

# CDMRP

X. Autism Spectrum Disorder  
Research Program

# PROGRESS

*Vision*

Improve the lives of individuals with autism spectrum disorder now.

*Mission*

Encourage innovative research that advances the understanding of autism spectrum disorder and leads to improved treatment outcomes.

## The Disease

Autism is a complex developmental disorder that recent evidence indicates may affect as many as 1 in 166 children. With this prevalence rate, it is estimated that there are approximately 500,000 individuals between the ages of 0–21 years with autism in the United States.<sup>1</sup> The manifestations of autism vary widely from mild to severe, leading to their general classification as autism spectrum disorders (ASDs). ASDs are described by serious impairments in social, emotional, and communication skills as well as the presence of unusual behaviors and physical manifestations, such as sleep disorders and depressed immune function. Only about 10 percent of individuals with ASD develop autism secondary to a known genetic disorder. The cause of ASD in the remaining individuals is not certain. However, progress is being made on several fronts. Like autism itself, the answer to this question will likely be multifaceted.



<sup>1</sup> <http://www.cdc.gov/ncbddd/autism/>.

## Red Flags of Autism

ASD usually develops before 3 years of age. In clinical terms, there are a few “absolute indicators,” often referred to as “red flags,” that indicate that a child should be evaluated.<sup>2</sup> For a parent, these are the “red flags” that your child should be screened for to ensure that he/she is on the right developmental path. However, no two individuals with ASD exhibit the same symptoms and, conversely, some individuals without ASD may present some of these behaviors.

- ❖ No big smiles or other warm, joyful expressions by 6 months or thereafter
- ❖ No back-and-forth sharing of sounds, smiles, or other facial expressions by 9 months or thereafter
- ❖ No babbling by 12 months
- ❖ No back-and-forth gestures, such as pointing, showing, reaching, or waving by 12 months
- ❖ No words by 16 months
- ❖ No two-word meaningful phrases (without imitating or repeating) by 24 months
- ❖ Any loss of speech or babbling or social skills at any age



<sup>2</sup> This information has been provided by First Signs, Inc. ©2001-2005. Reprinted with permission. For more information about recognizing the early signs of developmental and behavioral disorders, please visit <http://www.firstsigns.org> or the Centers for Disease Control and Prevention at [www.cdc.gov/actearly](http://www.cdc.gov/actearly).

## Program Background

The Congressionally Directed Medical Research Programs (CDMRP) began managing the Department of Defense Autism Spectrum Disorder Research Program (ASDRP) in response to the fiscal year 2007 (FY07) Appropriations Conference Committee Report No. 109-676, which provided **\$7.5 million** (M) for research on ASD. A stakeholders meeting was held in March 2007 in which renowned scientists, clinicians, and consumer advocates discussed issues and gaps critical to autism research and treatment as well as potential means to address them. Utilizing the recommendations from the stakeholders meeting, the first ASDRP Integration Panel (IP), composed of experts and consumer advocates in the ASD field, was then assembled in April 2007 and panel members determined the FY07 vision and investment strategy.



**Gary Goldstein, M.D.**  
Kennedy Krieger Institute  
FY07 ASDRP Integration  
Panel Member

“The ASDRP grant process opens the way to have a panel of experts and consumers establish priorities for autism research and then encourage grant submissions within these priorities. This year our focus is on possible environmental triggers of autism and novel medical therapies. The panel felt these areas of research are underfunded by other sources.”



**Lyn Redwood, R.N., M.S.N.**  
National Autism  
Association/SafeMinds  
FY07 ASDRP Integration  
Panel Member

“I had a perfectly normal baby. He hit all his developmental landmarks but after his first birthday he seemed to be sick all of the time, with infection after infection. He stopped eating and was no longer happy and playful. By 17 months he had stopped talking, interacting, or even looking at us anymore; he was in his own little world. At 4 years old, he had no language, was not potty trained... My baby had been stolen away from us.” This was the reality Lyn Redwood faced when her child was diagnosed with autism.

## Progress by Working with the Best People

Similar to other programs within the CDMRP, the ASDRP is networking with the best people—from scientists, clinicians, and research managers, to those ultimately affected by the disorder—to make a quantum leap in biomedical research that will benefit individuals with ASD.

### Consumer Advocates

Consumer advocates for the ASDRP are individuals living with or family members of individuals living with autism who are active participants in an autism-related support, outreach, or advocacy organization. They are active participants in practically all aspects of program execution. Consumer advocates work collaboratively with leading scientists and clinicians in setting program priorities and funding proposals where they contribute their unique perspectives and sense of urgency. Consumer advocates also serve as liaisons between their constituencies and the scientific community and are able to increase awareness about the program. More information about consumer advocate participation can be found in Section I, Overview.



**Shelley Reynolds' son Liam  
Unlocking Autism  
FY07 ASDRP Integration Panel  
Member**

“Children are like snowflakes, each one different, each one needing a different biomedical intervention. What makes treating autism difficult is that each combination to unlock each person affected is so unique. Families need help. We need to determine what is causing the sleeping disorders and the GI [gastrointestinal] symptoms that present in the majority of these children. We cannot just give these kids pharmaceutical interventions for their entire lives. We need effective treatments that address the root cause of the problems. With sleep and GI function operating optimally, many of the residual behaviors we see in children with autism decrease significantly.” Reynolds speaks from experience. With biomedical and behavior intervention, her son is now a well-functioning 11-year old. “We were lucky to find what worked best for him. I have friends who have tried everything, and their children are not progressing and are still presenting with infantile behavior as they enter adolescence.”

## Peer Review Panel Members

The first ASDRP scientific peer review panels will be composed of highly qualified investigators from scientific and clinical disciplines as well as consumer advocates. The primary responsibility of scientific peer review is to determine the scientific merit of proposals submitted to the program. Scientific reviewers for peer review are selected for their subject matter expertise and experience with scientific peer review. Consumer reviewers are nominated by an advocacy or support organization and are selected on the basis of their leadership skills, commitment to advocacy, and interest in science. Further details about peer review can be found in Section I.

## Integration Panel Members

Distinguished scientists, clinicians, and consumer advocates comprise the ASDRP IP. They work to serve the interest of the ASD community by recommending critical research priorities, cutting-edge investment strategies, and multidisciplinary research portfolios (for more information about the functions of the IP, see Section I). The ASDRP would like to thank the members of the program's first IP for shaping the future of this program.

### FY07 ASDRP IP Members

Peter Bell (Chair), Autism Speaks/Cure Autism Now

Gary Goldstein, M.D. (Alternate Chair), Kennedy Krieger Institute

Linda Brzustowicz, M.D., Rutgers University

Stephen Dager, M.D., University of Washington

Emanuel DiCicco-Bloom, M.D., UMDNJ Robert Wood Johnson Medical School

Lee Grossman, Autism Society of America

Susan Hyman, M.D., University of Rochester

Alice Kau, Ph.D., National Institute of Child Health and Human Development

Lyn Redwood, R.N., M.S.N., National Autism Association/SafeMinds

Shelley Reynolds, Unlocking Autism

Carole Samango-Sprouse, Ed.D., George Washington University

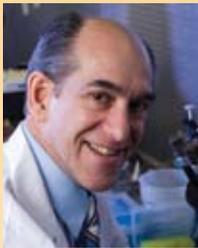


**Peter Bell**  
Autism Speaks/Cure  
Autism Now  
FY07 ASDRP Integration  
Panel Chair

“This is a very unique opportunity to allow the scientists and advocates to focus on a common cause, improving the lives of children with autism, to produce research that will lead to making a real difference. Parents have been playing a significant advocacy role and changing the way experts view the disorder. We need to move to a place in research where we are making discrete improvements focused on the urgency of helping our children. We don’t have 5 to 10 years to wait to find out which treatments work with which kids. We need these answers now.”

## Scientific Community

The scientific community is an integral part of the ASDRP. Scientists and clinicians are providing their expertise on setting the program's vision, reviewing proposals, and conducting the necessary laboratory and clinical studies to tackle this complex disorder.



**Emanuel DiCicco-Bloom, M.D.**  
UMDNJ Robert Wood Johnson  
Medical School  
FY07 ASDRP Integration Panel  
Member

“We have good reasons to expect significant progress in understanding and treating the autism spectrum disorders in the coming years. The increased attention from society has fostered enhanced research support and opportunities. And with the scientific community’s realization that it is a developmental brain disease with genetic and environmental components, we now have a convergence of the multiple basic and clinical disciplines that must work together to overcome such a complex yet uniquely human disorder. The ASDRP has been designed to address specific research areas that are receiving little support from other funding organizations and mechanisms.”



**Susan Hyman, M.D.**  
University of Rochester Medical  
Center  
FY07 ASDRP Integration Panel  
Member

“In 1997, \$22 million was spent on autism-related research. By 2007, \$108 million research dollars have been allotted. With the increased scientific scrutiny that this funding permitted, we know much more about what autism is and is not than we did 10 years ago. The nature of research has also changed in this time period. Translational approaches take research beyond the gene and synapse to the classroom and family. The interface of gene and environment, physiology, and behavior are the new sites for scientific study. Despite the growth in federal and private funding, there are many areas of unmet needs; many questions regarding treatment of individuals affected by autism that need to be answered. The ASDRP has carefully examined how to add to existing funding initiatives to promote research investigating treatment, environmental factors, and to bring together translational research teams.”



**Clinical Partnership Awards** support the development of translational research collaborations between two independent investigators to address a central problem or question in ASD in a manner that would be less readily achievable through approaches based in a single setting. In developing a research plan, the members of the partnership were encouraged not to view translational research as a one-way continuum from the bench to the bedside. Rather, observations that drive a research idea may be derived from a research discovery or a clinician’s firsthand knowledge of patients and anecdotal data.

**Idea Development Awards** support innovative research that advances the understanding of ASD and leads to improved treatment outcomes. Additionally, the FY07 ASDRP supports collaborative research to bring a new perspective to ASD research and/or facilitate progress in the field by combined effort. Up to three investigators may work on a single project.

**Concept Awards** support the exploration of an initial idea or novel observation that could give rise to a testable hypothesis. These awards provide Principal Investigators with the opportunity to pursue serendipitous observations.

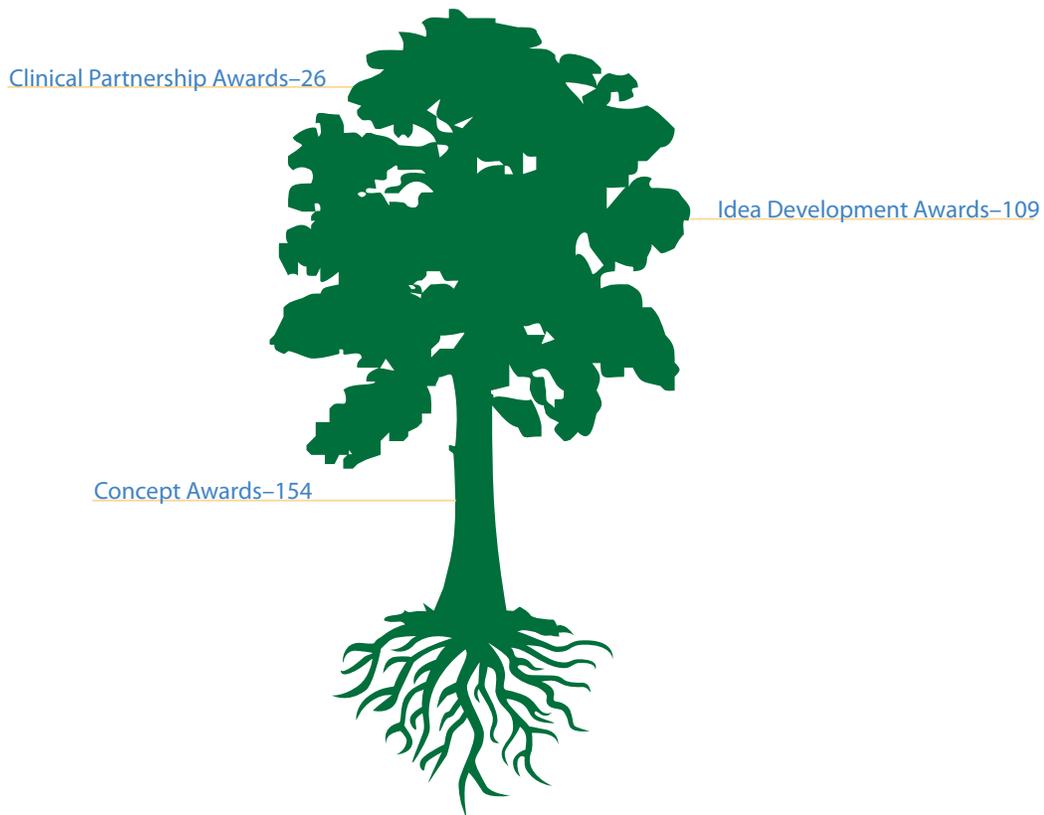


Figure X-1. Award Mechanisms Offered and Proposals Received for the FY07 ASDRP

