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National Tay-Sachs &
Allied Diseases Association



Friday, May 23, 2014

*Progress lies not in enhancing what is,
but in advancing toward what will be.*

- Khalil Gibran

More Experts to Advance Research Mission!

New NTSAD Corporate Advisory Council

NTSAD's Board of Directors has been engaged in Strategic Planning to develop Roadmap 2018, which outlines how NTSAD will advance research to treatments, better serve our families, and promote accurate and effective carrier screening.



NTSAD
NATIONAL TAY-SACHS &
ALLIED DISEASES ASSOCIATION

**Corporate
Advisory
Council**

One outcome of the Research Strategy was recognizing that NTSAD would benefit from expert industry insights as we navigate future clinical trials, the regulatory process, and getting treatments to people who need them. Additionally, we realized that some NTSAD friends working in the biotech industry have extensive experience and could advise us in these areas, as well as use their networks to explore funding and partnering options.

Thus, the idea of the Corporate Advisory Council (CAC) was born. The CAC will help NTSAD as we prepare for future treatments for this family of rare genetic diseases and will complement the scientific, clinical, and lab expertise brought by our Scientific Advisory Committee (SAC). Together, the SAC and CAC will help NTSAD advance research programs, build our clinical trial readiness, and make our diseases appealing to companies to study.

We held a CAC kickoff meeting on May 12th. One of the first priorities for the CAC is to help prioritize what needs to be ready for clinical trials, e.g., registries, biomarkers, clinical measures. We already have some animal models, some natural history studies, and a strong clinician and scientific network in place, but want to

better understand what's needed for all our diseases. The CAC will also be part of the team working with the Tay-Sachs Gene Therapy Consortium to help plan the path forward.

Stay tuned for further news about Roadmap 2018 in future *Topics*.

Its Mission and Role

How the Council will Help

Mission: The Corporate Advisory Council, through its collective industry expertise, serves as a resource to NTSAD to advance its research agenda and position itself as an attractive partner to industry.

Role: The Council advises NTSAD about its efforts to direct, fund and promote the development of treatments and cures for the NTSAD family of diseases. It will counsel NTSAD in expanding its evolving partnership model, recommend research strategies and assist NTSAD in leveraging its full range of capabilities.

Introducing the Team

Experience to Help NTSAD Move Forward

The **Corporate Advisory Council** members are professionals involved in rare diseases and industry. Each of them has become familiar with NTSAD, either through volunteering or participating in events, but the one commonality is that they all stand behind NTSAD's mission and are passionate about giving families hope.



Oved Amitay is Vice President and Head of Commercial at Alnylam Pharmaceuticals. Before joining Alnylam in 2012, Oved was VP for Strategic Development for the Personalized Genetic Health business unit at Genzyme, where he also led the internal research and development activities for their rare disease business. Oved joined Genzyme in 1998 and held positions in regulatory affairs, medical marketing, market development, and business development in Europe and the Middle East. Oved graduated from the School of Pharmacy in the Hebrew University in Jerusalem, and completed his graduate studies in Pharmacology at Northeastern University.



Ritu Baral is an analyst at Canaccord Genuity where she is a Senior Research Associate in Biotechnology. She has over seven years of experience in biotechnology finance, including over three years in biotechnology equity research. Previously, Ritu was biotechnology equity research associate at JMP Securities and before that was a Senior Associate at the Trout Group, a biotechnology focused investor relations agency. Ritu graduated with a B.A. in Biological Sciences from Barnard College.



Michael Gladstone is an associate in the life sciences group at Atlas Venture, a biotech venture capital fund focused on new company creation. Prior to joining Atlas in 2012, Mike was a senior associate consultant in the life sciences practice at L.E.K. Consulting, where he focused on business development and corporate strategy for biopharma clients. While at L.E.K., Mike also served as head of client development for Inspire, a volunteer consulting firm staffed by junior consultants. Steve Rosner, former NTSAD board member and an L.E.K. partner, introduced Mike and Inspire to NTSAD. Mike was part of a *pro bono* strategic consulting project for NTSAD. Michael received a BS in biochemical sciences with highest honors from Harvard College, where he graduated magna cum laude and was awarded the Harvard College Scholarship.



Kate Haviland recently joined Idera Pharmaceuticals as Vice President of Rare Diseases. Previously she was Head of Commercial Development at Sarepta Therapeutics, a company focused on developing therapeutics to treat rare genetic disorders and infectious diseases. Kate's responsibilities included marketing, patient advocacy relations, global access / reimbursement, medical education and commercial operations. Kate also worked at PTC Therapeutics, a company focused on orphan drug development in rare genetic diseases, and at Genzyme in Corporate Development and Marketing. Kate has a BA from Wesleyan University with a double major in Biochemistry and Economics, and an MBA from Harvard Business School. Kate was inspired to work in the field of genetics and to connect with NTSAD through her late uncle, Dr. David Rimoin, who was a pioneering physician and researcher in the field of medical genetics.



Marion A. Howard, MD, PhD is a business, medical and science professional with a proven track record in strategy design, competitive positioning, market analysis, and due diligence of early and late stage products and technologies. Prior to founding Cambridge BioStrategies, Marion helped several start-up companies in the US and Europe to refine their business strategy, raise capital, prepare commercial plans, and pursue licensing and acquisition opportunities. Marion was trained as an MD/PhD in Germany, the US and the UK. Marion has worked with NTSAD since 2009 as a *pro bono* consultant on research strategy. She joined the NTSAD Board of Directors in April, 2014, and chairs the Corporate Advisory Council.



Joan Keutzer, PhD, is the Vice President of Scientific Affairs at Genzyme Corporation which she joined in 1995. Joan has been involved in the development of therapies for MPS I, Fabry disease, and Pompe disease, including initiating efforts in developing newborn screening assays for the lysosomal storage diseases (LSDs), patient monitoring assays, and an improved diagnostic assay for Pompe disease. In 2003, she established the LSD diagnosis, monitoring and screening group in Genzyme R&D to focus on translating published research methods into protocols for use in clinical and newborn screening labs. She received her Ph.D. in cellular and molecular biology from the University of Kentucky, School of Biological

Sciences, and her B.S from Northern Kentucky University.



Greg Licholai, MD, is the VP & General Manager of Spotlight, a McKinsey Solutions Company, which is a proprietary information and analytics company providing software as a service for the healthcare industry. Greg is both an entrepreneur and executive in the biopharmaceutical industry. He was Chief Operating Officer at Proteostasis, a private biotechnology company in Cambridge, MA. Earlier, he had been one of the first employees at Amicus Therapeutics where he was Vice President of Medical Affairs. He was a Howard Hughes Medical Institute Research Scholar at the National Institutes of Health. Greg received his B.S. from Boston College and Pre-Medical studies at Columbia University, his M.D. from Yale Medical School and his M.B.A. from Harvard Business School. Greg was on NTSAD's Scientific Advisory Committee before transitioning to the Corporate Advisory Council.



Bradley Campbell is the Chief Operating Officer of Amicus Therapeutics. He brings 14 years of experience in the biotech and pharmaceutical industries. He received his B.A. in Public Policy Studies from Duke University and his M.B.A. from Harvard Business School. Bradley is a past president of NTSAD and is the the Board representative on the Corporate Advisory Council.



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