

Technology Advisory HST Interests Register

Topic [ID3995]

Publication Date: 10/01/2024

Name	Role with NICE	Type of interest	Description of interest	Interest declared	Comments
Emtiyaz Chowdhury	Committee Member	Non-financial professional	Emtiyaz is an employee of Parexel, a CRO that engages in work with the manufacturer. He has not been involved in any work directly with manufacturer.	17/04/2023 27/06/2023	It was agreed that Emtiyaz's declaration would not prevent him from participating in discussions on this evaluation.
Paul Arundel	Committee Member	Non-Financial Professional	Declarations are in relation to hypophosphatasia/asfotase alfa (with which Paul has been directly involved through his role as an NHS clinician with responsibility for children with bone diseases) and not the technology which is the subject of this evaluation. Declarations as follows: <ul style="list-style-type: none"> Is PI for ongoing Alexion-sponsored registry of hypophosphatasia. No direct 	17/04/2023 27/06/2023	It was agreed that Paul's declaration would not prevent him from participating in discussions on this evaluation.

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			<p>payment but NHS Trust paid for contracted work.</p> <ul style="list-style-type: none"> • Previously sub-investigator for Alexion-sponsored study of asfotase alfa for hypophosphatasia (now completed). • Previous work for Alexion for speaking about hypophosphatasia payments including travel and honoraria - none since 2019. Completed. • Previous work for Alexion for attendance at Advisory Board on treatment monitoring of hypophosphatasia in 2016 - payments including travel, expenses, and honorarium. Completed. • No additional ongoing financial or contractual arrangements with Alexion. 		

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Sophie Thomas	Patient expert	Indirect financial Direct professional	The MPS Society received a grant from the company to carry out a patient / care giver burden survey and a clinical meeting in relation to LAL D. The company had no input into either of the two areas of work. Sophie was approached by the EAG to share her insight of Infantile LAL D and its impact on patients and carers.	10/05/2023 13/07/2023	It was agreed that Sophie's declaration would not prevent her from providing expert advice to the committee.
Suresh Vijay	Clinical expert	Direct professional and financial	Suresh was a principal Investigator in the LAL-CL08 clinical trial and a sub-investigator in LAL-CL06 clinical trial sponsored by Alexion. He has received sponsorship and honoraria from Alexion for attendance at clinical meetings and conferences but has no ongoing financial relationship with Alexion. He is a member of the scientific advisory board for the international LAL-D registry sponsored by Alexion.	08/02/2023 13/07/2023	It was agreed that Suresh's declaration would not prevent him from providing expert advice to the committee.

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Simon Jones	Clinical expert		<p>Simon has been an investigator in multiple trials for Sebelipase alfa and, as such, consulted for Synageva and then Alexion.</p> <p>Specifically, Simon also gave support and advice to Alexion and the MPS society for their submissions to NICE on this and the previous HST.</p>	<p>08/02/2023</p> <p>13/07/2023</p>	<p>It was agreed that Simon's declaration would not prevent him from providing expert advice to the committee.</p>