Highly Specialised Technologies Evaluation Committee Interests Register

Onasemnogene abeparvovec for treating pre-symptomatic spinal muscular atrophy (MAA partial review of HST 15)

Publication Date: 19/04/2023

Name	Role with NICE	Type of interest	Description of interest	Interest arose	Interest declared	Interest ceased	Comments
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.
Portia Thorman	Patient expert	Financial Interest	Her organisation, Spinal Muscular Atrophy UK, has received funding from the industry.		22/06/22		It was agreed that her declaration would not prevent Portia from providing expert advice to the committee.
Elizabeth Wraige	Clinical expert	Financial and non-financial interests	She has undertaken paid and unpaid consultancy work for Novartis and other manufacturers of spinal muscular atrophy modifying treatments. Prior to the meeting Elizabeth declared		29/06/22		It was agreed that her declarations would not prevent Elizabeth from providing expert advice to the committee.

NICE National Institute for Health and Care Excellence

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			she is a member of the				
			national SMA Reach clinical				
			network (all paediatric				
			neuromuscular consultants in				
			England are members of this				
			group) – this group meets				
			regularly to review and				
			discuss topics of importance				
			with respect to standards of				
			clinical care; She contributes				
			data to the iSMAC registry				
			(mandatory with respect to				
			those patients receiving				
			treatment through managed				
			access agreement); She is co-				
			chair of the national				
			onasemnogene abeparvovec				
			multidisciplinary team which				
			oversees delivery of				
			treatment through the 4				
			infusion centres.				
Laurent Servais	Clinical expert	Financial and	He has taken part in all trials		30/06/22		It was agreed that his
		non-financial	for multiple sclerosis and he				declarations would not
		interests	has conducted consultancy or				prevent Laurent from
			been invited to lecture for				

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			Roche, Novartis and Biogen.				providing expert advice
			He has conducted				to the committee.
			consultancy for Scholar Rock				
			and Biohaven and he has had				
			research funded by Novartis,				
			Roche and Biogen. Prior to				
			the meeting, Laurent declared				
			he is Secretary of the world				
			Muscle Society and vice-chair				
			of the scientific advisory				
			board of SMA Europe.				