

In This Issue

UC Davis Researchers Win \$3 Million Grant from U.S. Congress to Study Fragile X

CDC Disability and Health Partners Meeting: Building Healthy Communities for Everyone

National Fragile X Family Survey

Join the Friends of NCBDDD

NCPAD Video Contest: How Do You Get Enough?

Registration Now Available:

[2011 Disability and Health Partners Meeting](#)

June 14-16, 2011
Chicago, Illinois

AUCD News

[Job Opportunities at AUCD](#)

UC Davis Researchers Win \$3 Million Grant from US Congress to Study Fragile X

Three internationally respected UC Davis researchers — two experts in fragile X syndrome and one in epilepsy — have joined forces to test the efficacy of an innovative new approach to treating children with fragile X, through a \$3 million grant from the US Congress. The collaboration includes Randi Hagerman, MD, Associate Director of the UC Davis UCEDD. The researchers will explore the safety and effectiveness of a synthetic neuroactive steroid drug, ganaxolone, for treating the anxiety that is common in children with fragile X, a condition that is the leading cause worldwide of inherited intellectual disability and the most common single-gene cause of autism. The collaboration includes Randi Hagerman, an international authority on fragile X-related disorders, Michael Rogawski, known worldwide for his epilepsy research, and David Hessel, an expert in psychophysiological studies. "We believe that this drug will be highly effective for treating the anxiety, inattention and impulsivity in children with the full fragile X syndrome mutation," said Hagerman, who is medical director of the UC Davis MIND Institute and treats people with fragile X syndrome. "This compound opens up a whole new avenue of treatment for people with fragile X." [View the full article.](#)



CDC Disability and Health Partners Meeting: Building Healthy Communities for Everyone

June 14-16, 2011

Chicago, Illinois

The Disability and Health Partners Meeting brings key disability and health leaders together with potential general public health partners annually. The 2011 meeting, with the theme "Building Healthy Communities for Everyone," will feature an Inclusive Fitness and Healthy Communities track. State Disability and Health State Implementation Projects, Communities Putting Prevention to Work Grantees, Public Health Resource and Information Centers, State Health Departments, Physical Activity and Obesity Prevention Partners, and officials from the Centers for Disease Control and Prevention (CDC) as well as others are invited to attend this meeting. Conference collaborators include AUCD, NCPAD, and CDC/NCBDDD. [Learn more.](#)

Quick Links

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[NCBDDD RTOIs](#)

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[AUCD Employment Opportunities](#)

Digest Submissions

Would you like to share important updates or innovative practices from your program?

Health & Disability Digest invites you to submit notable information from your project including information about your staff, network wide requests, upcoming or past events, available positions, and new research developments.

Articles can be submitted using the [online form](#) or emailed to [Danielle Edson](mailto:Danielle.Edson).

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Health & Disability

National Fragile X Family Survey

Anne Wheeler, PhD, Assistant Clinical Professor at the Carolina Institute for Developmental Disabilities has received new funding from the CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD) through AUCD's (Association of University Centers on Disabilities) cooperative agreement to expand knowledge about the nature and consequences of fragile X syndrome, both for affected individuals and their families. Information from this project, which builds upon a previous research grant, will be used to inform clinical practice and policy development. In 2006 the NCBDDD awarded a grant to Dr. Don Bailey and his colleagues at RTI International (a not-for-profit research institute in Research Triangle Park, North Carolina) to develop a data base and conduct a national survey of families of children with fragile X syndrome. The National Fragile X Family Survey project was highly successful, enrolling more than 1000 families who completed the comprehensive survey. Ninety-four percent of the survey respondents indicated that they would be willing to be re-contacted for future surveys about fragile X, making this a unique and invaluable resource for future research. To learn more about the National Fragile X Family Survey contact program manager Melissa Raspa, PhD 1-866-860-5229; mraspa@rti.org.



Join the Friends of NCBDDD

The Friends of NCBDDD (National Center on Birth Defects and Developmental Disabilities) is a coalition of government and private sector participants who work together to enhance the mission and activities of the National Center on Birth Defects and Developmental Disabilities (NCBDDD) in promoting child development; preventing birth defects and developmental disorders/disabilities; and enhancing the quality of life and preventing secondary conditions among people who are living with mental or physical disabilities, or a combination thereof. [Learn more.](#)

NCPAD Video Contest: "How Do You Get Enough?"

The National Center on Physical Activity and Disability is sponsoring a video contest entitled, "How do you get enough?" NCPAD is a nonprofit organization focused on physical activity and health promotion for people with disabilities. Being physically active is good for everybody. This is especially true for people with disabilities who tend to participate in less physical activity, carry excess weight, and have higher rates of chronic heart disease and other health conditions. The intention of this video contest is to illustrate to society that people with disabilities do live healthy active lifestyles as well as share various ways to get physical activity for individuals with disabilities and activity limitations. Whether it's indoor or outdoor, recreational or competitive, solo or team, easy or intensive, show us (and the rest of the world) how you (successfully or unsuccessfully) get enough activity in a 1- to 10-minute video clip! See the video contest rules and entry form at <http://www.ncpad.org/newsletter/newsletter.php?letter=123§ion=1593> . For a sample video, please visit <http://www.youtube.com/watch?v=9AGgD9rFdsA> .

For questions or comments about the *AUCD Health & Disability Digest*, please contact:

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Archive

View past issues of *Health & Disability Digest* in the [Issue Archive](#).

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