

TBDWG Mtg 12: Training, Education, Patient Access to Care (Video)

The Lyme Disease Association Inc. (LDA) feels it is imperative that the Lyme Community and the public understand the continued resistance by government agencies to provide information pertaining to chronic Lyme disease on their websites and in their programs despite Lyme disease being around 45 years. LDA has provided video clips from the HHS Tick-Borne Disease Working Group meeting in Philadelphia which portray that resistance. Decades long advocate, LDA President, Pat Smith, the WG patient rep, rebuts these entrenched positions. Please note, however, that the federal government WG representatives are required by FACA WG rules to espouse and vote their agency's position, which may not necessarily be their own personal position.

TBD Working Group Committee Members / Meeting #12 Agenda / LDA Written Summary of Meeting

Full Video: March 3rd – Day 1 / March 4th – Day 2

Other Video Clips: Sam Donta, MD and Other / Public Comment (9 speakers)

Working Group (WG) Discussion on Training, Education, Access to Care, and Reimbursement Subcommittee Recommendations
Co-Chairs: Pat Smith, President; LDA / Captain Scott Cooper, PA; CMS

1-Govt. Website Disclosures	10-B. Beard: Not Acknowledging Both Sets of Guidelines on Website	19-B. Beard: Raises Issue With Curriculum Recommendation – FACA Violation
2-CDC Surveillance Revisions	11-LA Soltysiak WG Co-Chair / D.Dixon NIH Response on Guidelines	20-P. Smith: Responds to Ben Beard FACA Violation Concern
3-Nationwide Lyme Clinical Training	12-P. Smith: Federal Agencies have not done their Job!	21-S. Cooper & WG Continue Curriculum Discussion
4-Govt. Website Disclosure Discussion	13-S. Donta: Agencies Must Revisit Failures/Limitations for Chronic/Persistent Disease	22-P. Smith: Rebuttal to CDC Curriculum Comments
5-P. Smith Defends Chronic Lyme Patients	14-B. Beard: Addresses what Chronic Lyme Patients have had to Endure and Complexity of Moving Policy Forward Within a Large Agency	23-WG Continues Curriculum Discussion & Votes
6-P. Smith Questions WG Process/FACA	15-Committee Edits/Votes on Government Website Disclosure Wording	24-P. Smith: Legal for D. Walker To Vote In Place of E. Shapiro / Answered by J. Berger, HHS

7-P. Smith Questions Communication Betwn. WG & the Non Transparent WG	16-P. Smith: Surveillance Revisions	
8-P. Smith: FDA Position on Guidance vs. Guidelines, Why Chronic Cannot be Acknowledged	17-Committee Discussion on Surveillance Revision / Vote: P. Smith, No!	25-Entire Discussion on Training, Education, Access to Care and Reimbursement: Day 1
9-P. Smith: NIH/CDC Agency Guidelines/Positions – why is chronic Lyme completely ignored?	18-S. Cooper & WG Discuss Nationwide Curriculum	26-Entire Discussion on Training, Education, Access to Care and Reimbursement: Day 2

1 – P. Smith: Govt. Website Disclosures (5 + min)

9:59:06 to 10:04:38

35946 to 36278

2- P. Smith: CDC Surveillance Revisions (5+ min)

10:04:39 to 10:10:37

36279 to 36637

3- S. Cooper: Nationwide Lyme Clinical Training (4+ min)

10:10:38 to 10:15:35

36638 to 36935

4- Govt. Website Disclosure Discussion (10 min)

10:16:15 to 10:36:14

36975 to 38174

5- P. Smith Defends Chronic Lyme Patients (4+ min)

10:36:14 to 10:40:18

38174 to 38418

DAY 2

6-P. Smith Questions WG Process/FACA (1+ min)

2:18:37 to 2:20:12

8317 to 8412

7-P. Smith Questions Communication Betwn. WG & the Non
Transparent WG (1+ min)

2:20:12 to 2:22:02

8412 to 8522

8-P. Smith: FDA Position on Guidance vs. Guidelines, Why
Chronic Cannot be Acknowledged (3+ min)

2:22:02 to 2:25:15

8522 to 8715

9-P. Smith: NIH/CDC Agency Guidelines/Positions – why is
chronic Lyme completely ignored? (9+ min)

2:25:15 to 2:34:30

8715 to 9270

10-B. Beard: Not Acknowledging Both Sets of Guidelines on
Website (11+ min)

2:34:30 to 2:35:41

9270 to 9341

11-LA Soltysiak WG Co-Chair / D.Dixon NIH Response on
Guidelines (4+ min)

2:35:42 to 2:39:45

9342 to 9585

12-P. Smith: Federal Agencies have not done their Job! (3+
min)

2:39:45 to 2:43:13

9585 to 9793

13-S. Donta: Agencies Must Revisit Failures/Limitations for Chronic/Persistent Disease (6+ min)
2:43:14 to 2:49:17
9794 to 10157

14-B. Beard: Addresses what Chronic Lyme Patients have had to Endure and Complexity of Moving Policy Forward Within a Large Agency (2+ min)
2:49:27 to 2:52:00
10167 to 10320

15-Committee Edits/Votes on Government Website Disclosure Wording (26+ min)
2:52:00 to 3:18:38
10320 to 11918

16-P. Smith: Surveillance Revisions (1+ min)
3:18:56 to 3:20:20
11936 to 12020

17-Committee Discussion on Surveillance Revision / Vote: P. Smith, No! (15+ min)
3:20:23 to 3:36:16
12023 to 12976

18-S. Cooper & WG Discuss Nationwide Curriculum (9+ min)
3:36:29 to 3:46:10
12989 to 13570

19-B. Beard: Raises Issue With Curriculum Recommendation – FACA Violation (11+ min)
3:46:12 to 3:47:25
13572 to 13645

20-P. Smith: Responds to Ben Beard FACA Violation Concern (1+ min)
3:47:27 to 3:48:54
13647 to 13734

21-S. Cooper & WG Continue Curriculum Discussion (4+ min)
3:48:54 to 3:53:42
13734 to 14022

22-P. Smith: Rebuttal to CDC Curriculum Comments (1+ min)
3:53:42 to 3:54:51
14022 to 14091

23-WG Continues Curriculum Discussion & Votes (27+ min)
3:54:51 to 4:22:34
14091 to 15754

24-P. Smith: Legal for D. Walker To Vote In Place of E. Shapiro / Answered by J. Berger, HHS (50 sec)
4:22:34 to 4:23:25
15754 to 15805

25-Entire Discussion on Training, Education, Access to Care and Reimbursement: Day 1 (43+ min)
9:57:06 to 10:40:26
35826 to 38426

26-Entire Discussion on Training, Education, Access to Care and Reimbursement: Day 2 (2 hr 4 min)
2:18:37 to 4:23:27
8317 to 15807