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## Epilepsy Therapy Development Project December 2006

### Acceleration

Time accelerates with age as each year becomes a smaller percentage of one's life experience. That is a somewhat unnerving realization, and it does not explain the acceleration of activity and of time that characterized our year at the Epilepsy Therapy Development Project in 2006.

As we take a moment to reflect back on the year behind us, I want to highlight a few of our important accomplishments and say thank you to all of you whose work and contributions brought these programs forward.

### Five New Therapy Grant Awards

Through our Epilepsy Research Foundation partnership with the Epilepsy Foundation, the NYU Finding a Cure for Epilepsy and Seizures (FACES) foundation and the Milken Family Foundation, we provided \$690,000 of funding towards five projects in 2006. These included three promising new pharmaceutical candidates and two projects involving novel delivery systems: the use of nanoparticles in drug delivery and pre-surgical imaging, and the use of adenosine releasing brain implants to provide long-term seizure suppression. Two of the three pharmaceutical candidates have previously been shown to be safe for human use which removes one significant element of risk and which will allow for an accelerated path of development. All three provide novel mechanisms of action with strong indications of efficacy in animal models of epilepsy. These are all programs which have real promise, and we are excited to move these projects forward.

### Founding of the Epilepsy Study Consortium

We have joined FACES in supporting the establishment of the Epilepsy Study Consortium (ESC) which brings together leading clinical care centers to accelerate the clinical testing of new therapies. The ESC promises to take time and cost out of the clinical trial process by innovating new effective clinical trial designs, by coordinating IRB approvals of new trials, and by more rapidly accruing patients able to participate in clinical trials. The ESC will begin patient enrollment in its first clinical trial of a new anti-epilepsy drug candidate early in 2007.

### New Spokespeople

Chanda Gunn, Bronze medalist and goalie of the US Olympic Women's Ice-Hockey Team, joined the Epilepsy TDP team in February. She has engaged our community with an ongoing blog and home page on [epilepsy.com](http://epilepsy.com) and has participated in print and TV media appearances and epilepsy events. In November, Scratch DJ Academy founder DJ Hapa joined Chanda as our second official spokesperson. Chanda and Hapa are talented individuals and great role models. Their willingness to speak out is critically important in giving a voice to a community that has too often been silent. I thank each of them once again for joining our team.

### New ITN Documentary for PBS: Epilepsy in Search of Effective Therapies

With editorial direction from SAB members Steve Schachter, Orrin Devinsky, and Eric Kossoff and support from numerous Epilepsy TDP families, the ITN Documentary *Epilepsy: in Search of Effective Therapies* began airing across the country at the end of November as part of the popular ITN series: *Healthy Bodies, Healthy Minds*. The documentary and a six minute Epilepsy TDP mission video completed in conjunction with this project can be seen on our home page at [www.epilepsy.com](http://www.epilepsy.com) where the schedule of local PBS station showings is also posted. Chanda Gunn speaks out in this

Brian Litt, MD

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film about the need for better treatments while also demonstrating that people with epilepsy can achieve anything when effective therapies exist to control their seizures. Both Chanda and DJ Hapa attended the successful New York City premier of *Epilepsy: in Search of Effective Therapies* which brought out more than 120 supporters on November 27.

Chanda also participated in a Chicago premier and a special event called, "Ice Skating to Cure Epilepsy" on December 17. City premiers are also planned for Boston, Denver, St. Louis and Los Angeles over the next several months.

## Progress on Epilepsy.com

*Epilepsy.com* provides the most in-depth content and community available on-line for patients, families, caregivers and professionals living with epilepsy. *Epilepsy.com* continued to see strong growth in users and page views in 2006 with page views increasing past one million per month for the first time. We are determined to build on this strength and continue to invest in important new content across the *epilepsy.com*, *epilepsy.com/professionals* and *epilepsytdp.org* websites. The *epilepsy.com* community continues to see remarkable growth in topical discussion threads and blogs, and we have continued to build out the *epilepsy.com* team with several important additions to our professional staff.

## Eilat Conference on New AEDs: 4 of 14

I was given the opportunity to open the major 2006 conference on the development of new Anti-Epileptic Therapies held in Sitges, Spain in September with a discussion of the Epilepsy TDP and our programs to support new therapy development. I am happy to say that a record 200 academic investigators and commercial research and development personnel attended this year's conference. Presentations were delivered on 14 new therapies under development. I regard it as both a great accomplishment and at the same time a clarion call that the Epilepsy TDP alone and through our Epilepsy Research Foundation partnership has provided important support to four of those 14 programs. In our fourth year of activity and with limited financial resources, we are already making a difference in building the pipeline of promising new therapies. These indications of real impact underline the urgency of building our organization and funding capabilities.

## Partnerships

As we work to build the Epilepsy TDP as an engine of support for translational research, we want at the same time to continue to highlight the important contributions of our key partners. The Epilepsy Foundation joined with us first to advance important translational therapies through our Epilepsy Research Foundation joint venture. The Milken Family Foundation and FACES have also joined with us to provide important funding for that grant and investment program. More recently we appreciate the support of the Anita Kaufman Foundation in joining with us to create greater awareness of the need for new therapies for epilepsy through our PBS documentary project. We worked with the American Epilepsy Society to capture presentations made at their first mid-year conference for ongoing broadcast on *epilepsy.com/professionals* and on the AES website. We have also recently joined with the Center for Integration of Medicine and Innovative Technologies (CIMIT) to support the creation of a CIMIT NeuroTechnology Program focused on advancing new therapies for patients living with epilepsy and other central nervous system disorders under the leadership of Steven Schachter, Editor-in-Chief of *epilepsy.com* and an active member of our Executive Board.

## Impact

Harnessing the expertise of our scientific and business advisory boards, the Epilepsy TDP invests to achieve the greatest possible impact in advancing new safe and effective therapies for the large number of people living with uncontrolled seizures and unacceptable side-effects. We are focused especially on the bottlenecks in the development pipeline that prevent compelling scientific research from translating forward into new therapies for patients. By addressing these obstacles, we have an opportunity to make a real difference in bringing new and better treatment options to patients faster.

## Inspirations

The Michael J. Fox Foundation under the inspirational leadership of CEO and Co-Founder Debbie Brooks is now making a \$20 million annual investment to accelerate new therapies in Parkinson's Disease. The prevalence of epilepsy is four to six times that of Parkinson's Disease; 30-40% of those with epilepsy live with seizures uncontrolled by any available therapy; many more live with side-effects from the

existing medicines that include cognitive slowing, fatigue and risks of birth defects. Thanks to your contributions, the Epilepsy TDP and our Epilepsy Research Foundation partners are making an impact on the pipeline of new therapies in epilepsy. But we should find inspiration in the accomplishments of the Michael J. Fox Foundation and of other forward looking cure organizations. We owe it to ourselves and our loved ones to increase the scale of our investment by an order of magnitude.

### **Support**

We need your support and your help in reaching out to a wider audience to make new therapies a reality for those living with epilepsy. You can help us by making tax-deductible contributions to drive innovation in epilepsy at [www.epilepsy.com/epilepsy/donation.html](http://www.epilepsy.com/epilepsy/donation.html) or by mail at the Epilepsy Therapy Development Project, 11921 Freedom Drive, Suite 730, Reston VA 20190. And do not forget our online mall [www.shop.epilepsy.com](http://www.shop.epilepsy.com) where a portion of every dollar you spend with merchants from Amazon.com to Target advances new therapies.

On behalf of the Epilepsy Therapy Development Project, I want to thank you for your support during 2006. I look forward to working with you to make progress against seizures and side-effects in the New Year.

Sincerely,

**Warren Lammert, Chairman & Co-Founder**

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