



Payments to Patient Organisations, Members of the Public and Collaborative Working in 2024

Background

The pharmaceutical industry is committed to 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. The industry aims to provide a service that ensures patient safety and benefits. 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.

We 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's international website (<https://kyowakirininternational.com/who-we-are/responsibility/>). Details will be given as to the Patient Organisation, the nature of the engagement, the amount paid, and, when provided, the ratio of the amount provided against total earnings for that calendar year. These details are updated annually and every effort is made to ensure the accuracy of this data. Kyowa Kirin UK Ltd and Kyowa Kirin International PLC remains steadfast in its commitment to working with Patient Organisations in a manner that ensures clarity of purpose for all parties, transparency, respect, and independence. Kyowa Kirin will not provide financial support that exceeds 50% of total earnings for the Patient Organisation in that calendar year.

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 Collaborative and 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.

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

All payments are inclusive of VAT where applicable.

Contact:

Please contact our Compliance Team for further information regarding disclosure

kki_compliance_northerncluster@kyowakirin.com

Useful reading:

<https://www.abpi.org.uk/reputation/disclosure-uk/about-disclosure-uk/definitions-disclosure/>

<https://www.abpi.org.uk/publications/disclosure-uk-faqs/>

<https://www.abpi.org.uk/publications/working-together-a-guide-for-the-nhs-healthcare-organisations-and-pharmaceutical-companies/>

<https://www.abpi.org.uk/publications/best-practice-guidance-supporting-patient-organisations-to-report-industry-funding/>

Payments to Patient Organisations:

The United Kingdom of Great Britain and Northern Ireland

<p>Brittle Bone Society (BBS) Grant-Paterson House 30 Guthie Street Dundee DD1 5BS</p> <p>Registered charity (SC050854) and company limited by guarantee (SC677346) https://www.brittlebone.org/</p> <p>Our support represented 5% of their overall income in 2024</p>	<p>£7,000</p>	<p>Arm's length s funding for various 2024 projects; :</p> <ul style="list-style-type: none"> • A patient day supported by Great Ormond Street Hospital • Education: BBS works with various educational institutions • Impact: measuring progress in healthcare improvements • Rare Bone Alliance collaboration <p>KKI/GB/NPR/0251</p>
	<p>£15,000</p>	<p>Arm's length s funding for various 2025 projects including: Secretariat of Adult Rare Bone Disease Collaborative Network</p> <ul style="list-style-type: none"> • Rare Bone Alliance Parliamentary showcase of • Family Conference <p>Dundee July 2025 Events - BBS</p> <p>KKI/GB/NPR/0291</p>
<p>Lymphoma Action UK 3 Cromwell Court New Street Aylesbury Buckinghamshire HP20 2PB</p> <p>Registered charity in England & Wales (1068395) & in Scotland (SC045850) https://lymphoma-action.org.uk/</p> <p>Our support represented 0.47% of their overall income in 2024</p>	<p>£12,520</p>	<p>Arm's length funding for Lymphoma Action Helpline</p> <p>https://lymphoma-action.org.uk/support-you/helpline-services</p> <p>KKI/GB/NPR/0243</p>

The total funding provided by Kyowa Kirin equates to 0.47% total income for the organisation		
<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>Our support represented 3.84% of their overall income in 2024</p>	£15,000	Rare Diseases UK Industry Membership to allow the charity to deliver on key strategic priorities and activities KKI/GB/NPR/0245
	£5,000	Arm's length funding to support Genetics Alliance UK with the project 'How decisions are made with regard to healthcare delivery for the people of Scotland and to understand if this differs from other parts of the UK'. KKI/GB/NPR/0244
	£5,000	Arm's length funding to support Genetics Alliance UK with their project " Seeking a rare diagnosis ". KKI/GB/NPR/0246
	£5,000	Arm's length funding to support 'Rare Disease Day 2024' Rare Disease Day - Genetic Alliance KKI/GB/NPR/0283
<p>Medics for Rare Diseases (M4RD) c/o Analogue Wonderland Unit 12 Treadaway Technical Centre Treadaway Hill Loudwater High Wycombe HP10 9RS</p> <p>Medics4RareDiseases is a registered UK charity (1183996)</p> <p>https://www.m4rd.org/</p> <p>Our support represented 3.65% of their overall income in 2024</p>	£10,00	Arm's length funding to support M4RD's 'Annual work programme to provide rare disease training to medical students and to integrate a rare disease pathway' https://www.m4rd.org/m4rdresources/ KKI/GB/NPR/0250
	£15,000	Arm's length funding to support M4RD's 'Annual work programme M4RD 2025' https://www.m4rd.org/annual-reports/ KKI/GB/NPR/0286

<p>XLH UK 21 Providence Street Greenhithe Kent DA9 9AA</p> <p>Registered charity no. 1182964 in England Wales https://xlhuk.org/</p> <p>Our support represented 40% of their overall income in 2024</p>	<p>£5,407</p>	<p>Arm's length funding to support XLH UK an UK Adult XLH Pathway working with Clinicians Publication</p> <p>https://xlhuk.org/about-xlh-uk/</p> <p>KKI/GB/NPR/0242</p>
<p>Leukaemia Care 1 Birch Court Blackpole East Worcester WR3 8SG</p> <p>Registered charity no. 1183890 https://www.leukaemiacare.org.uk/</p> <p>Our support represented 0.36% of their overall income in 2024</p>	<p>£7,500</p>	<p>Arm's length funding to contribute to the charity's core 2024 activities</p> <p>https://www.leukaemiacare.org.uk/our-campaigns/</p> <p>KKI/GB/NPR/0252</p>
<p>Cambridge Rare Disease Network c/o BCS Windsor House Station Road Great Shelford Cambridge CB22 5NE</p> <p>Registered Charity Number: 1166365 https://www.camraredisease.org/</p> <p>Our support represented 5.5% of their overall income in 2024</p>	<p>£12,000</p>	<p>Gold Sponsor of RAREfest 24 and membership of the industry roundtable</p> <p>https://www.camraredisease.org/rarefest24/</p> <p>https://www.camraredisease.org/rare-disease-research-network/</p> <p>KKI/GB/NPR/0253</p>

<p>Blood Cancer UK (BCUK) (registered company address) 5-11 Theobalds Road London WC1X 8SH https://bloodcancer.org.uk/</p> <p>Our support represented 5% of their overall income in 2024</p>	£5,000	<p>Arm's length funding for BCUK's Service Transformation Project KKI/GB/NPR/0257</p>
	£10,000	<p>Arm's length funding for BCUK's healthcare professionals' Engagement Strategy KKI/GB/NPR/0296</p>
	£10,000	<p>Arm's length funding to support BCUK's Direct Referral Programme KKI/GB/NPR/0295</p>
<p>Myeloma UK 22 Logie Mill Beaverbank Business Park Edinburgh EH7 4HG</p> <p>Registered Charity No. SC026116 https://www.myeloma.org.uk/</p> <p>Our support represented 0.1% of their overall income in 2024</p>	£5,000	<p>Arm's length funding to support for its healthcare equalities programme Healthcare Inequalities Programme KKI/GB/NPR/0293</p>
<p>Northern Ireland Rare Disease Partnership (NIRDP)</p> <p>2 William Street Newtownards BT23 4AH Northern Ireland</p> <p>CCNI Charity number 105261 Company number N1611153 https://nirdp.org.uk/</p> <p>Our support represented 9% of their overall income in 2024</p>	£3,500	<p>Membership of NIRDP's Corporate Council https://nirdp.org.uk/northern-ireland-rare-disease-partnership-corporate-council-nirdp-cc/ KKI/GB/NPR/0254</p>

Payments to Members of the Public:

Members of the public including patients	In 2024 Kyowa Kirin International worked with 10 members of the public (including patients)
Journalists	In 2024 Kyowa Kirin International did not work with any journalists

The Republic of Ireland

<p>Rare Diseases Ireland Carmichael House North Brunswick Street Dublin 7 D07 RHA8 Ireland</p> <p>https://rdi.ie/</p>	<p>€5,000</p>	<p>Membership of Rare Diseases Ireland Round Table of Companies for 2024</p> <p>Industry – Rare Diseases Ireland</p> <p>KKI/GB/NPR/0271</p>
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Collaborative and Joint Working:

Collaborative and 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 Collaborative and Joint Working policies in all discussions and arrangements as defined by the ABPI Code of Practice.

Name of Collaborative or Joint Working Project	No Collaborative or Joint Working Agreements were discussed or undertaken in 2024
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