



# The New England BEACON

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Dr. Carol Feghali-Bostwick   Dr. Philip Clements   Dr. Andrew Plaut   Dr. Robert Simms   Dr. Harrison Farber   Dr. David Leader

## PATIENT EDUCATION SEMINAR 2014

photo by Lee Ann Stanton

Our 2014 biennial Patient Education Seminar was an event that will be remembered long into the future. We were so fortunate to have world class speakers for our presentations and on the “Ask-the-Experts” panel discussion. Over one hundred and twenty attendees made the day an unprecedented success. We were represented by people from all over New England in various age groups that consisted of diagnosees, their family members, caregivers, volunteers and SFNE staff.

If we left assured of anything, it is that we are reaching more people, offering comprehensive advice and medical expertise, and building tremendous fellowship among those who are diagnosed, their caregivers and their support groups. We inch towards research success and we take great strides in peer support and excellent care modalities.



Congratulations and THANKS to all who attended, along with Rebecca, our staff, and volunteers. Where would we be without you? Thank you!

Dr. Philip Clements brought his dynamic personality and expertise to his presentation, *What the Doctor Should Have Told Me on My First Consult Visit – and Finished on the Second Office Visit*. His information resonated clearly with the attendees and with punctuations of humor, great photos and confident data, he brought a measurable energy to those attending. What a set-up for the afternoon Q&A session!

Dr. Carol Feghali-Bostwick is, as always, our greatest support from the world of research. She reviewed the current state of her E-4 Peptide studies and the very positive laboratory successes achieved in the reversal of fibrosis in tissue samples. Success in this area of research would be the most incredible news – and we are seeing marked advancement. Her presentation was clear and easy to understand, and she always engaged the audience. She finished with a rousing game of *Jeopardy*,

with the help of National staff members Kerri Connolly and Anne Sweeney.

Marie Coyle presented the new SFNE Commemorative Quilt in a grand unrolling, (see article on page 7) and Jack Armitage presented Maine support group leader Lori Chason with an award for her hard work over the years in running two support groups and coordinating the Portland Walk. Following that, the SFNE volunteers in attendance were called up and presented with certificates of appreciation for all their loyalty and energy. But, they had one more job to do, and that

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was to present a grand cheer with the scleroderma letters, just as they did at the Oldtime Baseball game and for the cover of the *Scleroderma Voice* magazine. The audience joined in and a great cheer came forth.

Lunch offered a time for meeting with new and old friends, discussing topics from the earlier presentations, and of course a delicious meal. Marie kept things hopping with a lively raffle that yielded multiple winners and a \$100 prize in a box of chocolates!

After the meal, Marie Coyle presented an award to the Lee Kennedy representative, Claire Costello, honoring the company's more than 20 years of generous contributions in support of the Patient Education Seminar.

Dr. Feghali-Bostwick and Dr. Clements sat on the Ask-the-Experts panel with Dr. Robert Simms, Dr. Andrew Plaut, Dr. Harrison "Hap" Farber, and Dr. David Leader. These five medical professionals arrived prepared to field the many questions provided by participants.

Marie Coyle presented questions to the panel, which were then answered thoroughly, with various doctors on the panel adding in any information they had. There never seems to be enough time for all of the information requested, as more answers stimulated more questions!

The day ended on a great note, and comments were overwhelmingly positive. One participant asked if we could "bottle" Dr. Clements to give out to each new diagnosee! We can't do that, but we can continue to present high-quality educational seminars throughout the days ahead. See you in 2016!



*PES Speakers Dr. Philip Clements and Dr. Carol Feghali-Bostwick*



*Marie Coyle consults with Dr. Philip Clements*



*Dr. Carol Feghali-Bostwick engages the crowd with a game of Research Jeopardy*



*PES volunteers Gerry Colantuoni and Fran Mauriello man the raffle table*



*Marie Coyle and Jack Armitage present Maine support group leader and Walk coordinator Lori Chason with an award of appreciation for all her past work*



*Scleroderma Foundation staffers Kerri Connolly and Anne Sweeney attend the event and even help Dr. Feghali-Bostwick with the Jeopardy game!*



*SFNE's dedicated group of volunteers receive certificates of appreciation, then lead the audience in a rousing cheer to Strike Out Scleroderma!*