



## Transparency of Payments to Patient Organisations, Members of the Public and Joint Working in 2022

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/uk/transparency/>). 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 2022. 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](mailto:kki_compliance_northerncluster@kyowakirin.com) for further information.

The United Kingdom of Great Britain and Northern Ireland

|  |                |  |
|--|----------------|--|
| <p>Metabolic Support UK (MSUK)<br/>5 Hilliards Court<br/>Sandpiper Way<br/>Chester Business Park<br/>Chester<br/>CH4 9PQ</p> <p>Registered charity No. 10895588</p> <p><a href="https://www.metabolicsupportuk.org/">https://www.metabolicsupportuk.org/</a></p> | <p>£1,050</p>  | <p>MSUK participated in the implementation of a framework to support patients and families with X-linked hypophosphatemia (XLH)</p>  |
|  | <p>£10,000</p> | <p>Support for Phase 1 long-term strategy for MSUK that includes 'Clinical Trial Hub' Development, training modules for Access to Medicines and supporting Healthcare Inequalities initiatives</p> |
| <p>Brittle Bone Society<br/>Grant-Paterson House<br/>30 Guthie Street<br/>Dundee<br/>DD1 5BS</p> <p>Registered charity (SC050854) and company limited by guarantee (SC677346)</p> <p><a href="https://www.brittlebone.org/">https://www.brittlebone.org/</a></p> | <p>£0</p>      | <p>Brittle Bone Society participated in the implementation of a framework to support patients and families with X-linked hypophosphatemia (XLH)</p>  |

|   |                |   |
|---|----------------|---|
| <p>Lymphoma Action UK<br/>3 Cromwell Court<br/>New Street<br/>Aylesbury<br/>Buckinghamshire HP20 2PB</p> <p>Registered charity in England &amp; Wales (1068395) &amp; in Scotland (SC045850)</p> <p><a href="https://lymphoma-action.org.uk/">https://lymphoma-action.org.uk/</a></p> | <p>£450</p>    | <p>Lymphoma Action reviewed the patient information documentation relating to a clinical study sponsored by Kyowa Kirin International</p>                   |
|   | <p>£700</p>    | <p>Lymphoma Action kindly provided independent advise relating to the development of online resource to support Health Care Professionals</p>               |
|   | <p>£700</p>    | <p>Lymphoma Action kindly provided independent advise on the development of an information tool for Health Care Professionals and members of the public</p> |
|   | <p>£10,000</p> | <p>Support for core information and support services</p>  |

|  |                |   |
|--|----------------|---|
| <p>Genetic Alliance UK<br/>3rd Floor<br/>86-90 Paul Street<br/>London<br/>EC24 4NE</p>   | <p>£5,000</p>  | <p>To support the design and development of the website for the Organisation and production of a video relating to a Rare Disease Awareness Day</p>   |
| <p>Registered charity nos. 1114195 &amp; SC039299<br/><br/><a href="https://geneticalliance.org.uk/">https://geneticalliance.org.uk/</a></p>   | <p>£12,800</p> | <p>Rare Disease UK Industry Support renewal</p>   |
| <p>The Patients Association<br/>PO Box 935<br/>Harrow<br/>Middlesex HA1 3YJ<br/><br/>Registered charity no. 1006733<br/><br/><a href="https://www.patients-association.org.uk/">https://www.patients-association.org.uk/</a></p>   | <p>£5,000</p>  | <p>Kyowa Kirin provided support to The Patients Association to be a corporate member for 2022</p>   |
| <p>Medics for Rare Diseases<br/>c/o Analgoue Wonderland<br/>Unit 12 Treadaway Technical Centre<br/>Treadaway Hill<br/>Loudwater<br/>High Wycombe<br/>HP10 9RS<br/><br/>Medics4RareDiseases is a registered UK charity (1183996)<br/><br/><a href="https://www.m4rd.org/">https://www.m4rd.org/</a></p> | <p>£5,000</p>  | <p>To support this Organisation in its mission – ‘MR4D provides education about the relevance of rare disease to everyday clinical medicine and equips doctors to manage their patients effectively. Our ultimate aim is to speed up the journey to diagnosis and improve the patient experience’</p> |
| <p>Duchenne UK<br/>Unit G20, Shepherd’s Building<br/>Charecroft Way<br/>Hammersmith<br/>London<br/>W14 0EE<br/><br/><a href="https://www.duchenneuk.org/">https://www.duchenneuk.org/</a></p>  | <p>£140</p>    | <p>Duchenne UK kindly organised for a speaker to attend an internal company meeting to discuss the impact the diagnosis of Duchenne muscular dystrophy can have on a patient and family.</p>  |

|  |                |   |
|--|----------------|---|
| <p>XLH International Alliance / XLH UK<br/>21 Providence Street<br/>Greenhithe<br/>Kent DA9 9AA</p>  | <p>£280</p>    | <p>XLH UK kindly agreed for provide support to Kyowa Kirin to attend a public website to Shine a Light on the impact of X-linked hypophosphatemia (XLH) on the patient and family (<a href="#">Shine a Light on XLH Virtual Exhibition</a>)</p> |
| <p>Registered charity no. 1182964 in England Wales<br/><a href="https://xlhuk.org/">https://xlhuk.org/</a></p> <p>International XLH Alliance<br/><a href="https://xlhalliance.org/">https://xlhalliance.org/</a></p> | <p>£140</p>    | <p>XLH UK kindly agreed to provide support to Kyowa Kirin International by providing an expert speaker at a Proposed Framework on a Networked Service Model Launch Meeting</p>  |
|  | <p>£1050</p>   | <p>XLH UK kindly agreed for provide support to Kyowa Kirin International on the development of a national framework on supporting patients diagnosed with X-linked hypophosphatemia (XLH) and their families</p>                                |
| <p>Leukaemia Care<br/>1 Birch Court<br/>Blackpole East<br/>Worcester WR3 8SG</p> <p>Registered charity no. 1183890</p> <p><a href="https://www.leukaemicare.org.uk/">https://www.leukaemicare.org.uk/</a></p>        | <p>£10,000</p> | <p>Core funding to support Leukaemia Care's key projects in 2022</p>  |
| <p>Cambridge Rare Disease Network<br/>c/o BCS<br/>Windsor House<br/>Station Road<br/>Great Shelford<br/>Cambridge<br/>CB22 5NE</p>   | <p>£10,000</p> | <p>Support for Rarefest 2022 (<a href="#">Link here</a>). This is an annual meeting run independent of the supporting pharmaceutical industry.</p>  |

|   |               |  |
|---|---------------|--|
| <p>Blood Cancer Alliance<br/>         Blood Cancer UK<br/>         Suite 31<br/>         Bonnington Bond<br/>         2 Anderson Place<br/>         Edinburgh<br/>         EH6 5NP</p> <p><a href="https://www.bloodcanceralliance.org/">https://www.bloodcanceralliance.org/</a></p> | <p>£5,000</p> | <p>Blood Cancer UK's Clinical Trials - Pilot Programme Support</p> |
|---|---------------|--|

|   |   |
|---|---|
| <p>Members of the public including patients</p> | <p>In 2022 Kyowa Kirin International worked with 8 members of the public (including patients) to develop a mobile application for patient support</p> |
| <p>Journalists</p>                              | <p>Kyowa Kirin International did not work with any journalists in 2022</p>  |

The Republic of Ireland

|   |                  |   |
|---|------------------|---|
| <p>Irish Platform for Patients<br/>Organisations, Science and Industry<br/>Limited<br/>77 Camden St Lower<br/>Dublin 2<br/>D02 XE80</p> <p>Registered company no. 408258</p> <p><a href="https://www.ipposi.ie/">https://www.ipposi.ie/</a></p> | <p>€8,500.00</p> | <p>Kyowa Kirin provided support to IPPOSI to be a corporate member for 2022</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 2022</p> |
|--------------------------------------|---|