

## Lyme Disease Committee meeting 1

**Date:** 14/09/2016

**Location:** Boardroom, NGC Office, 180 Great Portland Street, London, W1W 5QZ

**Minutes:** Confirmed

<b>Committee members present:</b>		
Saul Faust (SF) (Chair)		(Present for notes 1–4)
Srini Bandi (SB)		(Present for notes 1–4)
Stephen Barton (SBa)		(Present for notes 1–4)
Nick Beeching (NB)		(Present for notes 1–4)
Robin Brittain-Long (RBL)		(Present for notes 1–4)
Tim Brooks (TB)		(Present for notes 1–4)
Scott Hackett (SH)		(Present for notes 1–4)
Neil Hopkinson (NH)		(Present for notes 1–4)
Veronica Hughes (VH)		(Present for notes 1–4)
Stella Huyshe-Shires (SHS)		(Present for notes 1–4)
Melissa McCullough (MM)		(Present for notes 1–4)
Caroline Rayment (CR)		(Present for notes 1–4)
David Stephens (DS)		(Present for notes 1–4)

<b>In attendance:</b>		
Ben Doak (BD)	Guidelines Commissioning Manager, NICE	(Present for notes 1–4)
Simran Chawla (SC)	Public Involvement Advisor, NICE	(Present for notes 1–3e)
Kate Ashmore (KA)	Documents Editor/Process Assistant, NGC	(Present for notes 1–4)
Maria Cruickshank (MC)	Research Fellow, NGC	(Present for notes 1–4)
Andreas Freitag (AF)	Senior Research Fellow, NGC	(Present for notes 1–4)
Lina Gulhane (LG)	Joint Head of Information Science, NGC	(Present for notes 3c–4)
Rebecca Houghton (RH)	Clinical Trainee, NGC	(Present for notes 1–4)

Samantha Jones	Project Manager, NGC	(Present for note 3d)
Sophia Kemmis-Betty (SKB)	Senior Health Economist, NGC	(Present for notes 1–4)
Kate Lovibond (KL)	Health Economics Lead, NGC	(Present for notes 1–4)
Norma O’Flynn (NOF)	Guideline Lead, NGC	(Present for notes 1–4)

<b>Observers:</b>		
Meredith Faust (MF)	Documents Editor/Process Assistant, NGC	(Present for notes 1–4)

<b>Apologies:</b>	
Jill Cobb (JC)	Information Specialist, NGC
Cheryl Hemingway (CH)	Consultant Paediatric Neurologist

<b>1. Welcome and objectives for the meeting</b>				
<p>The Chair welcomed the Committee members and attendees to the first meeting of the Lyme disease Guideline Committee.</p> <p>SF informed the Committee that apologies had been received. These are noted above.</p> <p>The Chair outlined the objectives of the meeting.</p>				
<b>2. Confirmation of matter under discussion, and declarations of interest</b>				
<p>a) Matter under discussion: general introduction to NICE guidelines and methods.</p> <p>b) Declarations of interest:</p>				
<b>Name</b>	<b>Job title, organisation</b>	<b>Declarations of Interest, date declared</b>	<b>Type of interest</b>	<b>Decision taken</b>
Saul Faust	Professor of Paediatric Immunology and Infectious Diseases, Director, Southampton	Commercial relationships, 14/09/2016  Advisory Board participation (no personal payment of any kind from any organisation, all honoraria paid to	Non-personal financial	Declare and participate

	NIHR Wellcome Trust Clinical Research Facility	University or Trust employer) AstraZeneca influenza and RSV vaccine advisory board (2015) Merck Paediatric <i>C. Difficile</i> Advisory Board (2015-6), 14/09/2016		
		Clinical Trial investigator for commercial clinical trials (acting on behalf of University of Southampton and University Hospital Southampton NHS Foundation Trust, no personal payments of any kind), all NIHR portfolio commercial studies, 14/09/2016  2015 clinical trial in varicella vaccine in children (GSK) 2015 clinical trial (non-drug) in influenza epidemiology (Astra-Zeneca) 2015 clinical trial of anti-RSV monoclonal (Regeneron), 14/09/2016	Non-personal financial	Declare and participate
		Grant funding to institution: co-investigator on Pfizer-funded investigator led study in pneumococcal molecular epidemiology (funds held by University of Southampton), 14/09/2016  I am currently Chair of the NICE GC for Sepsis in children and adults, 14/09/2016	Non-personal financial  Personal non-financial	Declare and participate  Declare and participate

Srini Bandi	Consultant Paediatrician, Leicester Royal Infirmary	<p>Executive committee Member of CHIVA (Children's HIV Association) since 2012.</p> <p>I attend the CHIVA conferences twice a year, the registration and accommodation expenses are covered by CHIVA</p>	Personal non-financial	Declare and participate
		<p>Principal investigator for portfolio studies at University Hospitals Leicester, none of which relate to Lyme disease. I am currently the PI for following studies:</p> <ol style="list-style-type: none"> <li>1. CHIPS – Children's HIV, mainly a database</li> <li>2. MAGIC – oncology study, looking at the renal and ototoxicity of cisplatin</li> <li>3. ARCHIE – early use of antibiotics in children at risk of influenza like illness</li> <li>4. ODYSSEY – Children's HIV study. Use of Dolutegravir</li> </ol> <p>Individual researchers can avail a proportion of the income generated by the research towards study leave expenses.</p>	Non-personal financial	Declare and participate

		<p>Previous studies</p> <ol style="list-style-type: none"> <li>1. NEOMERO 2 – use of meropenem in neonatal meningitis</li> <li>2. DAP – daptomycin in osteomyelitis</li> <li>3. BREATHER – HIV study</li> <li>4. AALPHI – HIV study</li> </ol> <p>Individual researchers can avail a proportion of the income generated by the research towards study leave expenses.</p>	Non-personal financial	Declare and participate
Stephen Barton	Communications Manager, OBN Ltd.	Employee of a small membership organization that looks after the interests of early stage bioscience and medical technology companies. Member companies pay a Membership fee and some sponsor the organisation.	Non-personal financial	Declare and participate
		My partner is the Patient Editor of The BMJ.	Personal family interest	Declare and participate
Nick Beeching	Infectious Disease Specialist, Royal Liverpool University Hospital	Co-applicant and theme lead for NIHR Health Protection Research Unit in Emerging and Zoonotic Infection, Liverpool University/Liverpool School of Tropical Medicine/ Public Health England (2014-2018) £4M (Co theme leader for Clinical Surveillance theme including research on Lyme Disease)	Non-personal financial	Declare and participate

		Work in a referral centre which attracts referrals of patients with Lyme or possible Lyme from outside our catchment area. This centre also has a clinical and externally funded (MRC) research interest in chronic fatigue syndrome	Non-personal financial	Declare and participate
		PI for non-commercial grant to institution from Wellcome Trust for studies on Crimean Congo haemorrhagic fever.	Non-personal financial	Declare and participate
		Local PI for commercially funded NIHR portfolio study (Summit) on treatment of Clostridium difficile infection. Funds to institution.	Non-personal financial	Declare and participate
Robin Brittain-Long	Consultant physician in Acute medicine, Aberdeen Royal Infirmary	Local Principal Investigator for multicentre RCT trial of pandemic influenza (ASAP trial)—non-commercial trial assessing benefit of adding steroids to standard care in patients with pandemic influenza infection. NIHR funded.	Non-personal financial	Declare and participate
Tim Brooks	Clinical Services Director, Microbiologist, Rare & Imported Pathogens Laboratory	Head of the Rare & Imported Pathogens Laboratory of Public Health England, a national level diagnostic laboratory that offers testing for Lyme disease and a wide range of other diseases. In this role, I answer questions from members of the public and parliamentarians through the official channels of PHE and the Department of Health. I also give advice to clinicians on the interpretation of test results and their clinical significance, as well as	Non-personal financial	

		generic advice on treatment.		
Scott Hackett	Consultant in Paediatric Infectious Disease, Birmingham Heartlands Hospital	Paediatric infectious diseases consultant and as such receive referrals for patients with potential Lyme disease within a clinical NHS service.	Personal non-financial	Declare and participate
		Chair of RCPCH CSAC for Paediatric infectious disease, Immunology and allergies. I coordinate paediatric training across the UK in these fields; this includes Lyme disease as part of the syllabus. No payment received.	Personal non-financial	Declare and participate
		Companies (mostly allergy and immunoglobulin companies) have paid me for advice re milk products as well as to attend meetings. No payments received in the last 12 months.	Personal non-financial	
		I am the PI and Col in a number of research projects; none of them are Lyme disease. Funding goes directly to my employer/trust fund.	Non-personal financial	Declare and participate
		I have given a number of 'textbook'-type talks on paediatric Lyme disease as I have seen many patients with this condition.	Personal non-financial	Declare and participate
Cheryl Hemingway	Consultant Paediatric Neurologist, Great Ormond Street Children's Hospital	None.	N/A	N/A
Neil Hopkinson	Consultant Rheumatologist, Royal Bournemouth	None.	N/A	N/A

	& Christchurch Hospitals			
Veronica Hughes	CEO, Caudwell Lyme Disease	<p>I have held a salaried position on John Caudwell's personal staff since 4th January 2016, pending Caudwell Lyme Disease's registration as a charity, at which point my employment is expected to be transferred to the charity.</p> <p>As a part of this role, I meet and discuss potential scientific/medical research projects with doctors, university employees etc. in the field of Lyme disease, with a view to the charity potentially contributing funding to those research projects.</p> <p>As a part of this role, I write public education/awareness materials about Lyme and other tick borne diseases for publication on the Caudwell Lyme Disease charity website, which summarise published evidence and factual statements. As a part of this role, I have initiated social media surveys of Lyme disease patients that gather information about patients' treatment experiences, diagnostic testing, opinions etc. The results of these surveys have not been published</p>	Personal non- financial interest	
Stella Huyshe- Shires	Chair, Lyme Disease Action	<p>I am chair and managing director of Lyme Disease Action, a UK registered charity and company. These roles are unpaid. I have made public</p>	Personal non- financial	



		statements concerning Lyme disease on the Lyme Disease Action website and Twitter feed.		
		I wrote a letter that was published in The Times 6/9/2016 highlighting the need for specialist Lyme disease clinics.	Personal non-financial	Declare and participate
		I am regularly involved in reviewing and approving website pages and social media posts according to LDA's Information and Social Media policies.	Personal non-financial	
Caroline Rayment	GP, Grange Park Surgery	None.	N/A	N/A
David Stephens	Portfolio GP	None.	N/A	N/A
Melissa McCulloch	Non-executive director, Health and Social Care Board NI	Non-Executive Director, Health & Social Care Board NI	Personal financial	Declare and participate
		Company Director, Designco Ltd	Personal financial	Declare and participate
		Volunteer, Down's Syndrome Association NI	Personal non-financial	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. Presentations and Discussions

- a) NOF gave a presentation on the National Guideline Centre and the NICE guidelines programme.
- b) BD gave a presentation on working with NICE.
- c) SC gave a presentation on patient involvement throughout the guideline process.

- d) NOF gave a presentation on the NICE Declarations of Interest policy. The GC members then declared their conflicts of interest. These are noted above.
- e) LG gave a presentation on the role of the Information Specialist.
- f) AF gave a presentation on the role of the Research Fellow.
- g) MC gave a presentation on the methodology used in evidence reviews.
- h) KL gave a presentation on the role of the Health Economist.
- i) The Chair presented the scope to the committee. The GC members discussed the scope and the areas included.
- j) AF presented the planned review questions to the committee and these were discussed.

**4. Any other business**

None.

**Date of next meeting:** 15/09/2016

**Location of next meeting:** Boardroom, National Guideline Centre, 180 Great Portland Street, London, W1W 5QZ.