



Transparency of Payments to Patient Organisations, Members of the Public and Joint Working in 2023

The pharmaceutical industry is committed to providing a service that benefits patients and ensuring patient safety by operating in a professional, ethical, and transparent manner to ensure the appropriate and rational use of medicines and to support the provision of high quality healthcare. All interactions with patients and other stakeholders must comply with all applicable laws and regulations. The industry is also committed to ensuring that transparency is respected and that it is open about its activities and interactions with all stakeholders and encourage their stakeholders to act with the same openness.

The NHS and the pharmaceutical industry share a common goal in improving patient outcomes and this has been the foundation of collaborative working projects. The potential of such projects to deliver improvements that benefit patients has been proven in a range of services and therapies. Payments relating to Joint Working agreements will be disclosed via the company website and details will be given as to the NHS partner, the nature of the engagement and the amount paid. Information specific to Joint Working is disclosed prior to the project starting and updated throughout the course of the project.

Kyowa Kirin Ltd and Kyowa Kirin International believe it is important to be transparent regarding interactions with Healthcare Professionals, Healthcare Organisations, the NHS, with Patient Organisations and members of the public (including patients and journalists). Transfers of value (including payments) are disclosed via the company website (<https://international.kyowa-kirin.com/transparency.html>). Details will be given as to the Patient Organisation, the nature of the engagement and the amount paid. These details are updated annually.

Listed below you will find all financial interactions that Kyowa Kirin Limited and Kyowa Kirin International has had with Patient Organisations in the UK and Ireland during 2023. This includes financial donations to help with the services provided to patients, carers, and family members. Kyowa Kirin has made every effort to ensure the accuracy of this data.

Payments made to Healthcare Professionals (HCPs) and Healthcare Organisations (HCOs) are disclosed separately on the [Kyowa Kirin website](#) along with methodological notes explaining the manner in which transparency is managed by the company.

All payments are inclusive of VAT where applicable.

Please contact kki_compliance_northerncluster@kyowakirin.com for further information.

The United Kingdom of Great Britain and Northern Ireland

<p>Lymphoma Action UK 3 Cromwell Court New Street Aylesbury Buckinghamshire HP20 2PB</p> <p>Registered charity in England & Wales (1068395) & in Scotland (SC045850)</p> <p>https://lymphoma-action.org.uk/</p>	£2520	Fee for service: KKI-led CTCL Awareness Campaign
	£10000	Financial support towards the costs of a new position within Lymphoma Action – that of Project Lead – Healthcare Professional Education Service Development. This 12-month Project Lead role
<p>Genetic Alliance UK 3rd Floor 86-90 Paul Street London EC24 4NE</p> <p>Registered charity nos. 1114195 & SC039299</p> <p>https://geneticalliance.org.uk/</p>	£70	Fee-for-service: KKI-led Severity Modifier Roundtable
	£2850	Fee-for-service: Sex based inequalities in Rare Diseases project
	£280	Fee-for-service: KK-led Rare Diseases Roundtable at the Senedd
	£5000	Signposting Support - Turning www.geneticalliance.org.uk into a leading information and signposting hub for the UK's rare disease community
	£12800	Funding towards Genetic Alliance's Rare Disease UK events
	£3000	Funding Support for 2023 Core Funding
<p>XLH International Alliance / XLH UK 21 Providence Street Greenhithe Kent DA9 9AA</p> <p>Registered charity no. 1182964 in England Wales</p> <p>https://xlhuk.org/</p> <p>International XLH Alliance</p> <p>https://xlhalliance.org/</p>	£1050	Fee-for-service: XLH Framework Implementation
	£21000	Funding to Support for Patient Event in Bristol, Website Upgrade & Improving awareness of the charity in UK NHS specialist centres
	£212.85	Fee for services: Speaker at "Living with XLH – our patients' perspectives" session at KKI's XLH Matters meeting

	£261.30	Fee-for-service: Speaker at Internal Kyowa Kirin UK Conference
	£105	Fee-for-service: speaker at Paediatric SMC Advisory Board regarding Burosumab
	£834.50	Fee-for-service: KK-led Rare Diseases Roundtable at the Senedd (Wales)
<p>MSUK Centurion House, 129 Deansgate, Manchester M3 3WR https://metabolicsupportuk.org/ Registered no. 1089588 in England & Wales</p>	£ 1050	Fee-for-service: XLH Framework Implementation
<p>Alstrom 4 St Kitts Close, Torqya, Devon TQ2 7GD https://www.alstrom.org.uk/what-is/ Charity No. 1071196</p>	£1140	Fee-for-service: Sex based inequalities in Rare Diseases KKI-led project
<p>Metabolic Support Centurion House, 129 Deansgate, Manchester M3 3WR https://metabolicsupportuk.org/ Registered no. 1089588 in England & Wales</p>	£798	Fee-for-service: Sex based inequalities in Rare Diseases KKI-led project
<p>M4RD % Analogue Wonderland, Unit 12 Treadaway Technical Centre Treadaway Hill, Loudwater, High Wycombe, Bucks HP10 9RS https://www.m4rd.org/ Charity No. 1183996</p>	£10000	Funding Support for Annual Work Programme 2023
<p>IPPOSI 77 Camden Street Lower, Dublin 2, D02 XE80 https://www.ipposi.ie/</p>	€8500	Funding for 2023 Corporate Membership

Registered Company Number 408258/CRA number 20062934/ CHY Number 17079		
Leukaemia Care Birch Court Blackpole East Worcester WR3 8SG Registered charity no. 1183890 https://www.leukaemiacare.org.uk/	£5000	Funding Support for 2023 Core Funding
Rare Disease Ireland Carmichael House, North Brunswick Street, Dublin 7, Ireland https://rdi.ie/ Charity Number 105261	€5000	Funding for 2023 Membership of the Industry Roundtable of Rare Diseases Ireland
Brittle Bone Society 30 Guthrie Street, Dundee, DD1 5BS https://www.brittlebone.org/ Charity Number SCO50854	£10000	Funding support for Brittle Bone Society-led 1. Parliamentary Events x 2, Holyrood and Westminster), 2. HCP Event x 1 (Launching Rare Network)
The Patient Association PO Box 935, Harrow, Middlesex, HA1 3YJ https://www.patients- association.org.uk/ Charity Number 1606733	£3000	Funding Support for Core Funding
Cambridge Rare Disease Network c/o BCS Windsor House Station Road Great Shelford Cambridge CB22 5NE https://www.camraredisease.org/	£5000	Funding for Company Forum Membership



Charity Number 1166365		
Blood Cancer Alliance Blood Cancer UK Suite 31 Bonnington Bond 2 Anderson Place Edinburgh EH6 5NP https://www.bloodcanceralliance.org/		Funding Support for Health Information Transformation Project
Charity number 1202693	£3000	

Members of the public including patients	In 2023 Kyowa Kirin International worked with n.5 members of the public (including patients).
Journalists	Kyowa Kirin International did not work with any journalists in 2023