



Press Release for PAL Conference:

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## PAL INAUGURAL FORUM UNITES LYME COMMUNITY

*Arlington, VA, October 5, 2013:* Representatives of 33 organizations from 20 states and Canada enthusiastically collaborated Saturday at George Mason University (GMU) for the first time at a day-long Inaugural Partnership Forum of the newly formed Partners Against Lyme and Tick Associated Diseases. PAL currently has members in 44 states and 8 countries and is continuing to grow.

Comments such as "what a great success" and "we hoped for a day like this" made clear that this well organized, unprecedented, forum met the expectations of its nearly 200 attendees. Journeying from Oregon to Florida, Michigan to Texas, and most states in between, representatives explained their organization's activities supporting patients with tick-borne diseases, detailed what collaborative initiatives interested them most, and provided their ideas on how they hoped to pool and expand their resources to achieve the PAL slogan of "Working Smarter Together Instead Of Harder Alone."

A heartfelt welcome by Gary Kreps, Director of the GMU's Center for Health and Risk Communications was followed by an outstanding presentation of the important new testing under development at GMU's Center for Applied Proteomics and Molecular Medicine (CAPMM). Dr. Lance Liotta and Dr. Alessandra Luchini described the new Nanotrap Urine Antigen Test for Lyme disease. Luchini explained "Our research goal is to use our technology to provide the highest possible objective evidence for the presence of a Lyme infection at the earliest stages of disease". Facilitator Sandra Cheldelin of GMU did an outstanding job of both keeping focus on the session topics and the proceedings on schedule.

Dr. Joseph Jemsek, one of the foremost Lyme treating physicians in the world, was the first PAL honoree and keynote speaker. Attendees fought back tears as this amazing and dedicated physician, who has restored the health of countless and often difficult cases, spoke of his incredible and tumultuous journey treating Lyme patients. Dr. Jemsek challenged those assembled: "Today's PAL event is affirmation and a strong message that we need to 'carry on' . . . I know many of you have suffered with illness or watched loved ones suffer . . . and that is why you are here in a selfless commitment for change. Please find a way to unify and thereby strengthen . . . I do know good where I see it. And I see a lot of good in our

audience. And today is a good day for millions who are questing for some remnant of hope . . . and you provide this hope through unity."

PAL founders Monte Skall (National Capital Lyme Disease Association), Linda Lobes (Michigan Lyme Disease Association), and Lisa Torrey (Texas, National Tick-borne Disease Advocates), joined by Elizabeth Wood representing Judith Weeg, (Lyme Disease United Coalition) and twenty advocates from PAL organizations shared their success stories, clearly exhibiting the great benefits of PAL.

Gregg Skall, Legal Counsel for NatCapLyme, and Mark Harkins from the Government Affairs Institute at Georgetown University, addressed the role of Congress and investigative hearings. Next came a revealing session with Monte and Gregg Skall, Susan Green, and Rob Catron (Alcalde & Fay) on lessons learned in advocating for the 2013 Virginia Lyme Disease Disclosure Act, requiring that health care providers inform patients that Lyme test results may be unreliable.

The forum concluded with a lively brainstorming session discussing how PAL could best support patients and to accomplish change. Asked to identify initiatives, attendees' highest priorities included Education and Training, Database and Resources, Branding, Legislation, and Funding. A comprehensive report will be posted on the PALtad website.

PAL encourages all parties interested in Lyme and tick-borne diseases to work together to find solutions. Before dialogue can be created amongst the scientific research community, health agencies, medical societies, and the full spectrum of treating physicians, we must create it amongst ourselves.

The National Capital Lyme Disease Association was a gracious host of the first PAL conference. Another forum is anticipated in a year.

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