

Technology Advisory Committee B Interests Register

ID3822 Burosumab for treating X-linked hypophosphataemia in adults

Publication Date: Tbc.

Name	Role with NICE	Type of interest	Description of interest	Interest declared	Interest ceased	Comments
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Margarita Vidal	Patient expert	Direct – non-financial	<p>Margarita is a patient with XLH, receiving burosumab (the technology) through the Early Access Program.</p> <p>From February 1st, 2022 – January 31st, 2023</p> <p>XLH UK received £21,000 in financial support from Kyowa Kirin which represented 95% of its income.</p> <p>The financial support, received in January 2023, from Kyowa Kirin has been allocated to deliver on three priorities identified in our 2023 strategic plan:</p> <p>Patient event: £3,000 for venue, equipment and marketing; £6,000 towards evidence underpinning fresh insights.</p> <p>Improve awareness of the charity in UK NHS</p>	05/09/2023	N/A	It was agreed that Margarita's declaration would not prevent her from providing expert advice to the committee.
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			<p>specialist centres: £2000 for materials and printing.</p> <p>Upgrade of website: £10,000 for design of a secure, off the shelf wireframe which can be maintained by non-specialist volunteers.</p> <p>(Kyowa Kirin were not involved in any of the above priorities)</p> <p>In our current financial year, from February 1st, 2023 – January 31st, 2024</p> <p>XLH UK has received no financial support from Kyowa Kirin during our current financial year.</p> <p>Our income to date from public donations and support has been £14,292.</p>			
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Margarita Vidal	Patient expert	Direct – non-financial	<p>The International XLH Alliance (IXLHA) is also a registered charity in England and Wales and is a collaborative network of XLH patient organisations.</p> <p>It's financial year also runs from February 1st – January 31st</p> <p>From February 1st, 2022 – January 31st, 2023</p> <p>IXLHA received a restricted grant of £57,280 from Kyowa Kirin which represented 71% of its income.</p> <p>The financial support, received in 2022 from Kyowa Kirin helped support us in being able to:</p> <p>Create the 3rd International XLH</p>	05/09/2023		<p>It was agreed that Margarita's declaration would not prevent her from providing expert advice to the committee.</p>
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			<p>Symposium in Dublin, Ireland in 2022.</p> <p>To bring together IXLHA member organisations for a face-to-face strategy, improvement and training meeting also in Dublin, Ireland in 2022.</p> <p>(Kyowa Kirin were not involved in the programme or planning of either event)</p> <p>In our current financial year, from February 1st, 2023 – January 31st, 2024, IXLHA received:</p> <p>£515 from Kyowa Kirin Australia as unrestricted donation in May.</p> <p>£175 compensation from Kyowa Kirin for speaking at a private industry event. (as declared on .2 below</p>			
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Kassim Javaid	Patient expert	Direct – non-financial	<p>From February 1st, 2022 – January 31st, 2023</p> <p>XLH UK received £21,000 in financial support from Kyowa Kirin which represented 95% of its income.</p> <p>The financial support, received in January 2023, from Kyowa Kirin has been allocated to deliver on three priorities identified in our 2023 strategic plan:</p> <p>Patient event: £3,000 for venue, equipment and marketing; £6,000 towards evidence underpinning fresh insights.</p> <p>Improve awareness of the charity in UK NHS specialist centres: £2000 for materials and printing.</p> <p>Upgrade of website: £10,000 for design of a</p>	05/09/2023	N/A	It was agreed that Kassim's declaration would not prevent him from providing expert advice to the committee.
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Kassim Javaid	Patient expert	Direct – non-financial	<p>The International XLH Alliance (IXLHA) is also a registered charity in England and Wales and is a collaborative network of XLH patient organisations.</p> <p>It's financial year also runs from February 1st – January 31st</p> <p>From February 1st, 2022 – January 31st, 2023</p> <p>IXLHA received a restricted grant of £57,280 from Kyowa Kirin which represented 71% of its income.</p> <p>The financial support, received in 2022 from Kyowa Kirin helped support us in being able to:</p> <p>Create the 3rd International XLH</p>	05/09/2023		It was agreed that Kassim's declaration would not prevent him from providing expert advice to the committee.
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Richard Keen	Clinical expert	Direct – financial	<p>Consultancy work for Kyowa Kirin in the field of XLH and its treatment</p> <p>Honorarium from Kyowa Kiron for lectures on XLH</p>	05/09/2023	N/A	It was agreed that Richard's declaration would not prevent him from providing expert advice to the committee.
Richard Keen	Clinical expert	Direct – non-financial	<p>Managing patients treated with Burosumab through an Early Access Programme funded by Kyowa Kirin</p> <p>Medical advisor and advocate for XLH-UK a patient charity.</p>	05/09/2023	N/A	It was agreed that Richard's declaration would not prevent him from providing expert advice to the committee.

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