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## Epilepsy Therapy Development Project Summer News 2006

Dear Friends,

We all know someone whose life is affected by epilepsy, either within our own family, extended family, or community. Despite all available therapies, as many as one-third of those with epilepsy continue to have seizures and live each day without effective treatment. Even those who rely on medications to control their seizures have side effects that most of us would find unacceptable. The mission of the Epilepsy Therapy Development Project (Epilepsy TDP) is to advance new treatments for everyone living with epilepsy.

Thanks to your efforts and contributions Epilepsy TDP is making a difference although we have a long way to go. Some highlights this year include:

- Granting two awards supporting the development of innovative epilepsy products.
- Supporting the creation of a clinical consortium focused on shortening drug development timelines to bring help to patients as rapidly as possible.
- Welcoming Chanda Gunn, Bronze Medal USA Olympic athlete, as our spokesperson.

### LEADING INNOVATION IN EPILEPSY TREATMENT

**May 2006 New Therapy Grant Awards:** Two awards, valued at \$190,000, went to innovative research projects. These were funded by the Epilepsy Research Foundation, our partnership with the Epilepsy Foundation, and F.A.C.E.S. (Finding a Cure for Epilepsy and Seizures) at New York University.

- *Nanoparticle Imaging Contrast Agent:* Researchers at UCLA are working with a newly synthesized epilepsy-specific contrast agent for use in improving surgical outcomes.
- *Promising Epilepsy Drug Candidate:* At the University of Wisconsin and NeuroGenomeX, Inc., a new neurogenomic sciences company, researchers are discovering and developing new drug targets for the treatment of disorders associated with neuronal plasticity that appear to have potent acute anticonvulsant and chronic antiepileptic activity.

**The Epilepsy Study Consortium:** The consortium will join leading epilepsy centers in the Northeast and eventually across the country to support the rapid accrual of patients for clinical trials in epilepsy. Under the leadership of Epilepsy TDP SAB Chair Jackie French, MD, and Co-Chair Orrin Devinsky, MD, and supported in partnership with F.A.C.E.S., the Consortium could drastically streamline epilepsy drug development by reducing time and costs for developing new therapies.

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**Anti-Epilepsy Drug (AED) IX:** We have partnered with the University of Pennsylvania Medical School in co-sponsoring the March 2007 Anti-Epilepsy Drug (AED) IX conference and Emerging CNS and Epilepsy Company Partnership and Financing Forum. This conference brings together thought leaders from academia, industry, NIH, and the FDA to review the pipeline of new therapies as well as critical clinical issues and regulatory development. More information is available at [www.epilepsytdp.org/sec/drug\\_trial\\_IX](http://www.epilepsytdp.org/sec/drug_trial_IX).

## WEBSITE: NEW DEVELOPMENTS

Our two major websites are highly regarded information sources in the epilepsy field: [www.epilepsy.com](http://www.epilepsy.com) and [www.epilepsy.com/professionals](http://www.epilepsy.com/professionals). Unique visitors to these sites reached 177,000 in July, up 34% year to year. Page views increased at a faster pace led by the explosive growth of our community site, <http://my.epilepsy.com/> and reached 972,000 a 48% increase over July of 2005.

**New award:** In June we received the prestigious 2006 Gold IN-AWE award for [www.epilepsy.com](http://www.epilepsy.com) from the Medical Marketing Association for best website design.

**New team member:** In April, professional writer, editor, and consultant, Jacki Gordon, PhD was hired to develop content for the websites, especially [www.epilepsy.com/professionals](http://www.epilepsy.com/professionals). She is also assisting in preparation of materials for projects that have received educational grants. She is President of JRC Innovations, Inc., and worked on Quality Of Life In Epilepsy instruments.

**Advances in Epilepsy Management Conference:** In May, Epilepsy TDP supported the live recording of a conference, "Translating Recent Data Into Clinical Applications," presented by the NYU Post-Graduate Medical School. Professionals who were unable to attend may access this material and apply for CME credit at [professionals.epilepsy.com/page/CME\\_clinical\\_applications.html](http://professionals.epilepsy.com/page/CME_clinical_applications.html).

**AES Mid-year Conference:** In June, we collaborated with the American Epilepsy Society to capture presentations at the Society's two-day mid-year meeting. These presentations will soon be available on [www.epilepsy.com/professionals](http://www.epilepsy.com/professionals) on the AES website [www.aesnet.org](http://www.aesnet.org).

## PUBLIC EDUCATION

**Spokesperson:** Chanda Gunn, the USA Olympic Women's Hockey Team goaltender, and winner of a Bronze Medal, joined Epilepsy TDP as a national spokesperson. Chanda attends epilepsy events nationwide and inspires kids and adults with her story of challenge and accomplishment. She reminds them that finding the right therapy has allowed her to move forward with her life but that for far too many people with epilepsy, there is no acceptable and effective therapy.

**Press coverage:** The first press release for Epilepsy TDP in connection with the New Therapy Grants award process was issued in May. Co-Founder and Chairman Warren Lammert received further coverage in *Nature*, *Dow Jones Venture Wire*, and *The New York Times*.

**Magazine feature articles:** We have partnered with *Exceptional Parent Magazine* to prepare and publish a series of twelve articles concerning epilepsy which commenced in June. These articles can be found at the

Exceptional Parent section of our website at [www.epilepsy.com/info/exceptional\\_parents.html](http://www.epilepsy.com/info/exceptional_parents.html).

**New team member:** To further public education, Rita Watson, MPH, has joined us as Director of Education for Epilepsy TDP and Senior Editor for [www.epilepsy.com](http://www.epilepsy.com). She has been an editor and writer with *The New York Times*; director of education and policy within Yale University's Department of Psychology and Psychiatry; and communications director for CIMIT.

## TO YOU OUR FRIENDS, OUR SUPPORTERS

**We have had an extraordinary first half of the year.** However, to enhance our ability to find management and treatment options for those with epilepsy, we need your support. Your contributions will help us:

- Provide grants to researchers for developing new therapies.
- Create new website tools for patients and professionals to help them manage epilepsy.
- Team with thought leaders in academia and business to advance our mission.

**What can you do?** Be an active player in finding new therapies for people living with epilepsy.

- Visit [www.epilepsy.com](http://www.epilepsy.com) and learn more about this condition.
- Shop at our on-line mall ([shop.epilepsy.com](http://shop.epilepsy.com)) with merchants from Amazon.com to Target as well as full travel resources. A percentage of every dollar you spend will support research and new therapies.
- Help us innovate and advance new treatments through your tax-deductible contributions, which can be made on line at [www.epilepsy.com/epilepsy/donation.html](http://www.epilepsy.com/epilepsy/donation.html).

We promise to keep you posted on our accomplishments and progress.

Our thanks and our appreciation,

Warren Lammert, Chairman  
[Warren@epilepsytdp.org](mailto:Warren@epilepsytdp.org)

Bill Braunlich, President  
[Bill@epilepsytdp.org](mailto:Bill@epilepsytdp.org)