

Highly Specialised Technologies Evaluation Committee Interests Register Ataluren for treating Duchenne muscular dystrophy with a nonsense mutation in the dystrophin gene (review of HST3) [ID1642]

Publication Date: 22/02/2023

Name	Role with NICE	Type of interest	Description of interest	Interest arose	Interest declared	Interest ceased	Comments
Professor Ron Akehurst	Committee Member	Financial interest	His company, Lumanity, is working with PTC Therapeutics and he has been involved in the work	-	18/08/22	-	As a direct conflict Professor Akehurst did not take part in this meeting.
Emtiyaz Chowdhury	Committee Member	Non-financial professional & personal Interest	Parexel is a CRO which works with the manufacturer for HST3 and HST6. However, he is not aware of any work that Parexel have done for this specific technology, nor has he or his team been involved in any work related to this technology.	-	22/08/22 25/11/22	-	It was agreed his declaration would not prevent Emtiyaz from participating in discussions on this appraisal
Sarah Davis	Committee Member	financial interests	she is a member of Scharr-tag the EAG on this appraisal, but she has had no involvement with their work.	-	18/08/22 01/12/22	-	It was agreed her declaration would not prevent Sarah from participating in discussions on this appraisal.

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Mark Silverman	Patient Expert	Direct Non-Financial Interest	He is a trustee of Action Duchenne and this charity has received sponsorship from PTC Therapeutics and other companies as part of its ongoing work.	-	08/02/22 15/12/22	-	It was agreed that his declaration would not prevent Mark from providing expert advice to the committee.
Dr Anne-Marie Childs	Clinical Expert	Direct financial and non-financial interests	she has previously contributed to advisory boards for PTC Therapeutics and has been sponsored to attend educational meetings and given invited lectures on their behalf. Last year I was asked to present the current data from the STRIDE study to the national investigators meeting, in the last 5 yrs, she has also contributed to advisory boards for Roche, Biogen, and Novartis in relation to novel therapies in SMA as is a PI for a number of commercial studies in DMD, including trials	-	17/01/22 15/12/22	-	It was agreed that her declaration would not prevent Dr Childs from providing expert advice to the committee.

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			sponsored by Sarepta and Fibrogen				
Dr Stuart Mealing	Committee Member	Indirect professional interests	As the company he works for, YHEC, has worked for PTC in the past but he personally has never done any work with PTC	-	15/12/22	-	It was agreed that his declaration would not prevent Dr Mealing from participating in discussions on this evaluation.
Rob Burley	Patient Expert	Financial interest	his organisation has received funding from PTC Therapeutics.	-	07/01/22	-	It was agreed that his declaration would not prevent Rob from providing expert advice to the committee.
Katherine Wedell	Patient Expert	personal interest	Her son is taking Translarna (ataluren).	-	08/02/22	-	It was agreed that her declaration would not prevent Katherine from providing expert advice to the committee.
Professor Francesco Mutoni	Clinical Expert	Direct financial interests	he works with PTC Therapeutics and has taken part a PTC SAB held during the World Muscle Society meeting, Halifax, this year. He also took part in Stride Registry virtual meetings and	-	07/01/22	-	It was agreed that his declaration would not prevent Francesco from providing expert advice to the committee.

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			was chairperson at the PTC Therapeutics EPNS Symposium this year in Glasgow.				