Where do we go from here? Lessons from the ALS Ice Bucket Challenge as an awareness and research fundraising tool

co-chairs: Michele Dupree, Teresa Thurtle, and Scott Pansky

The 2014 ALS Ice Bucket Challenge raised more than $200 million worldwide for ALS/MND organizations, including $3.5 million for the ALS Therapy Development Institute (ALS TDI). We are proud to be the first organization to announce where the funds raised will be spent and utilized as we begin to put the money to work to accelerate the discovery and development of potential medicines for ALS patients today. With this unprecedented level of awareness and support, the Institute is calling on the ALS community to attend a round table discussion on how to keep momentum going forward, developing creative ways to continue raising money and awareness for ALS.

We are seeking to organize an initial group of 50 people for this initial discussion. We strongly encourage folks to preregister for this round table conversation by indicating their attendance on the leadership symposium registration form.

MICHELE DUPREE

Michele has been a staple within the ALS community for nearly 9 years, following the diagnosis of her best friend, Pam Callahan. She is known throughout social media as a go-to resource for information regarding the latest communication technology, navigating health coverage and helping patients and families connect with local resources along their battle. Michele has worked with dozens, perhaps hundreds of PALS and CALS worldwide. She is also an activist and fundraiser for ALS research. Through the ALS Facebook Family team, she contributes to reaching the largest team fundraising totals for the Joan Dancy Polar Plunge. Michele has worked on countless campaigns local, national and global in scope to raise awareness of ALS and important funding toward a cure.

TERESA THURTLE

More than 20 years ago, Teresa lost her paternal grandmother Dianna to the disease. In 2011, her father Robert was diagnosed with ALS, only to find out their family carries the SOD1 mutation. Teresa and her 3 brothers each have a 50% chance of developing the disease. Teresa is also a member of the U.S. Air Force and has served in support of Operation Enduring Freedom and Operation Deep Freeze. Her commitment to end ALS is twofold: to save the lives of not only
her direct family members, but her military family members as well. Teresa co-created Bottoms Up to Down ALS in 2013 along with another FALS family member, Kristin Quinn. The campaign, centered in the greater Washington DC, is designed to bring young people together behind ALS research. Teresa is also a proud member of the Institute’s Young Faces of ALS campaign and has been an active and outspoken advocate at ALS meetings, conferences, events, and social media around the world.

**SCOTT PANSKY**

Scott Pansky, Senior Partner and Co-Founder, is a recognized expert on cause-related marketing and strategic philanthropy. He is known for his ability to build strong associations between corporations and their core causes, and for creating strategic platforms for internal and external programs that strengthen reputation and brand loyalty. As a public relations practitioner for more than 20 years, Scott has counseled and led teams in creative strategy and partnership marketing efforts. Scott has created award-winning programs for Allison+Partners clients ranging from Hyundai to Hasbro, and is a frequent speaker on strategic philanthropy, cause marketing, sponsorship and branding. He teaches courses on these topics at UCLA and frequently writes opinion and strategy articles for major public relations, branding and philanthropic publications. In addition, he is an active member of the Academy of Television Arts and Sciences, the Los Angeles Chamber of Commerce, the Los Angeles chapter of the March of Dimes and the President of the Los Angeles Unified School District Partnership Council.