



SPECIAL EDITION

research review

april 2, 2013



The [Tay-Sachs Gene Therapy Consortium \(TSGT\)](#) has been working hard to unravel the mystery of an adverse neurological response in non-affected primates during the pre-clinical studies. The TSGT team has just proposed a new plan, budget and timeline to get to clinical trials. The earliest possible start of a clinical trial is now July 2014. This new plan is still being developed with major scientific and financial decisions to be discussed and thoughtfully addressed.

We will have the opportunity to discuss the challenges and steps ahead with Miguel Sena-Estevés, PhD, Principal Investigator, during the Research Update session at our 35th Annual Family Conference in San Diego this week. Please stay tuned for further updates.

And, as a side note, we must all remember that we are navigating uncharted territory and every stone that is turned over is progress.

We are so very proud of the work our research team, our families and generous supporters have accomplished over the years leading up to this time.

Thank you.

**one must maintain a little bittle of summer, even in the middle of winter.**

*~ henry david thoreau*

**national tay-sachs & allied diseases association**

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