \$9,000,000 over 5 years</i></p>	<p>The recommended budget for this objective was met, and more than twenty projects were funded, but further efforts are needed, especially on wandering, metabolic and immune conditions related to ASD, as well as a systems-biology approach to understand how these co-occurring conditions are related to ASD.</p>	\$16,531,078
<p>2.S.F. Launch two studies that focus on prospective characterization of children with reported regression to investigate potential risk factors by 2012.</p> <p><i>IACC Recommended Budget: \$4,500,000 over 5 years</i></p>	<p>The recommended budget for this objective has been partially met. The number of recommended projects has been met, but further work is needed on comparing regressive autism to non-regressive autism. High-risk siblings may present an opportunity for studying regression prospectively.</p>	\$993,134
<p>2.S.G. Support five studies that associate specific genotypes with functional or structural phenotypes, including behavioral and medical phenotypes (e.g., nonverbal individuals with ASD and those with cognitive impairments) by 2015.</p> <p><i>IACC Recommended Budget: \$22,600,000 over 5 years</i></p>	<p>The recommended budget for this objective has been met, over 40 projects have been funded in this area, and the projects cover the areas described, so the objective appears to be on track.</p>	\$41,777,028
<p>2.L.A. Complete a large-scale, multidisciplinary, collaborative project that longitudinally and comprehensively examines how the biological, clinical, and developmental profiles of individuals, with a special emphasis on females, youths, and adults with ASD, change over time as compared to typically developing people by 2020.</p> <p><i>IACC Recommended Budget: \$126,200,000 over 12 years</i></p>	<p>The recommended budget for this objective was partially met and several projects have been funded in this area. More clinical studies are needed over a longer trajectory to identify issues faced as people with ASD age, especially with regard to risk factors for other medical conditions.</p>	\$20,690,241
<p>2.L.B. Launch at least three studies that evaluate the applicability of ASD phenotype and/or biological signature findings for performing diagnosis, risk assessment, or clinical intervention by 2015.</p> <p><i>IACC Recommended Budget: 7,200,000 over 5 years</i></p>	<p>The recommended budget for this objective was partially met, and more than 3 studies were launched, but more funding and work in this area is needed.</p>	\$3,599,806
<p><i>IACC Recommended Budget: 7,200,000 over 5 years</i> Not specific to any objective</p>		\$201,661,561

