

Highly Specialised Technologies Evaluation Committee Interests Register
Eladocagene exuparvovec for treating aromatic L-amino acid decarboxylase deficiency [ID3791]
Publication Date: 19/04/2023

Name	Type of interest	Description of interest	Interest arose	Interest declared	Interest ceased	Comments
Mr Emtiyaz Chowdhry	Non-financial professional and personal interest	Emtiyaz's employer - Parexel - is a CRO which works with PTC. Neither Emtiyaz or Parexel has have not been involved in any consulting activities for this specific technology.	17/10/2022	17/10/2022	-	It was agreed that this declaration would not prevent Emtiyaz from participating in this section of the meeting.
Dr Stuart Mealing	Non-financial professional and personal interest	Dr Mealing's employer – YHEC - has undertaken work for PTC in relation to this molecule in the recent past. He has never personally worked on this, or for the company.	19/10/2022	19/10/2022	-	It was agreed that this declaration would not prevent Stuart from participating in this section of the meeting.
Jess Doyle	Indirect financial interest	Jess's employer – Metabolic Support UK has received funding from PTC towards core programmes and their annual event.	08/07/2022	08/07/2022	-	It was agreed that her declarations would not prevent Jess from providing expert advice to the committee.
Professor Manju Kurian	Non-financial professional	Professor Kurian's employer - Great Ormond Street - have been in discussions with PTC about bidding to be one of	29/04/2022	29/04/2022	-	It was agreed that her declarations would not prevent Manju from

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	and personal interests	the clinical sites for this gene therapy, and Professor Kurian was part of the team involved the discussions. Professor Kurian has also worked with Professor Krys Bankiewicz on an alternative gene therapy approach using a similar viral vector but different brain target. This work has been undertaken on a research basis, but his team has not received any financial remuneration from PTC for involvement in this research. Furthermore, Professor Kurian also declared her position on the medical and scientific advisory board for the AADC research trust.				providing expert advice to the committee.
Richard Poulin	Financial and non-financial interests	Richard has received non-paid benefits and remuneration for speaking engagements from PTC. The speaking engagements were regarding parent experience regarding misdiagnosis, genetic testing experience, and symptoms related to aromatic l-amino acid	08/07/2022	08/07/2022	-	It was agreed that his declaration would not prevent Richard from providing expert advice to the committee.

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		decarboxylase deficiency, however, Richard Poulin is not receiving any payments from PTC for activities in the UK or related to the eladocogene exuparvovec NICE appraisal.				
Dr Simon Heales	Financial interests	Dr Heales has received speaker fees and an unrestricted grant from PTC.	24/03/2022	24/03/2022	-	It was agreed that his declaration would not prevent Simon from providing expert advice to the committee.