

Technology Advisory Committee C Interests Register

Topic: Danicopan as an add-on treatment to a C5 inhibitor for treating extravascular haemolysis in adults with paroxysmal nocturnal haemoglobinuria [ID5088]

Publication Date: 23/10/2024

Name	Role with NICE	Type of interest	Description of interest	Interest declared	Comments
Dr Richard Nicholas	Committee Member	Direct – financial	Dr Nicholas has carried paid advisory boards for Roche and Novartis in an unrelated disease area (multiple sclerosis).	16/04/2024 16/06/2024	It was agreed that Dr Nicholas' declaration would not prevent him from participating in discussions on this appraisal.
Satish Venkateshan	Committee Member	Direct – financial	Regeneron has been developing pozelimab which targets complement factor C5 for Paroxysmal nocturnal haemoglobinuria and other conditions. Satish works for Regeneron pharmaceuticals/biotech company. He also owns shares in the company and has stock options.	18/04/2024 12/06/2024	It was agreed that Satish's declaration would not prevent him from participating in discussions at the first committee meeting (May 2024). Following concerns raised by a stakeholder after this committee meeting, it was agreed that Satish would withdraw from further participating on this appraisal.

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Maria Piggin	Patient Expert	Indirect organisational interests	<p>Maria is Chair of the PNH Global Alliance which has received grant funding from Alexion, Roche, Novartis, Regeneron and Amgen for two projects: the PNH Advocate Development Programme and a Global PNH Awareness Day.</p> <p>PNH Support has received the following:</p> <p>Novartis</p> <ul style="list-style-type: none"> • 30.04.24 - £560.50 - advice provided regarding patient safety programme and discussions regarding patient engagement activities. • 14.11.23 - £501.50 - advice provided regarding market research study, patient advisory board content. • 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. • 06.06.23 - £737.50 - providing patient advocate perspective regarding discussing awareness 	14/04/2024	It was agreed that Maria's declaration would not prevent her from providing expert advice to the committee.

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			<p>raising campaign; proposed patient engagement plans.</p> <ul style="list-style-type: none"> 30.06.23 - £236.00 - providing patient advocate perspective regarding advice on sharing trial results and patient engagement strategy. <p>Alexion Pharmaceuticals (danicopan eculizumab, ravulizumab)</p> <ul style="list-style-type: none"> 01.09.23 - £190 - providing a patient advocate perspective on trial design <p>Alexion AstraZeneca Rare Diseases, Roche (crovalimab) and Swedish Orphan Biovitrum (pegcetacoplan) contributed to funding for a National Community Survey project which surveyed 7 rare disease communities including PNH Support. The report of this survey called "Rare Voices" can be found at the link here.</p> <p>Roche Products (crovalimab)</p> <ul style="list-style-type: none"> 25.05.23 - £1,125.00 - preparation, attendance and follow up for 2 day patient advisory board 09.11.23 - £750.00 - attending patient advisory board meeting 		

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Dr Talha Munit	Clinical Expert	Direct - financial	<p>Dr Munit has been part of advisory boards for AstraZeneca, Janssen, Alexion, Sobi, BeiGene, and Abbvie.</p> <p>Dr Munit has received honoraria from AstraZeneca, Janssen, Alexion, Sobi, BeiGene, and Gilead</p>	25/10/2023	It was agreed that Dr Munit's declaration would not prevent him from providing expert advice to the committee.
Dr Richard Kelly	Clinical Expert	Direct - financial	<ul style="list-style-type: none"> • November 2022 - Speaker fees for lectures for Sobi and Alexion AstraZeneca Rare Disease • November 2022 - National co-ordinator for the Alexion PNH registry - Alexion AstraZeneca Rare Disease • November 2022 - Consultancy work - Alexion AstraZeneca Rare Disease • March 2023 - Advisory board participation - Sobi • October 2023 - Speaker fees for a webinar - Alexion AstraZeneca Rare Disease • November 2023 - Speaker fees for a lecture - 2 meetings/speaker fees - Alexion AstraZeneca Rare Disease 	<p>07/10/2024</p> <p>16/10/2023</p>	It was agreed that Dr Kelly's declaration would not prevent him from providing expert advice to the committee.

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			<ul style="list-style-type: none"> December 2023 - Advisory board participation - Alexion AstraZeneca Rare Disease 		
Morag Griffin	Clinical Expert	Direct Financial	<p>Alexion AstraZeneca</p> <ul style="list-style-type: none"> July 2023: General advisory board October 2023: Danicopan related advisory work May 2024: Danicopan related advisory work <p>Morag Griffin was an invited speaker for Alexion rare disease sponsored symposium</p> <ul style="list-style-type: none"> 1: British society of haematology: Not related to Danicopan; PNH presented in general 2: Northern Ireland meeting on PNH: Not related to Danicopan: PNH presented in general 	27/06/2024	It was agreed that Morag Griffin's declaration would not prevent her from providing expert advice to the committee.
		Direct-non-financial	<ul style="list-style-type: none"> PI of ALXN 2040-301/303 clinical trial for danicopan add on therapy Advisory board/speaker fees/consultancy: Pfizer, Sobi, Amgen, Regeneron, Novartis 		