

Transparency of Payments to Patient Organisations and Joint Working

The pharmaceutical industry is committed to ensuring the transparency of relationships with Patient Organisations.

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 and with Patient Organisations. Transfers of value (including payments) are disclosed via the company website (<https://international.kyowa-kirin.com/uk/transparency/>). Details will be given as to the Patient Organisation, the nature of the engagement, the amount paid and 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 2021. 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. Kyowa Kirin has a commitment to supporting Patient Organisations in an ethical manner which is transparent, respectful and in alignment with the ABPI and IPHA Codes of Practice.

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>The Royal Osteoporosis Society Manor Farm Skinners Hill Camerton Bath BA2 0PJ</p> <p>Registered charity no. 1102712</p> <p>https://theros.org.uk/</p>	£12,000	Investor Level Membership of the Bone Health Partnership
	£5,400	Payment for space for an exhibition stand at a Royal Osteoporosis Society professional educational event for UK Healthcare Professionals
<p>Metabolic Support UK 5 Hilliards Court Sandpiper Way Chester Business Park Chester CH4 9PQ</p> <p>Registered charity No. 10895588</p> <p>https://www.metabolicsupportuk.org/</p>	£10,000	Kyowa Kirin provided support to the delivery of Metabolic Support's Strategy including individual support for people with metabolic conditions, awareness raising and community's empowerment
	£280.00	Participation in an Advisory Board meeting
	£5,000	Kyowa Kirin was a bronze sponsor at Metabolic Support UK's Rare Thinking Festival
	£455.00	Participation in an Advisory Board meeting
<p>Blood Cancer Alliance c/o Atlas Communications ``Partners 23 West Lodge Avenue London W3 9SE</p> <p>https://www.bloodcanceralliance.org/</p>	£18,000	Donation to the Patient Organisation to help its focus of key policy strategies
<p>Blood Cancer UK 39 Eagle Street Holborn London WC1R 4TH</p> <p>Registered charity no. 216032</p> <p>https://bloodcancer.org.uk/</p>	£5,000	Grant to support the Blood Cancer UK COVID-19 Emergency Appeal.

<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>	<p>£14,000</p>	<p>Core funding to support Lymphoma Action's key projects including support services. Webinars and publications.</p>
<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>	<p>£10,000</p>	<p>Donation to support funding of the Genetic Alliance UK Rare Disease Day.</p>
<p>Cancer 52 c/o Teenage Cancer Trust Third Floor 93 Newman Street London W1T 3EZ</p> <p>https://www.cancer52.org.uk/</p>	<p>£10,000</p>	<p>Annual membership of the Patient Organisation's corporate supporter's programme.</p>
<p>European Parkinson's Disease Association Kings Lodge London Road West Kingsdown Sevenoaks Kent TN15 6AR</p> <p>https://www.epda.eu.com/</p>	<p>£9,047.32</p>	<p>Grant to support the general funding of the activities of the organisation.</p>
	<p>£9,047.32</p>	<p>Donation to contribute towards the costs of events organised by the Association.</p>
	<p>£716.26</p>	<p>Participation in an Advisory Board meeting</p>

<p>International Alliance of Patients Organisations CAN Mezzanine 49-51 East Road London N1 6AH</p> <p>Registered charity no. 1155577</p> <p>https://www.iapo.org.uk/</p>	<p>£356.13</p>	<p>Participation in an Advisory Board meeting</p>
<p>The Patients Association PO Box 935 Harrow Middlesex HA1 3YJ</p> <p>Registered charity no. 1006733</p> <p>https://www.patients-association.org.uk/</p>	<p>£356.13</p>	<p>Participation in an Advisory Board meeting</p>
<p>Rare Disease UK c/o Genetic Alliance UK CAN Mezzanine 49-51 East Road London N1 6AH</p> <p>Registered charity no. 1114195 in England Wales & SCO39299 in Scotland</p> <p>https://www.raredisease.org.uk/</p>	<p>£12,000</p>	<p>Kyowa Kirin provided support to Rare Disease UK (RDUK) to become a member of its industry support group. This contribution enabled Rare Disease UK to deliver a number of key activities to help those affected by rare conditions.</p>
<p>https://www.raredisease.org.uk/</p>	<p>£245.00</p>	<p>Genetic Alliance participated in an internal Kyowa Kirin Lunch & Learn to share Genetic Alliance's mission and priorities</p>
<p>XLH International Alliance / XLH UK 21 Providence Street Greenhithe Kent DA9 9AA</p>	<p>£420.00</p>	<p>Participation in a policy round table meeting</p>
<p>Registered charity no. 1182964 in England Wales</p>	<p>£280.00</p>	<p>Participation in a media round table meeting</p>
<p>https://xlhuk.org/</p>	<p>£280.00</p>	<p>Participation in an Advisory Board meeting</p>
<p>International XLH Alliance https://xlhalliance.org/</p>	<p>£455.00</p>	<p>Participation in an Advisory Board meeting</p>

<p>Cambridge Rare Disease Network (CRDN) c/o BCS Windsor House Station Court Station Road Great Shelford Cambridge CB22 5NE</p> <p>Registered charity no. 1166365</p> <p>https://www.camraredisease.org/</p>	<p>£5,000</p>	<p>Kyowa Kirin was a sponsor at Cambridge Rare Disease Network's Rare Summit 21</p>
<p>Leukaemia Care 1 Birch Court Blackpole East Worcester WR3 8SG</p> <p>Registered charity no. 1183890</p> <p>https://www.leukaemiacare.org.uk/</p>	<p>£10,000</p>	<p>Core funding to support Leukaemia Care's key projects in 2021</p>
<p>Neurological Alliance c/o Parkinson's UK 125 Vauxhall Bridge Road London SW1 1EJ</p> <p>Registered charity no. 1039034</p> <p>https://www.neural.org.uk/</p>	<p>£10,888</p>	<p>Kyowa Kirin is a corporate partner of Neurological Alliances and is a member of its Industry Reference Group (IRG)</p>
<p>Fibrous Dysplasia Support Society UK (FDSSUK) 82 Nottingham Road Somercotes Alfreton DE55 4LY</p> <p>Registered charity no. 1175622</p> <p>https://www.fdssuk.org.uk/</p>	<p>£280.00</p>	<p>FDSSUK participated in a policy roundtable on improving care for people with rare diseases</p>

The Republic of Ireland

<p>Irish Platform for Patients Organisations, Science and Industry Limited 77 Camden St Lower Dublin 2 D02 XE80</p> <p>Registered company no. 408258</p> <p>https://www.ipposi.ie/</p>	<p>€8500.00</p>	<p>Kyowa Kirin provided support to IPPOSI to become a corporate member</p>
<p>Rare Diseases Ireland Carmichael House North Brunswick Street Dublin 7</p> <p>Registered company no: 140743</p> <p>https://rdi.ie/</p>	<p>€3,500.00</p>	<p>Kyowa Kirin is one of Rare Disease Ireland corporate supporters and was a member of its Roundtable of Companies for the calendar year 2021</p>

Joint Working:

Joint Working describes situations where, for the benefit of patients, NHS and industry pool skills, experience and/or resources for the joint development and implementation of patient-centred projects and share a commitment to successful delivery. Kyowa Kirin Limited and Kyowa Kirin International will comply with Joint Working policies as defined by the ABPI Code of Practice in all discussions and arrangements.

<p>Name of Joint Working Project</p>	<p>No joint working Agreements were discussed or undertaken in 2021</p>
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