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The Stanford Autism Center at Packard Children's Hospital Newsletter

New website: Please check out our new Stanford Autism Center at Packard Children's Hospital website at autism.lpch.org.

Parent Advisory Board: The Autism Center has started a Parent Advisory Board, consisting of parents of children on the autism spectrum. Many of the parents have a connection to Stanford University. The mission of the Parent Advisory Board will be to enhance the activities and further the mission of the Center by providing the unique wisdom and perspective it's members have earned in the course of raising children with an Autism Spectrum Disorder. The Board will support the mission of the Center to elevate the level of clinical care, research, and training for ASD by fostering program innovation, meaningful and reciprocal communication with parents and care providers, and enhancing community outreach. It will consult directly to the Director of the Center and provide input to the Executive Board of the Center. The board has met twice and is moving forward enthusiastically to work on several projects proposed by the board members. They are: A Center parent support group, and an Autism Education Resource (including latest research on various intervention techniques, best practices and parent tools).

Autism Spectrum Disorders: Educational Series for Parents: The Center's Autism Spectrum Disorders: Educational Series for parents continues to flourish. The classes are offered three times a year in a 10-part series for parents of children and adolescents with an Autism Spectrum Disorder (ASD). The series is designed to provide parents with information about ASD diagnoses, treatment, and services. Many sessions apply to parents of any child with ASD; others apply to certain age groups or levels of language ability. The classes have been very well received by the parents, and we continue to have full classes, averaging about 35-40 parents. Parents may register for the classes by logging on to <http://childpsychiatry.stanford.edu>.

Autism Spectrum Disorders: Educational Series for Spanish Speaking Parents: A new series of classes will start up on September 13, 2010 at Parents Helping Parents in San Jose. The classes are taught by Maria Elena DeAnda, PhD. Parents may register for the classes by calling Parents Helping Parents at (408) 727-5775.

Autism Spectrum Disorders: Educational Series for Parents (videoconferencing): The Autism Center will be offering Autism Spectrum Disorders: Educational Series for parents by videoconferencing the classes to the San Andreas Regional Center in Salinas. Parents who may not be able to travel to Palo Alto may now watch, ask questions and interact with Dr. Linda Lotspeich during the classes.

Autism Working Group: In an effort to increase collaboration, the Autism Working Group encourages Stanford autism researchers to collaborate and share knowledge with each other. It was co-founded by Richard Tsien, PhD, the co-director of the Neurosciences Institute at Stanford, Carl Feinstein, MD, the Division Chief for Child Psychiatry in the Department of Psychiatry and Behavioral Sciences. Joachim Hallmayer, MD, is the Chair of the AWG, and Dr. Tsien is co-chair. The Autism Working Group meets once a month at Stanford University.

New Autism Research Project: Pivotal Response Treatment (PRT) Group for Parents

Stanford Autism Center researchers are launching a new study, funded by the organization Autism Speaks, to investigate the effectiveness of group parent education in Pivotal Response Treatment (PRT). PRT is a naturalistic form of applied behavior analysis which focuses on motivating children with autism to interact and communicate during daily routines. PRT is an evidence-based treatment which has been demonstrated to be effective in individual parent-child therapy sessions. With the high demand for treatment services, more efficient and cost-effective methods of delivery are needed, and systematic research regarding PRT delivered in a group format has not yet been conducted. The study, led by principal investigator Dr. Antonio Hardan, will consist of a randomized controlled 12-week trial to examine whether the language skills of children with autism improve after their parents participate in group PRT training sessions. These results will be compared with parents who are participating in a psychoeducational group. The groups will be led by Dr. Grace Gengoux, child psychologist and clinical instructor in Child and Adolescent Psychiatry at Stanford, and Stanford Autism Center postdoctoral fellow, Dr. Kari Berquist. The study is currently seeking participants. Parents who have children ages 2-6 with autism spectrum disorder and significant language delays may be eligible to participate. More information is available by calling (650) 736-1235.

Active Research Projects: The Autism Research Registry numbers continue to grow. At this date, there are 330 families signed up. For more information on the registry, please call (650) 736-1236. Researchers at Stanford University and Packard Children's Hospital are currently recruiting healthy children to participate in a research study about children with Autism Spectrum Disorder to better understand the causes of this condition. For more information please call (650) 736-1235. Participants are also needed for Autism Twin Research. Researchers are currently recruiting same-sex twin pairs with autism and twin pairs without autism (i.e. typically developing) to participate in a research study. The study compares twins with Autism Spectrum Disorder to typically developing twins so we can better understand the causes of autism. For more information on this study, please call (650) 723-7809.

DSM-5 Field Trials: Stanford University Department of Psychiatry has been selected as one of the leading Medical Center Field Trials and will be using revised diagnostic criteria for four diagnoses: The disorders to be tested at Stanford are: Autism Spectrum Disorder, Avoidant/Restrictive Food Intake Disorder, Major Depressive disorder and Mixed anxiety and Depression Disorder. The changes proposed at a national level for ASD are expected to have a major impact on diagnosis in the future and are somewhat controversial. Therefore, we take our participation as a leader in Field Trials in ASD as an important responsibility which we take very seriously. At the Stanford site we will be studying children and young adults between the ages of 6 years to 25 years old. Other sites will do field trials on younger children. DSM-4 – current field trails, has been used since 1994. Numerous proposed revisions were made based on clinical trials used for the last fifteen years. In May 2113, the American Psychiatric Association will publish the statistical manual

BAAC: The Bay Area Autism Consortium continues to move forward with the goal of being the major informational site for Bay Area resources, research and treatments for patients with an ASD. The consortium met again on June 23, 2010 at Stanford University. Decisions were reached during the meeting on the organization and structure of the consortium that will allow the group to move forward expeditiously. The founding institutions are the Stanford Autism Center at Packard Children's Hospital, UCSF, Kaiser, Oakland Children's Hospital, Children's Health Council, and California Department of Public Health. Representatives from the six core institutions will make up the Executive Committee. Members of the consortium will identify and appoint an Executive Committee with one person from each

institution rotating every three months. BAAC will identify and appoint a Steering Committee, based on institution. Three to five people from each institution will be appointed to serve on the Steering Committee. The BAAC Steering Committee will meet on a yearly basis. BAAC will invite other organizations to join, including San Francisco State University, CMPC, The Department of Education and SRI. The mission of the BAAC will be to improve the lives of people on the autism spectrum disorders, with their families and care providers. Among the many short term goals of the consortium will be to establish a website, for both internal and external use. The internal website can be used as a resource for members only as a way to communicate on research projects. The public website will be complete with a catalog of resources organized in such a way that parents can find a central location for information.

Bay Area Autism Regional Task Force: Background [information](#) on SB1283 (DMHC Grievances and Appeals Process). Preliminary recommendations of the task force may be found [here](#). Highlighted transcripts of the insurance hearing can be found at www.senate.ca.gov/autism .