

Disclosure of Payments made by BioMarin Europe Limited to UK Patient Organisations in 2015

BioMarin Europe Limited and its affiliates¹ (“BioMarin”) are committed to ensuring that the highest ethical standards are met at all times when interacting with patient organizations. BioMarin may interact with these organizations in order to assist with the appropriate use of medicines, the protection and safety of patients and the general improvement of public health and knowledge and awareness of rare and orphan disorders.

As a member of the Association of the British Pharmaceutical Industry’s (“ABPI”) BioMarin is also fully committed to adhering to the ABPI Code of Practice. As part of the ABPI’s Code and the pharmaceutical industry’s desire to be clear and transparent with all qualifying payments made to patient organisations, BioMarin provides details of the monetary value of certain types of support provided to patient organisations as well as those that provide consultancy services.

BioMarin notes that it has contracted for services with a separate commercial arm of UK patient organisations. The payments relating to those contracts are not provided herein as it understands this information falls outside the scope of the disclosure requirement.

The following is a list of the payments made by BioMarin to United Kingdom patient organizations from January 1, 2015 to December 31, 2015:

Action Duchenne	SPONSORSHIP: £25,000 in support of the Action Duchenne International Annual Conference being held on the 6 th -7 th November 2015 in London, United Kingdom.
Association of Glycogen Storage Diseases (“AGSD-UK”)	SPONSORSHIP: £10,000 in support of AGSD-UK Annual Patient and Family Conference 2016 (30 th Anniversary Commemoration) to be held in the United Kingdom.
Association of Glycogen Storage Diseases	GRANT: £2,000 in support of Pompe disease support team meetings and organizing venues for future meetings.

¹ Payments made to UK-based HCPs and HCOs by BioMarin’s global affiliates are disclosed within this patient organisation report regardless of the source of funding.

Association of Glycogen Storage Diseases

TRAVEL GRANT: £372 in support of AGSD-UK representative's attendance at an International Congress in February 2015.

Association of Glycogen Storage Diseases

SPONSORSHIP: £6,000 in support of annual patient conference, Pompe Support Team Meeting and AGSD Medical Advisory Board February 25, 2015.

Batten Disease Family Association ("BDFa")

COLLABORATIVE WORK: £8,000 in support of a collaboration delivering a programme of work investigating the burden of disease for families, carers and siblings living with a diagnosis of CLN2.

Battens Disease Family Association

TRAVEL GRANT: £1,750 in support of BDFa representative's attendance at an International Congress in February 2015.

Battens Disease Family Association

SPONSORSHIP: £6,780 in support of the meeting for the Batten Disease International Alliance to be held on June 22nd 2015.

Batten Disease Family Association

COLLABORATIVE WORK: £5,000 in support of collaboration delivering a programme of work investigating the burden of disease for the families, carers and siblings living with a diagnosis of CLN2 taking place September 2015.

Batten Disease Family Association

SPONSORSHIP: £8,000 in support of BDFa Annual Family Conference to be held on 17th–18th October 2015 in the Village Hotel Coventry, United Kingdom.

Contact a Family

GRANT: £5,000 in support of "Pictures from Home" exhibition portraying the lives of children including those with MPS to be held on 26th–31st January 2015 in London.

Genetic Alliance UK

SPONSORSHIP: £5,000 in support of a workshop to actively engage up to thirty five patient groups in understanding the appraisal and commissioning of medicines for rare diseases in Scotland.

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G. Eggleton (UK), J. Lennertz (USA)
Corporate Secretary: G.E. Davis (USA) and
R. Morris (UK)

Society for Mucopolysaccharide Diseases (“MPS Society”)

GRANT: £25,000 in support of a MPS IVA communications officer.

Society for Mucopolysaccharide Diseases

GRANT: £7,000 in support of MPS Society’s campaign to support access to Vimizim in Scotland, Wales and Northern Ireland.

Society for Mucopolysaccharide Diseases

SPONSORSHIP: £1,500 in support of the 20th Anniversary of the First Northern Ireland Outreach MPS Clinic to be held on the 14th May 2015 at the Hilton Hotel, Temple Patrick, Northern Ireland.

Society for Mucopolysaccharide Diseases

COLLABORATIVE WORK: £20,000 in support of MPS IIIB primary caregiver questionnaires and focus group to be held June 21st – 26th June 2015 in Amersham, United Kingdom.

Society for Mucopolysaccharide Diseases

CONSULTING SERVICES: £500 to provide consulting services at a meeting.

Society for Mucopolysaccharide Diseases

CONSULTING SERVICES: £2,475 to provide consulting services at a meeting.

TOTAL SPEND IN 2015:

£139,377

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