

Technology Advisory HST Interests Register

Topic: Iptacopan for treating paroxysmal nocturnal haemoglobinuria [ID6176]

Publication Date: 04/09/2024

Name	Role with NICE	Type of interest	Description of interest	Interest declared	Comments
Dr Paul Arundel	Committee Member	Non-Financial professional interests	I was principal investigator for ALX-HPP-501 - registry study of children with hypophosphatasia - sponsored by Alexion pharma. This is conducted within the NHS and costs are paid to employing NHS Trust according to contracting and not to me. Interest arose 2022 (when I took over from colleague who retired) and ceased in 2024 (when I passed over to new consultant colleague).	10/04/2024	It was agreed that Dr Arundel's declaration would not prevent him from participating in discussions on this appraisal.
Stuart Mealing	Committee Member	Non-Financial Professional interests	I have undertaken work for Novartis in a different therapy area (Still's Disease) in the recent past (<2 years) but have never worked in PNH for them or any of the potential other stakeholders.	10/04/2024	It was agreed that Stuart Mealing's declaration would not prevent him from participating in discussions on this appraisal.

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Emtiyaz Chowdhury	Committee Member	Non-Financial Professional interests	I am employed by Parexel, a clinical research organisation that offers services to the manufacturer. However, I have had not personally provided any consulting services to the manufacturer for this technology.	10/04/2024	It was agreed that Emtiyaz Chowdhury's declaration would not prevent him from participating in discussions on this appraisal.
Tina Garvey	Committee Member	Non-Financial Professional interests	My employer (Retina UK) has received donations from Novartis. October 2023 (professional honorarium), £450. June 2022, £13,200.	10/04/2024	It was agreed that Tina Garvey's declaration would not prevent her from participating in discussions on this appraisal.
Morag Griffin	Clinical expert	Financial interest	Advisory board: July 2023: £2226, June 2022: £1113	10/04/2024	It was agreed that Morag Griffin's declaration would not prevent her from providing expert advice to the committee.
Morag Griffin	Clinical expert	Non-Financial professional interests	PI of Iptacopan clinical trial: ongoing	10/04/2024	It was agreed that Morag Griffin's declaration would not prevent her from providing expert advice to the committee.

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Dr Austin Kulasekararaj	Clinical expert	Financial interest	<ul style="list-style-type: none"> Novartis- Related to <i>Iptacopan</i>- Scientific advisory boards, speaker fees and data monitoring committee. Alexion/Astra Zeneca- Related to <i>Eculizumab</i>, <i>Ravulizumab</i> and <i>Danicopan</i>- Scientific advisory boards, and speaker fees SOBI- Related to <i>Pegcetacoplan</i>- Scientific advisory board and speaker fees Roche Pharmaceuticals- Related to <i>Crovalimab</i>- Scientific advisory board and speaker fees Amgen- Related to <i>Eculizumab biosimilar</i> - Scientific advisory board and speaker fees Samsung- Related to <i>Eculizumab biosimilar</i>- Scientific advisory board and speaker fees 	10/04/2024	It was agreed that Dr Kulasekararaj 's declaration would not prevent him from providing expert advice to the committee.

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Dr Austin Kulasekararaj	Clinical expert	Non-Financial professional interests	<ul style="list-style-type: none"> • Arrowhead- Scientific advisory board • Silence Therapeutics- Scientific advisory board • Regeneron- Data monitoring committee • Published in scientific journals on management of PNH and emerging novel therapies (including Iptacopan and all the comparators) • Medical advisor for PNH UK support group (a dedicated PNH patient support organisation) • Involved in several Phase 1-4 clinical trials of drug development in PNH, including Iptacopan trials. PI for both APPLY and APPOINT PNH Phase 3 trials using Iptacopan and Steering Committee member for the APPLY PNH trial. • Currently Principal and Chief investigator for several ongoing 	10/04/2024	It was agreed that Dr Kulasekararaj 's declaration would not prevent him from providing expert advice to the committee.

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			trials in PNH (Commodore 1 &2, BCX9930, Danicopan, Vemircopan).		
Alex Naylor	Patient expert	Financial interest	<ul style="list-style-type: none"> • Novartis <ul style="list-style-type: none"> o 15.08.23 - £619.50 - providing patient advocate perspective as part of the Novartis Global Oncology Patient Involvement Panel (GOPIP) on awareness raising campaign, preparation for a September 2023 patient advisory board, working together o 06.06.23 - £737.50 - providing patient advocate perspective re discussing awareness raising campaign; proposed patient engagement plans o 30.06.23 - £236.00 - providing patient advocate perspective re advice on sharing trial results and patient engagement strategy o 15.11.22 - £649.00 - providing patient advocate perspective re 	10/04/2024	It was agreed that Alex Naylor's declaration would not prevent him from providing expert advice to the committee.

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			<p>informed consent form and future GOPIP involvement</p> <ul style="list-style-type: none"> o 01.09.22 - £383.50 - providing patient advocate perspective on switch study o 14.11.23 - £501.50 - advice provided regarding market research study, patient advisory board content • Roche Products (crovalimab) o 25.05.23 - £1,125.00 - preparation, attendance and follow up for 2 day patient advisory board o 09.11.23 - £750.00 - attending patient advisory board meeting • Swedish Orphan Biovitrum (pegcetacoplan) o 30.09.22 - £948.75 - providing patient advocate perspective on: developing symptom app; 		

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			ethnographic research into PNH burden of illness; and patient survey		