



Partners Against Lyme and Tick Associated Diseases (PAL)

The Inaugural Partnership Forum

A Collaborative Effort

George Mason University Founders Hall

Arlington, Virginia

October 5, 2013

Executive Summary

Introduction

The newly organized Partners Against Lyme and Tick Associated Diseases (PAL) held its initial conference, *A Collaborative Effort*, on Saturday October 5, 2013, at George Mason University (GMU). Some 200 members representing tick-borne disease support and advocacy groups from 20 states as well as Canada gathered in a day-long conference to hear key speakers, discuss the many issues associated with Lyme and other tick-borne diseases, and plan the next activities of PAL. PAL currently has members in 44 states and 16 countries, and is continuing to grow.

A key objective of the conference was to develop mutually acceptable and achievable goals that would alleviate some of the uncertainty and suffering that individuals with Lyme and associated tick-borne diseases, as well as their family, friends, and caregivers, often experience. The forum was intended to advance the work of patients and advocates, as well as other stakeholders such as physicians, scientists, and researchers by complementing each other's efforts, resources and talents.

Sandra Cheldelin, Professor of Conflict Analysis and Resolution at George Mason University, facilitated the vibrant, lively, and emotionally charged discussion on Lyme and tick associated diseases that most attendees felt had not received the attention it deserved. She began by establishing ground rules to assure that the group focused on its main goals, and monitored the tight agenda necessary to complete its work. She guided the group successfully through the day, ending with a session to decide the most important next steps for PAL.

GMU's Gary Kreps Welcomed Participants

Gary Kreps, Director of George Mason University's Center for Health and Risk Communications opened the conference with a warm welcome, setting an upbeat mood for the day. A strong believer in consumer advocacy, he told the audience that the key

to success hinged on the human equation and the ability to leverage and influence policy makers. His remarks emphasized that the conference was not about listening to any one particular group but that the inputs of everyone there were equally important.

Presentation on New Lyme Test

Drs. Lance Liotta and **Alessandra Luchini** from the Center for Applied Proteomics and Molecular Medicine (CAPMM) at GMU next presented a breakthrough in detecting Lyme disease with their development of a new Nanotrap Urine Antigen Test. They explained how the test provides a higher level of specificity and sensitivity in identifying the disease in the human body at all three stages—early stage, recurrent disease following therapy cessation, and disease that persists in the face of therapy. More importantly, their procedure was non-invasive.

Although their test was still in the clinical trial stage, Drs. Liotta and Luchini were very optimistic that they could open it up for commercial testing by the summer of 2014. An attendee asked how the scientists would convince the Center for Disease Control (CDC) about the efficacy of their test and possibly making it the standard test. The Mason scientists' response was that their first step would be to publish a strong scientific paper of their findings, with the objective that the weight of the science would be enough to counter any skepticism. However, an alternative strategy would be to seek FDA approval, which could then lead to an FDA approved clinical test choice for treating physicians.

Introduction of PAL

The next panel was comprised of - **Monte Skall**, Executive Director, National Capital Lyme Disease Association, **Elizabeth Wood**, LDUC Canadian Group, **Lisa Torrey** President, National Tick-Borne Disease Advocates, and **Linda Lobes** President, Michigan Lyme Disease Association. Representing the PAL founding member organization, they officially introduced the organization PAL. Together, they explained the purpose, values, benefits, and vision of PAL, respectively. Each shared a personal story as to why they were part of the organization. A recurring theme in their individual presentations was that it was very important to "*Work Smarter Together Instead Of Harder Alone*" in order to achieve the best possible result.

Keynote by Dr. Joe Jemsek

Dr. Joseph Jemsek of Jemsek Specialty Clinic, Washington D.C. delivered the keynote. He did not disappoint! He offered a touching and genuine narrative and everyone appeared to relate to his journey. He told of his own challenges as a physician in North Carolina as well as a family member whose daughter and wife had both contracted a chronic illness. These challenges, he noted, did not derail his efforts to continue working for the common good, and he encouraged those attending to "carry on" with their efforts by strengthening PAL. Dr. Jemsek also took the medical profession to task as he urged more physicians to do more in helping to alleviate the

pain and suffering associated with contracting Lyme disease. “The only purpose of the medical profession is the patient,” he said. He also encouraged the medical profession to eliminate corruption and the financial motives in the medical system.

Dr. Jemsek also noted that published, good data about Lyme disease are missing, and far more research and medical studies need to be conducted to further advance the objectives of the group. He ended his presentation with a call for more peer-reviewed research journals, a need to think about building a Center for Excellence, and the creation of an accreditation program for training future doctors to provide hope for patients ill with Lyme and tick-borne illness.

PAL presented Dr. Jemsek with its first award for outstanding service to advance the healing and well being of Lyme patients. Dr. Jemsek’s ability to connect with Lyme patients was evident in his presentation and in the audience’s response to him. Many commented that they were impressed that Dr. Jemsek stayed and participated in the conference most of the day.

Organization Success Stories

The next four panels consisted of twenty individual representatives who were tasked to share stories of their organization’s experience and achievements. Each group’s spokesperson gave enthusiastic accounts of the many ways they had supported Lyme patients and advocated for them in their states and local communities.

Presenters included **David Roth**, President, Tick-borne Disease Alliance (New York), **Leo Shea**, MD, President ILADS, **Elizabeth Wood**, Canadian National Lyme and Associated Diseases/LDUC, **Lisa Torrey**, National Tick-Borne Disease Advocates (Texas), **Kori Kroger**, PANDORAorg (Michigan), **Eva Haughie**, Empire State Lyme (New York), **Carol Kaye**, LifeLyme, The Landford Foundation (Florida), **Joseph Annibali**, M.D., Amen Clinics (Virginia), **Mary Jane Heppe**, The Mid-Columbia Lyme Group (Oregon), **Char Healy**, Hope to Heal Lyme (Virginia), **Jason Chow**, OD, NC Lyme Advocacy (North Carolina), **Monte Skall**, National Capital Lyme Disease Association (DC, VA, MD, NC), **Linda Lobes**, Michigan Lyme Disease Association, **Julia Wagner**, PA Lyme Resource Network, **Regina Weichert**, Lyme Nation (New York), **Melissa Bell**, Florida Lyme Disease Association, **Allison Curuana**, Florida Lyme League, **Marilyn Williams**, Lyme Disease Association Eastern Shore of Maryland Inc., **Trish McCleary**, S.L.A.M (Sturbridge Lyme Awareness of Massachusetts), **Lane Poor**, The Lyme Newport Support Group (Rhode Island), and **Connie Dickey**, Lyme Disease Association of Tennessee.

Susan Green delivered a touching statement from Connie Dickey from Tennessee, who was unable to attend. Many attendees commented that these talks were a highlight, as they shared many of the achievements from around the country that had not before received widespread attention. They also demonstrated the very diverse nature in efforts to bring awareness to the plight of having Lyme and tick-borne diseases. Included were stories about raising a million dollars through fundraising, developing a similar program in bringing awareness of Lyme disease in other countries, lobbying state and federal government and passing meaningful Lyme disease legislation,

educating physicians and health care providers, and distributing tick-borne disease educational materials to the public including schools, parks, local health departments and civic associations.

What Could Congressional Investigative Hearings Accomplish?

Following the panel presentations, **Gregg Skall**, Legal Counsel for NatCapLyme, and **Mark Harkins** from the Government Affairs Institute at Georgetown University discussed legislative hearings. They encouraged the attendees to think strategically in their efforts to educate the state and federal government officials and to better understand the system in order to succeed in passing legislation. The discussion included the best ways to use “new media” such as e-mail campaigns, the system of committee jurisdiction and how priorities are set in most legislatures.

Next came another legislation session with **Monte** and **Gregg Skall**, **Susan Green**, and **Rob Catron** (Alcalde & Fay), who discussed the process that led to successful Virginia Legislation the *2013 Virginia Lyme Disease Disclosure Act*. The group provided a number of strategies that had worked in their favor such as knowing which members of the legislature would be most influential on the necessary topics, seeking bipartisan support, proposing a bill that was realistic in the current legislative environment, and gaining constituent support in a strong grassroots effort.

What Can PAL Do?

The final session shifted from panel presentations to all-inclusive group discussions among the participants. The large number of conference attendees began this segment by dividing into smaller groups. Following the ground rules laid out at the beginning of the day, their main objective was to discuss within their groups three questions (see below). Each group had an easel with paper for recording brainstorming concepts. Each selected a recorder who also reported the results of their group’s discussion.

- 1) What can PAL do to support activists’ efforts that would have the greatest impact for positive change in our community?
- 2) What does PAL need to do to help encourage and support your fundraising efforts?
- 3) What can PAL do to further patient support with Lyme and tick-borne diseases?

Following the first group discussions, rapporteurs from George Mason University **Cassie Ammen** and **Kwaw G. de Graft-Johnson** compiled the responses to the three questions from each of the nine groups. The general theme from many responses was the importance of creating a centralized source for educational materials, data collection, and support for the education and training about Lyme and tick-borne diseases. The addendum below is the full list of responses.

The final group discussion focused on forming a consensus for the highest priority initiatives for PAL partner focus moving forward. There was strong consensus on the following five interrelated initiatives:

Education and Training:

- National education campaign
- Physician and nurse training
- Medical and information codes and best practice/treatment options
- Mentorship programs for healthcare professionals.

Database and Resources

- Hotline
- Cloud based, streamlined information center
- Resources for Lyme groups
- National calendar of events
- Database of all advocacy groups and their contact information
- Consolidated online resource database

Branding

- Generating a consistent message

Legislation

- Focus on state laws around the country

Funding

- Generating partnerships to tap for funding

The conference concluded at 5:45 followed by a reception and further informal conversations.

Conclusion

The first PAL forum clearly reached its goals and broke new ground. The forum was well attended by organizations from across the United States and Canada. This meeting brought together a diverse group of many members from different organizations whose lives have all been touched by Lyme, including patients, physicians, scientists, and advocates. They collaborated by unifying their voices, "*To Work Smarter Together Instead Of Harder Alone.*" The participants focused on improving the quality of life for Lyme patients. The varied groups found that they had even more in common than they had realized and that they could unite for many purposes but still retain the uniqueness of their own organization. Sharing their many success stories with each other was deemed immensely beneficial to PAL members as a whole. The creativity and profusion of ideas in the last sessions were indicative of the inspiration gained from the speakers throughout the day.

The kick-off event of the new PAL organization created an unprecedented spirit of collaboration among its attendees. They departed with renewed vigor to work together toward the goals they set based on the needs they perceived in the tick-borne disease community. The participants enthusiastically agreed that PAL was launched well and off to a great start.

Addendum 1:

These are the specific responses to the three questions, sorted by broad topics:

1) Where do we go from here?

- Need help getting the word out. Signage (helps with awareness)
- More structure: Blueprint. Common lessons learned, what worked to be published for groups
- List-serve or an archive for successful projects
- Education: Want PAL to help put a model together: how to approach target audiences, the legislature, canned PowerPoint
- Social media: can PAL make a social media package? YouTube tutorial
- All politics are local: have a pamphlet or a question to ask politicians – “What is your position on Lyme disease?”
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- Coordinating similar efforts beyond state and local level
- Idea of a ‘cloud’ or database, events lists, etc.
- Recommended procedures, outlining of the legislative process and policies for uniform and consistent information; create database for all of our talents
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- What is the information that is crucial?
- Library of PR: Groups can post their posters, media etc. so they can learn from each other
- Interactive learning experiences online – like games and educational efforts
- National and regional conferences
- Database of self-reporting: are people sending in ticks to get tested? Is there something that people can report? Gather vet statistics, so they can report
- Media awareness training, press packages, YouTube videos, etc.
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- Key theme in all questions: Come up with a communication theme: professionally designed model that anyone and everyone can use
- In the database: info would be vetted, perhaps organized by regions, by initiatives, etc. Include best practices
- Develop a train the trainer: Train advocates how to be good advocates
- Webinars
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- Unified effort from a larger group to rewrite the Wikipedia page (claps)
- Unified brand and advertising for a national campaign and education effort
- National spokesperson. Work with groups in Canada
- Work with medical students and nurse practitioners – to work with them at the beginning to give them a good foundations
- National calendar of events
- Coordinating a body for federal legislation
- Database of what is out there in each of the different states

- Outreach to different ethnic groups who are not getting the message
- In any public awareness campaign, show the suffering and the stories, important to have a unified message and agree on language for these campaigns
- Would like to focus on laws, and have other states model on Virginia's law House Bill 1933 – sunshine law

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- Central hotline for everything: in addition to suicide hotline, hotline for resources, etc.
- Have a one-stop shop for medical issues: get testing, treatment, etc. all in one place
- In the Cloud, have a patients list for everyone to put their story up there
- Include trainings in different languages, sign language, etc.
- Training for advocates, hospital advocates, lawyer advocates, patient advocates, etc.
- Have PAL grow so large and important, better to influence change
- Conferences – not only conferences sponsored by PAL but to send experts to medical conferences to present and discuss, or work with people who are presenting
- Reporting and statistics: start generating more stats

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- Informational brochure for consistent info – each group can stamp their info on it, so they can be contacted
- Marketing materials: good bumper sticker, billboard – these validate people
- Communicate success stories, and lessons learned – monthly newsletter?
- Consistent accurate message across the board. Sound bites
- Change local policy – funding

2) What does PAL need to do to help encourage and support your fundraising efforts?

- PAL can help with suggestion for activities
- Direct funding for groups
- Template for how to reach out to leaders and fundraising communities, and the database can include successful Lyme fundraising activities
- Tri-state doctors meeting
- Assistance with grant writing
- Assistance with organizing tick drags

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- Looking for sponsorship and support
- There are documents and templates that all you need are to fill in the blank; these templates can be purchased
- Harness power of social media to spread information consistently – this will help with fundraising to disseminate correct information
- Fundraiser boot camp: organize a webinar for info on how to fundraise

- Evaluation tool so that a layman can look at a research document and understand what it is saying

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- Branding: Put things together to create a common brand, letterhead, logos, materials, so that people can sell and use this. The green wristbands and ribbons perhaps are too common and not effective.

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- Templates: there are templates out there, but one could be made more specific by PAL
- Also show where/when fundraisers are being held so groups can support each other
- Central resource for grants
- Unified Lyme walks through the country which can be a way to raise money as well
- Train how to be a part of a 501c3
- Have PAL share when one of the local organizations is trying to get a grant, some of the funding is through voting – so have people know when and how to participate for local group efforts
- Corporate sponsors having to do with the outdoors, REI, Outdoors, etc. This has the potential capacity to reach many more

3) What can PAL do to further patient support with Lyme and tick-borne diseases?

- Set up mentor database, for people who can help
- Helpful info for different populations: for patients vs. caregivers, to talk to the school
- What are some examples of different treatments
- How to have a basic lab order for treatment options, to help patients be an advocate for themselves

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- Webinars about info a new patient would need, links to Lyme resources, how to navigate the insurance policies
- More uniform in how information is presented, as different groups are posting different things
- Delegate structure for the states so that people could be overseeing each of the initiatives and projects
- Centralized hotline for patients with Lyme disease rather than hotlines monitored by a small group; hotline helps to identify resources for their area as well
- Meals on wheels for patients who don't have caregivers

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- Employment opportunities for people with Lyme, have a job base to assist
- National help line