

Highly Specialised Technologies Evaluation Committee Interests Register
Lumasiran for treating primary hyperoxaluria type 1 [ID3765]
Publication Date: 19/04/2023

Name	Role with NICE	Type of interest	Description of interest	Interest arose	Interest declared	Interest ceased	Comments
Professor Ron Akehurst	Committee Member	Direct - Financial	Professor Ron Akehurst's company has provided advice to Alnylam on this product.	16/03/22		N/A	It was agreed that this declaration would prevent Professor Akehurst from attending this discussion.
Dr Mark Sheehan	Committee Member	Direct - Financial	Dr Mark Sheehan received payment by Alnylam, via Clinigen (who was advising the company) for providing feedback on ethical issues in their planned Early Access to Medicines Scheme for Lumasiran.	13/04/22	13/04/22	N/A	It was agreed that this declaration would not prevent Dr Sheehan from attending this discussion
Mrs Jess Doyle	Patient Expert	Non-Financial Personal and Professional	Jess Doyle is Head of Insight at Metabolic Support UK and has been a member of various boards and directives, including the Metabolic Clinical Referencing Group - but nothing in relation to this technology.	29/03/22	13/04/22	N/A	It was agreed that this declaration would not prevent Jess Doyle from providing expert advice in this discussion.

		Indirect - Financial	Metabolic Support UK has historically received core funding for individual support, empowerment and advocacy services from the pharmaceutical company linked to this appraisal, but not within the last 12 months.				
Dr Sally-Anne Hulton	Clinical Expert	Direct – Financial Direct – Non-financial	<p>Dr Sally-Anne Hulton has received consultation fees, honoraria, and travel grant support from Alnylam and Dicerna pharmaceuticals.</p> <p>Dr Hulton has participated as Chief Investigator for a number of trials on behalf of Alnylam and Dicerna, and has received consultation fees and a travel grant from Chiesi, a pharmaceutical company engaged in rare disease therapies.</p> <p>More detail added for above interests: she has been Chief Investigator since 2016 for all the Alnylam studies engaged in PH1: ALN GO1, ALN GO1 002, ALN GO 003 Illuminate, ALN GO 004 Illuminate B (although her site did not recruit to this study due to</p>	24/01/22	13/04/2022 09/02/22	N/A	It was agreed that these declarations would not prevent Dr Hulton from providing expert advice in this discussion.

			<p>Covid restrictions, she was involved with the study protocol and results review). In the role as Chief Investigator, she also acted on the safety review panel for ALN GO1. These studies were the original trials of Lumasiran (ALN GO) in healthy volunteers, followed by the studies in all patient groups in descending order of age and kidney function. She has separately received consultancy fees during the last 3 years from the company for provision of educational materials</p>				
Dr Shabbir Moochhala	Clinical Expert	<p>Direct – Financial</p> <p>Direct – Non-Financial</p>	<p>Dr Shabbir Moochhala is a Scientific advisory board member for Alnylam and Dicerna, and works in clinical private practice for renal medicine.</p> <p>Dr Moochhala has worked in the following positions: Chair of NHS Rare Disease Collaborative Network for hyperoxaluria, Chair of the renal Rare Disease Group for</p>	08/12/21	13/04/22 09/02/22	N/A	It was agreed that these declarations would not prevent Dr Moochhala from providing expert advice in this discussion.

			<p>hyperoxaluria, Steering committee member of OxalEurope, Guidelines committee member of OxalEurope, Chief Investigator for Alnylam Illuminate-C study, Principal Investigator for Alnylam BONAPH1DE Phase IV study in PH1 and Chief Investigator for 3 Dicerna trials and one trial in enteric hyperoxaluria.</p> <p>He has been scientific advisory board member for Alnylam and Dicernahas</p>		09/02/22		
Dr Wesley Hayes	Clinical Expert	Indirect - Financial	Dr Wesley Hayes has acted as co-investigator on Illuminate clinical trials and had received travel expenses when attending the international trial investigator meeting.	25/11/21	13/04/22 09/02/22	N/A	It was agreed that this declaration would not prevent Dr Hayes would from providing expert advice during this discussion.
Emtiyaz Chowdhury	Committee Member	Non-financial professional interest	He is an employee of Parexel who may have completed work for both manufacturers. He has not been directly involved with any work related to the technologies under consideration.		04/01/23		It was agreed that his declaration would not prevent Emtiyaz from participating in discussions on this evaluation.

Helen Morris	Patient Expert	Professional interests	She works for Metabolic Support UK and works alongside the Alnylam to produce patient educational materials.				It was agreed that her declarations would not prevent Helen from providing expert advice to the committee.
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