# Lyme Disease Committee meeting

**Date:** 21/02/2017

Location:Boardroom, National Guideline Centre, 180 Great Portland Street,<br/>London, W1W 5QZMinutes:Confirmed

Committee members present:	
Saul Faust (SF, Chair)	(Present for notes 1–5)
Nick Beeching (NB)	(Present for notes 1–5)
Robin Brittain-Long (RBL)	(Present for notes 1–5)
Tim Brooks (TB)	(Present for notes 1–5)
Scott Hackett (SH)	(Present for notes 1–5)
Cheryl Hemingway (CH)	(Present for notes 1–5)
Neil Hopkinson (NH)	(Present for notes 1–5)
Veronica Hughes (VH)	(Present for notes 2–5)
Stella Huyshe-Shires (SHS)	(Present for notes 1–5)
Melissa McCullough (MM)	(Present for notes 1–5)
Caroline Rayment (CR)	(Present for notes 1–5)
David Stephens (DS)	(Present for notes 1–5)

In attendance:		
Ben Doak (BD)	Guideline Commissioning Manager, NICE	(Present for notes 1–5)
Maria Cruickshank (MC)	Research Fellow, NGC	(Present for notes 1–5)
Meredith Faust (MF)	Document Editor/Process Assistant, NGC	(Present for notes 1–5)
Andreas Freitag (AF)	Senior Research Fellow, NGC	(Present for notes 1–5)
Rebecca Houghton (RH)	Clinical Trainee, NGC	(Present for notes 1–5)
Sophia Kemmis-Betty (SKB)	Senior Health Economist, NGC	(Present for notes 1–5)
Norma O'Flynn (NOF)	Guideline Lead, NGC	(Present for notes 1–5)

Apologies:	
Srini Bandi	Consultant paediatrician

Stephen Barton	Lay member
Nick Davies	Co-opted expert; Consultant neurologist
Jill Cobb	Information specialist, NGC
Samantha Jones	Project manager, NGC

#### 1. Welcome and objectives for the meeting

The Chair welcomed the committee members and attendees to the fifth meeting of the Lyme Disease Guideline Committee. The committee members and attendees introduced themselves.

The Chair informed the committee that apologies had been received. These are noted above.

The Chair outlined the objectives of the meeting, which included drafting diagnostic test recommendations, drafting general recommendations, finalising protocols, and reviewing the evidence for the management for Lyme disease.

### 2. Confirmation of matter under discussion, and declarations of interest

The Chair confirmed that, for the purpose of managing conflicts of interest, the matter under discussion was drafting diagnostic test recommendations, drafting general recommendations, finalising protocols, and reviewing the evidence for the management for Lyme disease.

The Chair asked everyone to declare verbally any interests that have arisen since the last meeting.

Name	Job title, organisation	Declarations of Interest, date declared	Type of interest	Decision taken
Scott Hackett	Consultant in paediatric allergy, immunology and infectious diseases	Consult advice for BPL and immunoglobulin manufacturer who paid me for my time. No links to Lyme disease only immune deficiencies.	Non-personal financial non- specific	Declare and participate
Veronica Hughes	CEO, Caudwell Lyme Disease	Caudwell Lyme receives restricted funds from Innatoss, a research and medical testing	Non-personal financial specific	Declare and participate

		laborator: in the		
		laboratory in the Netherlands.		
		This information is		
		declared in the		
		public domain on		
		caudwelllyme.com.		
Stella	Chair, Lyme	In February 2016, I	Non-personal	Declare and
Huyshe-	Disease Action	posted and co-	non-financial	participate
Shires	Diocuso / totion	authored a poster	specific	participato
Chines		with Lyme Disease	opeoine	
		Action's medical		
		director at		
		NordTick 2016		
		describing a		
		potential specialist		
		clinic for Lyme		
		disease involving		
		greater public		
		involvement to		
		enable a more		
		detailed analysis		
		of relevant patient		
		history. I did not		
		speak about this		
		poster, but I was		
		present as the		
		medic discussed it		
		with anyone who		
		approached her.		
		No payment was		
		received. The		
		poster was		
		affiliated with		
		Lyme Disease		
		Action.		
		In November	Non-norsonal	Declare and
		2016, at the	Non-personal non-financial	
		request of my MP,	specific	participate
		I attended a	specific	
		meeting of 11 MPs & their researchers		
		to answer their		
		questions		
		prompted by their constituents'		
		concerns. A		
		briefing note by LDA was		
		presented		
		explaining facts		

and controversies around Lyme disease. The need for specialised commissioning of a Lyme disease clinic, with public involvement, was discussed.		
In November 2016, I gave an awareness talk on ticks and Lyme disease at a local Ramblers Association AGM. No funds were received. The talk on ticks was affiliated with Lyme Disease Action.	Non-personal non-financial specific	Declare and participate

The Chair and a senior member of the Developer's team noted that the interests declared did not prevent the attendees from fully participating in the meeting.

### 3. Minutes of last meeting

The Chair asked the committee if it wanted any changes made to the minutes of the last meeting. The committee suggested a minor change.

The Chair confirmed that all matters arising had been completed or were in hand.

### 4. Discussions and presentations

A. Diagnostic test reviews:

- TB explained the types of immunoblot tests conducted at RIPL to the committee.
- The committee refined draft recommendations.
- B. SKB lead a discussion on health economics.
- C. AF presented the following protocols for finalisation:
  - Signs and symptoms
  - Prevalence
  - Transmission

- D. AF presented the intervention reviews (methodology) for the committee's review.
- E. AF presented the management evidence report for the committee's review and input.

## 5. Any other business

None.

Date of next meeting:	28/03/2017
Location of next meeting:	Sloane Room, Royal College of Physicians, 11 St Andrews Place, Regents Park, London NW1 4LE