

CDMRP



Department of Defense

Autism Research Program



U.S. Army Medical Research and Materiel Command



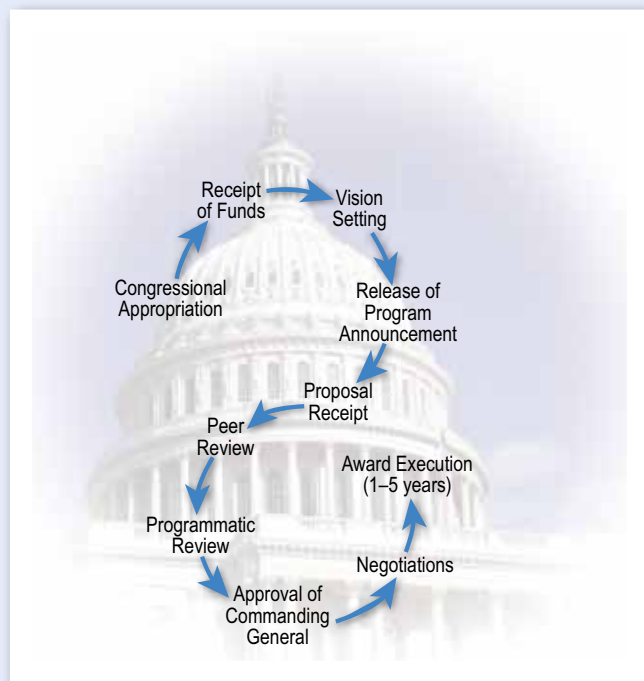
Congressionally Directed Medical Research Programs



HISTORY The Office of the Congressionally Directed Medical Research Programs (CDMRP) was created in 1992 from a powerful grassroots effort led by the breast cancer advocacy community that resulted in a congressional appropriation of funds for breast cancer research. This initiated a unique partnership among the public, Congress, and the military. Since then, the CDMRP has grown to encompass multiple targeted programs and has received nearly \$7 billion in appropriations from its inception through fiscal year 2012 (FY12). Funds for the CDMRP are added to the Department of Defense (DoD) budget in which support for individual programs, such as the Autism Research Program (ARP), is allocated via specific guidance from Congress.

Application Review Process

The CDMRP uses a two-tier review process for application evaluation with both tiers involving dynamic interaction among scientists and consumer advocates (individuals living with autism spectrum disorders [ASD] or family members of individuals living with ASD). The first tier of evaluation is a scientific peer review of applications measured against established criteria for determining scientific merit. The second tier is a programmatic review conducted by the Integration Panel (IP), which is composed of leading scientists, clinicians, and consumer advocates. The IP compares applications to each other and makes recommendations for funding based on scientific merit, portfolio composition, and relevance to program goals.



Autism Research Program

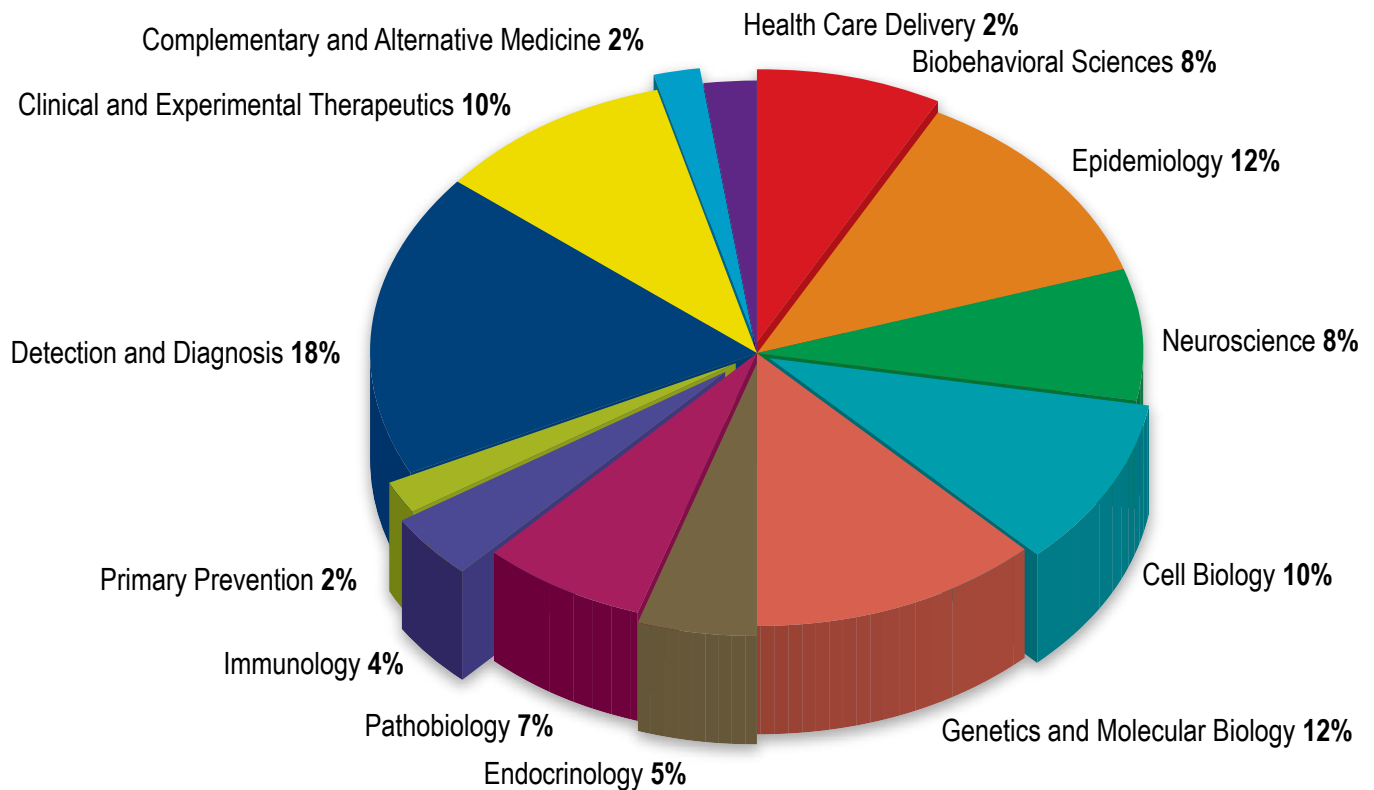
HISTORY With the alarming rise of ASD in the United States where 1 in 88 children and as many as 1 in 54 boys are diagnosed on the spectrum yearly, Congress has answered the call and appropriated funds to the DoD budget to execute and manage the ARP. The cause of ASD is unknown; however, progress is being made on several fronts and the answers related to ASD will likely be multifaceted. The immediacy of the ARP vision, to improve the lives of individuals with ASD now, has imparted a strong sense of action and has steered the investment strategy of the ARP for the past 5 years. The imperative to improve the lives of all individuals living with ASD and their families drives the ARP toward innovative, high-risk/high-gain research for the present and the future. From its inception in FY07 through FY12, the ARP has invested \$41.4 million to fund 85 awards for the advancement of autism research to assist and improve the lives of individuals living with ASD.

VISION:

Improve the lives of individuals with autism spectrum disorders now

MISSION:

Promote innovative research that advances the understanding of autism spectrum disorders and leads to improved outcomes



FY07-FY11 ARP Portfolio by Research Area

Research Highlights

Technology-Enhanced Early Intensive Behavior Intervention Services for Children with Autism Spectrum Disorders in Military Families



"It is indeed a privilege to be among such a distinguished and caring group of people who spend countless hours on behalf of improving the lives of persons with autism spectrum disorders. The focus on research that can have an immediate impact is certainly an important goal for this process."

Mark Durand, Ph.D.
University of South Florida
Integration Panel member



Photo credit: University of Nebraska Medical Center

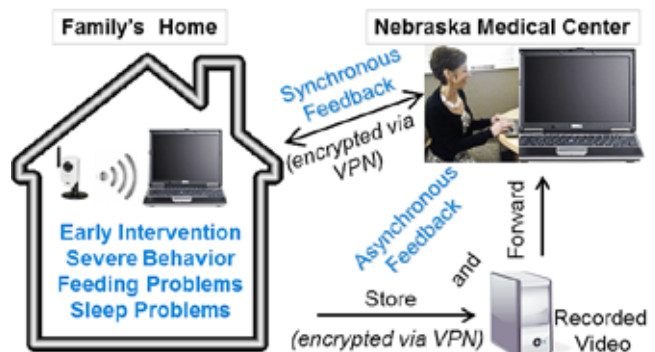
Wayne Fisher, Ph.D., University of Nebraska Medical Center

ASD encompass a range of developmental disorders that involve impairments in language, social relatedness, and repetitive behaviors. ASD affect approximately 13,000 children whose parents are active duty military service members. Early intensive behavior intervention (EIBI) has been demonstrated to improve long-term outcomes for children with ASD when started at 2 to 3 years of age and practiced at least 25 hours per week. Unfortunately, only 10% of military children are receiving this treatment because access to services and trained professionals is severely limited or lacking entirely in many areas where military families are stationed.

Dr. Wayne Fisher of the University of Nebraska Medical Center and FY10 recipient of an ARP Clinical Trial Award is leading an effort to greatly increase the availability of EIBI to military families anywhere in the world through web-based training curricula developed to educate paraprofessionals as EIBI tutors and instruct parents in the use of EIBI techniques in the home. These training curricula use slide-by-slide narration and video demonstrations as well as scripted role-plays for practicing the techniques with other adults.

While trained paraprofessional tutors will help to implement EIBI services locally, it will continue to be important for children to receive care from one physician with ASD expertise who knows their medical history. Imperative to making EIBI available remotely, therefore, is the use of in-home video recording and video conferencing. Clinicians will be able to record and annotate video clips of problem behavior from multiple cameras strategically located throughout the home and store them on a secure server where they can be viewed by the child's behavior analyst regardless of location. Similarly, video conferencing will allow the child to be cared for by a single professional no matter where the military family is stationed or how frequently they relocate.

Dr. Fisher believes that this web-based training program will increase the number of trained EIBI tutors near military bases and other remote areas, provide long-lasting clinical benefits to children with ASD, reduce parental stress in military families, and eliminate geography as a barrier to effective EIBI treatment. The effectiveness of this technology-driven enhanced intervention will be evaluated in a randomized clinical trial with 50 paraprofessionals and 50 military parents along with their children who have been diagnosed with ASD.



Did you know?

1 in 88 children
(and 1 in 54 boys)
in the United States
are diagnosed
with ASD.

Evaluating and Enhancing Driving Skills of Individuals with Autism Spectrum Disorders

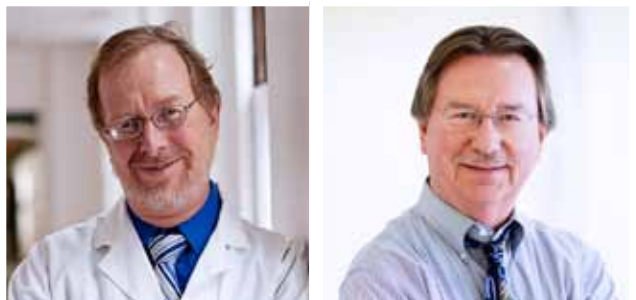


Photo credit: University of Virginia

Daniel Cox, Ph.D. (left)
Ronald Reeve, Ph.D. (right)
University of Virginia

Achieving independence is a challenge for individuals living with ASD. Individuals with ASD may experience difficulties with motor coordination, planning, cognitive flexibility (e.g., shifting between

hyperfocus and limited attention), and emotion regulation. These symptoms are particularly problematic when learning to drive, which is an important step toward independence for all teenagers. Given that motor vehicle collisions are a leading cause of injury and mortality among all adolescents (*Web-Based Injury Statistics Query and Reporting System [WISQARS] [Online]. 2010. National Center for Injury Prevention and Control, Centers for Disease Control and Prevention [producer]. [Cited 2010 October 18]*), it is critical to determine which individuals with ASD can learn to drive safely and which instructional methods are most successful.

Dr. Daniel Cox of the University of Virginia received an FY10 Exploration–Hypothesis Development Award to establish the feasibility of using a virtual reality driver simulator (VRDS) to train and evaluate driving skills in teens with ASD. To establish feasibility, 15- to 25-year-olds with Asperger's and high-functioning autism who have recently obtained their learner's permits are recruited to participate in this study.

Participants are first given a simulator pretest to identify individual strengths and weaknesses. Half of the participants then receive 10 VRDS training sessions. The trainer uses the pretest results to guide the participant through an individualized training plan in which each new skill introduced is built upon previously mastered skills. Participants will not be exposed to traffic, for example, until they have mastered basic steering and braking skills. After the treatment sessions, they receive another simulator test as well as an on-road examination by an independent driving professional. Preliminary results demonstrate that participants were able to use the simulator without any major difficulties and that driving performance was significantly improved (e.g., following instructions, speed, turns, stops, unexpected events, and road rules) in the VRDS group compared to those who continued only with standard driver's training.

Based on these preliminary results, Dr. Cox received an FY11 Idea Development Award to further develop the VRDS training tool. For this project, he is partnering with Dr. Timothy Brown of the University of Iowa to recruit 60 adolescents with a broader range of ASD symptoms and identify key predictors of driving performance and safety. These investigators predict that higher-level executive functioning (e.g., the ability to anticipate consequences, inhibit impulses, plan ahead, problem solve, and be creative) and fewer ASD symptoms of inattention will correlate with better baseline driving performance and a greater improvement in driving performance after VRDS training. Data from this study will enable guidelines to be generated that will help predict which individuals may best benefit from this type of driver training and are more likely to become independent drivers and will also identify the VRDS training procedures that are most effective for acquiring safe driving skills. The results of this study may greatly assist individuals living with ASD on the journey toward independence.



“The Autism Research Program Integration Panel is a remarkable group that merges different expertise (including parent expertise) toward the single goal of finding treatment strategies for autism. I have learned a great deal from serving on the Integration Panel, and I hope that the discussions we have and the recommendations upon which we agree help the field to better understand autism.”

Daniel Campbell, Ph.D.
University of Southern
California
Integration Panel member



VRDS for training and evaluating driving skills in teens with ASD.

A Consumer's Perspective: Yolanda Cosby – From Denial to Acceptance and Beyond



"I have served on the Department of Defense Autism Research Program since its inception in 2007. I think it is incredibly important to have consumer input on the investment into the type of research for every precious dollar spent. Every year during programmatic review, I am impressed with the portfolio's diversity of projects that are funded and equally impressed that the opinions of the consumers are weighed as heavily as the interests of the scientists and clinicians. It has meant so much to me to be able to stand my ground as a mother and advocate and say, 'Please recommend funding for this because it could help people with autism now—today.'"

Shelley Hendrix-Reynolds, B.A. (consumer)
Unlocking Autism
Integration Panel member



Yolanda Cosby knew about autism. As a special education teacher, she had worked at a school for autistic children. She could see the signs; she knew the actions and reactions. It became familiar; it became routine.

Perhaps too routine.

When her oldest son, Eric, was diagnosed with autism at 2 years of age, Yolanda refused to believe it. Following the path of the five stages of grief, Yolanda experienced denial, anger, bargaining, and depression before finally accepting her son's diagnosis.

"After he was diagnosed with a developmental disability, I thought, 'Eric is fine—he just needs some speech services,'" said Yolanda. "I didn't even discuss it with my friends and family because I thought it would clear up if he went to Early Intervention Services. Then I thought 'Why Me?' and then I tried to make a deal with God. I said I would go to church every Sunday if he would help Eric."

Yolanda also blamed herself for Eric's diagnosis. It was her fault, she reasoned, because she did not take her daily vitamins during pregnancy and also suffered from gestational diabetes. She second-guessed her decision to allow doctors to give Eric recommended vaccinations.

Once she experienced the final stage of grief—acceptance—Yolanda said her life and Eric's dramatically improved and came into focus.

"When I finally realized that autism is here in my family to stay, I came to grips and asked myself, 'What can I do to help the situation?'" Yolanda said. "That is the point when advocacy became part of my life."

After Eric's fifth birthday, Yolanda was still coming to grips with his autism and getting suggestions from doctors, family members, and friends. She needed a foundation upon which to begin her advocacy efforts and began volunteering her time with Autism Speaks.

"I got so much advice when he was diagnosed, my head was spinning," Yolanda said. "I had two children, 17 months apart, and I needed some support. I wanted to bond with a group that understood what was going on with me. Advocacy has provided me a sort of therapy by helping other families that had loved ones with autism."

Six years after Eric's diagnosis and 5 years after she plunged into the world of advocacy, Yolanda said she is right where she wants to be. She continues to work with Autism Speaks, as well as with the Interactive Autism Network (IAN), and recently served as a peer reviewer for the DoD ARP. In future years she said she hopes to learn more about autism to help families struggling to accept the diagnosis.

"Today, I am strong thanks to Autism Speaks, the IAN Project, and the Autism Research Program," Yolanda said. "I feel like I am working to assist with funding the cause for autism. I know that I am making a difference for the future."

Did you know?

The ARP has invested more than \$4.8 million in clinical trials.

The Autism Research Program Joins the Collaborative Effort of the Interagency Autism Coordinating Committee

The Combating Autism Act of 2006 was signed into law in December 2006 and recently reauthorized in 2011. Part of the law established the Interagency Autism Coordinating Committee (IACC), which was charged with developing an annual update on research and advances in ASD, monitoring and informing federal ASD work, and developing an annual strategic plan for ASD research and its funding. In 2012, the DoD ARP was added to the IACC with an official representative on the full committee. All ARP awards have been included in the IACC portfolio report. The annual portfolio report includes funded projects from various federal funding agencies and private funders (see IACC organizations below).

Inclusion on the IACC means a more active role for the ARP and cross-communication with other federal and nonfederal agencies on funding initiatives. The ARP IP is briefed on the IACC strategic plan and portfolio (overall funding by agencies and organizations and a topic-level analysis) each fiscal year. The ARP team evaluates the funding landscape by utilizing the IACC portfolio reports to identify the research projects and mechanisms of other federal and nonfederal agencies. Using these analyses as a foundation, the ARP IP develops novel award mechanisms to target the areas that represent research gaps and are most critically in need. Through these interactions, funding through the ARP will complement and support investments by other agencies. With a more active role in the IACC, the ARP team will be better suited to ensure good stewardship of federal funds, prevent funding overlaps, and increase transparency to the community. The ARP's annual funding strategy and associated award mechanisms provide the framework necessary to most effectively invest the congressional appropriation in autism research toward ARP's vision to improve the lives of individuals with ASD now. ARP promotes innovative research that advances the understanding of ASD and may lead to improved outcomes.



"The DoD Autism Research Program provides hope to families, stakeholders, and persons with autism spectrum disorders. The involvement of advocates ensures our reviews focus on the science as well as what really matters."

Craig Powell, M.D., Ph.D.
University of Texas
Southwestern Medical Center
Integration Panel member

IACC Representation and Organizations

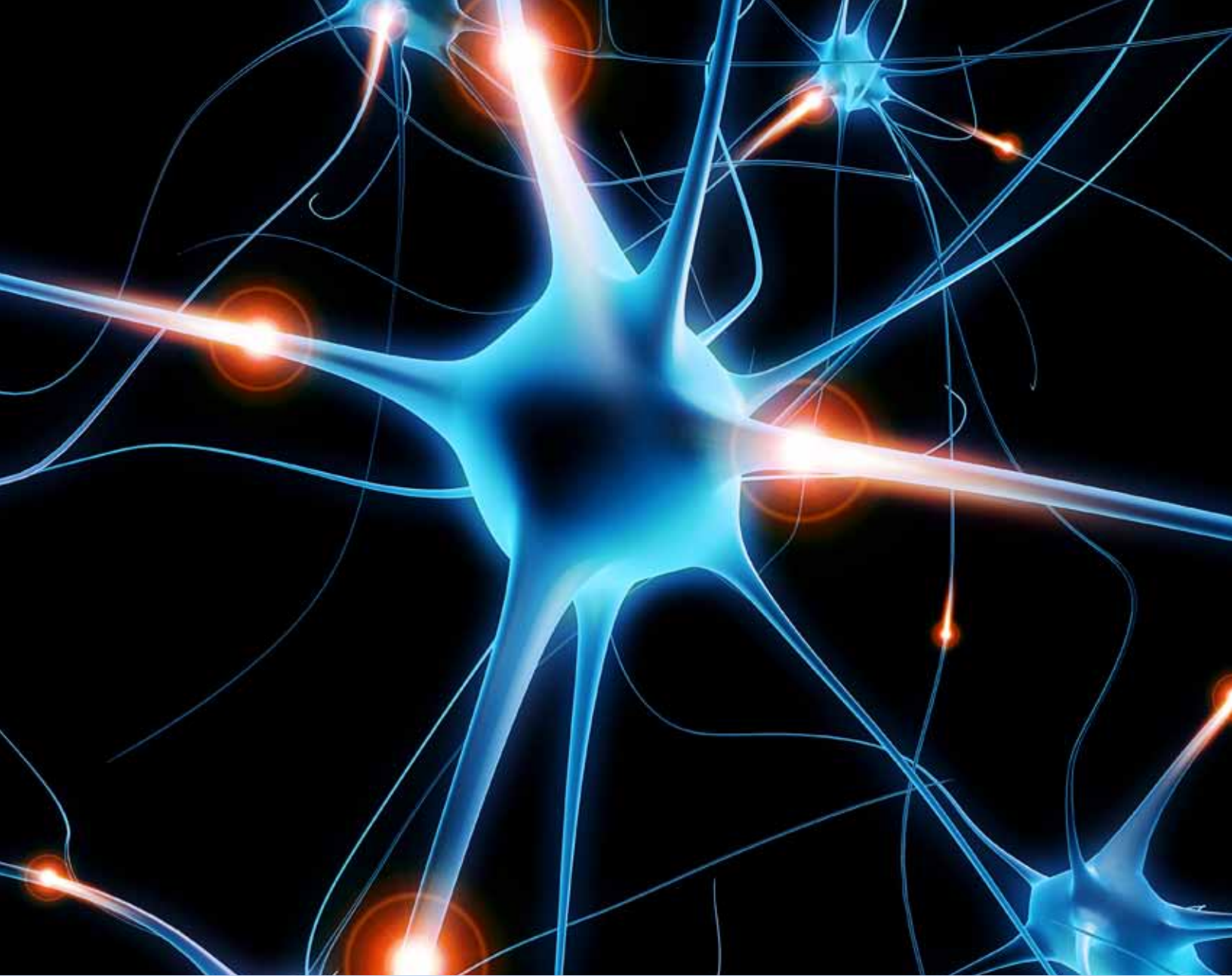
Federal Organizations

<i>Administration for Children and Families*</i>	<i>Centers for Medicare and Medicaid Services*</i>	<i>Food and Drug Administration</i>
<i>Administration for Community Living</i>	<i>Department of Defense (Congressionally Directed Medical Research Programs)</i>	<i>Health Resources and Services Administration*</i>
<i>Agency for Healthcare Research and Quality*</i>	<i>Department of Education*</i>	<i>National Institutes of Health*</i>
<i>Centers for Disease Control and Prevention*</i>	<i>Environmental Protection Agency*</i>	<i>National Science Foundation*</i>

Private Organizations

<i>Autism Research Institute*</i>	<i>Left Brain Right Brain Autism Blog</i>	<i>Southwest Autism Research and Resources Center*</i>
<i>Autism Science Foundation*</i>	<i>Nevada Commission on Autism Spectrum Disorders</i>	<i>University of North Carolina, Neurodevelopment Disorders Research Center</i>
<i>The Autistic Self Advocacy Network</i>	<i>Organization for Autism Research*</i>	<i>University of Pennsylvania, Department of Psychiatry and Pediatrics</i>
<i>Autism Speaks*</i>	<i>Our Special Kids</i>	<i>University of Puerto Rico, Graduate School of Public Health</i>
<i>Center for Autism and Related Disorders*</i>	<i>Self Advocates (2)</i>	
<i>Coalition for SafeMinds*</i>	<i>Simons Foundation*</i>	
<i>Eastern Michigan University, Department of Special Education</i>	<i>Somali American Autism Foundation</i>	
<i>JB Autism Consulting</i>		

Italics – Committee members | *Funding agencies



For more information, visit:

<http://cdmrp.army.mil>

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08-2012

