



Transparency of Payments to Patient Organisations and Joint Working

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. Payments made to Patient Organisations are disclosed via the company website. Details will be given as to the Patient Organisation, the nature of the engagement, the amount paid and updated annually.

Patients benefit from the collaboration between Healthcare Professionals and the pharmaceutical industry through the development and appropriate use of innovative treatments that aim to improve patient care. Healthcare Professionals and pharmaceutical companies regularly work together throughout the life of a medicine. As an integral part of the medicines development process it is entirely appropriate that fees are paid to Healthcare Professionals to reimburse them for their time and expertise.

The pharmaceutical industry is committed to ensuring the transparency of relationships with Healthcare Professionals. Across Europe the industry announced its intention to disclose payments to Healthcare Professionals at an individual level annually.

The NHS and the pharmaceutical industry share a common goal in improving patient outcomes and this has been the foundation of Joint 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. Such information is disclosed prior to the project starting and updated throughout the course of the project.

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 2020. 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.

United Kingdom

<p>The Royal Osteoporosis Society Manor Farm Skinners Hill Camerton Bath BA2 0PJ</p> <p>Royal Osteoporosis Society is a registered charity no. 1102712 in England and Wales, no. SC039755 in Scotland, and no. 1284 in Isle of Man. https://theros.org.uk/</p>	£12,000.00	Investor Level Membership of the Bone Health Partnership. The relationship exists at an organisational level (not product or brand) and provides a means by which a corporate member can demonstrate its commitment and show its support of the charity.
	£5,400.00	Payment for space for an exhibition stand at a Royal Osteoporosis Society professional educational event for UK healthcare professionals.
<p>Brittle Bone Society Grant-Paterson House 30 Guthrie Street Dundee DD1 5SB</p> <p>Brittle Bone Society is a registered Charity No. 272100 in England and Wales, SC010951 in Scotland https://brittlebone.org/</p>	£10,000.00	Donation to support the general funding of society activities, including frontline patient and healthcare professional support via access to their Support Development Officer and signposting to a wide range of specialised services.
<p>Metabolic Support UK 5 Hilliards Court Sandpiper Way Chester Business Park Chester CH4 9PQ</p> <p>MSUK is a registered Charity No. 10895588 in England and Wales, SCO44634 in Scotland https://www.metabolicsupportuk.org/</p>	£10,000.00	Sponsorship of the Metabolic Support UK annual conference
	£10,000.00	Donation to support of Metabolic Support UK 's work to build and expand the XLH patient community.
	£540.00	Metabolic UK supported Kyowa Kirin to fulfil SMC data collection requirements.

<p>Blood Cancer Alliance c/o Atlas Communications ``Partners 23 West Lodge Avenue London W3 9SE</p> <p>https://www.bloodcanceralliance.org/</p>	<p>£18,000.00</p>	<p>Donation to the patient organisation to help its focus of three key policy areas:</p> <ol style="list-style-type: none"> 1. Raising awareness of blood cancer, to improve early diagnosis and provision for patients within health policy and care design. 2. Ensuring blood cancer patients have the emotional and psychological care and support that they need. 3. Securing access to the most effective treatments for blood cancer patients.
<p>Blood Cancer UK 39 Eagle Street Holborn London WC1R 4TH</p> <p>Blood Cancer UK is the trading name of Bloodwise, 39-40 Eagle Street, London, WC1R 4TH. A company limited by guarantee 738089 (registered in England and Wales). Registered charity 216032 (England and Wales) SCO37529 (Scotland)</p> <p>https://bloodcancer.org.uk/</p>	<p>£5,000.00</p>	<p>Grant to support the Blood Cancer UK COVID-19 Emergency Appeal.</p>

<p>Lymphoma Action UK 3 Cromwell Court New Street Aylesbury Buckinghamshire HP20 2PB</p>	<p>£245.00</p>	<p>Fee for participation in a round table discussion to educate attending media about CTCL including diagnosis, symptoms, and impact of the disease. Highlight the lack of awareness in the UK and key issues for those living with the disease. Obtain insights and guidance on how we can amplify this disease in the media to increase public awareness and understanding of CTCL</p>
<p>Lymphoma Action is a registered charity in England and Wales (1068395) and in Scotland (SC045850) https://lymphoma-action.org.uk/</p>	<p>£14,000.00</p>	<p>Funding to support the patient organisation to develop and further promote Lymphoma TrialsLink, its clinical trials information service that delivers impartial, understandable, and realistic information on lymphoma-specific trials and research studies across the UK.</p>

<p>Genetic Alliance UK 3rd Floor 86-90 Paul Street London EC24 4NE</p> <p>Registered charity numbers: 1114195 & SC039299 https://geneticalliance.org.uk/</p>	<p>£10,000.00</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>£10,000.00</p>	<p>Annual membership of the patient organisations 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>	£9,047.32	Grant to support the general funding of the activities of the organisation.
	£9,047.32	Donation to contribute towards the delivery costs of events organised by the association.
	£716.26	Fees and expenses for participation by two members of the organisation in a patient organisation Advisory Board.
<p>International Alliance of Patients Organisations CAN Mezzanine 49-51 East Road London N1 6AH</p> <p>IAPO is a UK-registered charity (Number 1155577) https://www.iapo.org.uk/</p>	£356.13	Fees and expenses for participation by a member of the organisation in a patient organisation Advisory Board.
<p>The Patients Association is a registered charity in England and Wales (1006733)</p>	£356.13	Fees and expenses for participation by a member of the organisation in a patient organisation Advisory Board.
<p>Rare Disease UK c/o Genetic Alliance UK CAN Mezzanine 49-51 East Road London N1 6AH</p> <p>Genetic Alliance UK is a registered Charity No. 1114195 in England Wales, SCO39299 in Scotland https://www.raredisease.org.uk/</p>	£12,000.00	Payment for Rare Disease UK Industry Membership.
	£6,000	Kyowa Kirin provided support to Rare Disease UK (RDUK) for the organisation to run Rare Disease Day 2020 (https://www.raredisease.org.uk/rduknews/rare-disease-day-2020-2/)

XLH International Alliance / XLH UK 21 Providence Street Greenhithe Kent DA9 9AA XLH UK is a registered Charity No. 1182964 in England Wales https://xlhuk.org/ International XLH Alliance https://xlhalliance.org/	£7,311.55	Donation to support XLH UK 's work to support the XLH patient community.
	£50,000.00	Grant to support the general funding of the activities of the organisation in 2020.
	£23,040.00	Funding to provide XLH UK with strategic support through the engagement of an external consultant, to improve the business focus of the organisation.
	£356.13	Payment to support participation by a member of the organisation in a patient organisation Advisory Board.

Republic of Ireland

Irish Platform for Patients Organisations, Science and Industry Limited 77 Camden St Lower Dublin 2 D02 XE80 Registered Company Number 408258 https://www.ipposi.ie/	€2125.00	Payment for Annual Membership of the organisation.
Rare Diseases Ireland Carmichael House North Brunswick Street Dublin 7 https://rdi.ie/	€3,500.00	Payment for Annual Membership of the organisation.

All payments are inclusive of VAT where applicable.

Joint Working:

Joint Working describes situations where, for the benefit of patients, NHS and industry organisations 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. Such Joint Working policies are under review as part of the ABPI Code of Practice 2021.

Name of Joint Working Project	No joint working Agreements were discussed or undertaken in 2020
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