

Disclosure of payments to Patient Organisations by PTC during 2022

Principal Address				Type of Support	Description of Support	Total Amount of Support
Association Name	Address Line 1	Address Line 2	Post Code			
Action Duchenne Ltd	Wellesley House, Duke of Wellington Avenue	London	SE18 6SS	Grant	Supporting families through diagnosis	25,000
Action Duchenne Ltd	Wellesley House, Duke of Wellington Avenue	London	SE18 6SS	Grant	STRIVE grant award	2,1739
Action Duchenne	Wellesley House, Duke of Wellington Avenue	London	SE18 6SS	Event	Annual conference	35000
Sub Total						81,739
Ataxia UK	12 Broadbent Close	London	N6 5JW	Event	Ataxia UK Annual Patient Conference	5,000
Sub Total						5,000
Euro Ataxia	12 Broadbent Close	London	N6 5JW	Event	Advisory board meeting for patients and caregivers	3,800
Sub Total						3,800
Findacure Foundation	66 Devonshire Road	Cambridge	CB1 2BL	Event	The International Rare Disease Showcase	1,500
Sub Total						1,500
Gene People	Nightingale House, 46-48 East Street	Epsom	KT17 1HQ	Event	Gene People Leadership Symposium	5,000
Gene People	Nightingale House, 46-48 East Street	Epsom	KT17 1HQ	Sponsorship	Corporate connection membership	15,000
Sub Total						20,000

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Association Name	Address Line 1	Address Line 2	Post Code			
Genetic Alliance	Creative Works, 7 Blackhorse Lane	London	E17 6DS	Grant	Rare Disease Day 2022	8,000
Genetic Alliance	Creative Works, 7 Blackhorse Lane	London	E17 6DS	Sponsorship	RD UK membership	12,800
Sub Total						20,800
Metabolic Support UK	Unit 11, Technology Park, 12 Gwenfro	Wrexham	LL13 7YP	Event	Rare Thinking Festival	5,000
Metabolic Support UK	Unit 11, Technology Park, 12 Gwenfro	Wrexham	LL13 7YP	Event	Patient education series	15,000
Sub Total						20,000
Motor Neurone Disease Association	Francis Crick House, 6 Summerhouse Road	Northampton	NN3 6BJ	Event	33rd Virtual International Symposium on ALS/MND	8,000
Sub Total						8,000
Muscular Dystrophy UK	61A Suffolk Street	London	SE1 0BU	Event	Muscles Matter 2022 online seminars	18,000
Muscular Dystrophy UK	61A Suffolk Street	London	SE1 0BU	Event	Neuromuscular translational research	7,500
Sub Total						25,500
Neurological Alliance	The Junction, Station Road	Watford	WD17 1EU	Sponsorship	Reference group membership	11,470
Sub Total						11,470

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Association Name	Address Line 1	Address Line 2	Post Code			
Pathfinders	Flat 1, 80 Coley Avenue	Reading	RG1 6FJ	Grant	Co-production study examining transition to adulthood for people with DMD	31985
Sub Total						31,985
Young Epilepsy	St Piers Lane, Lingfield	Surrey	RH7 6PW	Event	Young Epilepsy Research Retreat	3,000
Sub Total						3,000
Total						233,064

Disclosure of payments to Members of the Public by PTC during 2022

	Annual Disclosure of Contracted Services Provide by The Public								
	Number of Members of the Public / Journalists Contracted	Country	Contracted Services Provided		Not applicable	Description of Support ¹	Not applicable	Not applicable	Fees for Services/ Expenses
Patients and carers	2	UK	Contracted Services (Fees and expenses should be disclosed separately) add a line for each different service provided	Fees		Fees for speaking at PTC internal meeting			300
				Out of pocket expenses					
Patients and carers	6 patients and 4 carers	UK	Contracted Services (Fees and expenses should be disclosed separately) add a line for each different service provided	Fees		Market research interviews			625
				Out of pocket expenses					0
Journalists	6	UK	Contracted Services (Fees and expenses should be disclosed separately) add a line for each different service provided	Fees		Media advisory board meeting			2834.5
				Out of pocket expenses					0

Disclosure of payments to Patient Organisations by PTC during 2023

Principal Address				Type of Support	Description of Support	Total Amount of Support	As a % of turnover*
Association Name	Address Line 1	Address Line 2	Post Code				
Action Duchenne Ltd	Wellesley House, Duke of Wellington Avenue	London	SE18 6SS	Event	Annual conference	35,000	
Sub Total						35,000	5
Euro Ataxia	12 Broadbent Close	London	N6 5JW	Consultancy fee	Health-related Quality of Life study support	1,600	
Euro Ataxia	12 Broadbent Close	London	N6 5JW	Event	Euro-ataxia research conference	5,172	
Sub Total						6,772	82
Pathfinders	103 London Road	Hailsham	BN27 3AH	Grant	A co-production study examining Transition to adulthood for young people with DMD	32,985	
Pathfinders	103 London Road	Hailsham	BN27 3AH	Consultancy fee	Project - Transition from paediatric to adult care in DMD	13,312	
Sub Total						46,297	26

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Association Name	Address Line 1	Address Line 2	Post Code				
Genetic Alliance	Creative Works, 7 Blackhorse Lane	London	E17 6DS	Grant	Rare Disease Day 2023	10,000	
Genetic Alliance	Creative Works, 7 Blackhorse Lane	London	E17 6DS	Membership	RDUK membership 2023	12,800	
Genetic Alliance	Creative Works, 7 Blackhorse Lane	London	E17 6DS	Grant	Signposting to support website 2023 project	5,000	
Sub Total						27,800	4
Wheelchair Football Association	c/o Birmingham County Football Association, Ray Hall Lane	Birmingham	B43 6JF	Sponsorship	Annual sponsorship of the Wheelchair Football Association	25,000	
Sub Total						25,000	12
Muscular Dystrophy UK	61A Great Suffolk Street	London	SE1 0BU	Event	2023 UK Neuromuscular Translational Research Meeting	8,000	
Sub Total						8,000	<1%
Young Epilepsy	St Piers Lane, Lingfield	Surrey	RH7 6PW	Event	Better Understanding the Rare Epilepsies	3,000	
Young Epilepsy	St Piers Lane, Lingfield	Surrey	RH7 6PW	Event	Young Epilepsy Symposium	3,000	
Sub Total						6,000	<1%

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Association Name	Address Line 1	Address Line 2	Post Code				
Dystonia UK	89 Albert Embankment	London	SE1 7TP	Event	Dystonia Matters Live 2023	5,000	
Sub Total						5,000	<1%
Beacon	66 Devonshire Road	Cambridge	CB1 2BL	Event	Empowerment Programme	10,000	
Sub Total						10,000	35
Metabolic Support	Unit 11-12 Gwenfro Technology Park	Wrexham	LL12 7YP	Grant	Grant for patient education series	15,000	
Metabolic Support	Unit 11-12 Gwenfro Technology Park	Wrexham	LL12 7YP	Event	MSUK Annual Conference	5,000	
Sub Total						20,000	7
The Lily Foundation	31 Warren park, Warlingham	Surrey	CR6 9LD	Sponsorship	Representatives of the Lily Foundation to attend 3 conferences in 2024	4,000	
Sub Total						4,000	<1%
Motor Neurone Disease Association (MND)	Francis Crick House, Summerhouse Road, Moulton Park	Northampton	NN3 6BJ	Event	34th International Symposium on ALS/MND	9,800	
Sub Total						9,800	<1%

Disclosure of payments to Members of the Public by PTC during 2023

	Annual Disclosure of Contracted Services Provide by The Public								
	Number of Members of the Public / Journalists Contracted	Country	Contracted Services Provided		Not applicable	Description of Support ¹	Not applicable	Not applicable	Fees for Services/ Expenses
Patients and carers	1	UK	Contracted Services (Fees and expenses should be disclosed separately) add a line for each different service provided	Fees		ITN/Genetic Alliance interview for Rare Disease Day			200
				Out of pocket expenses					
Patients and carers	1	UK	Contracted Services (Fees and expenses should be disclosed separately) add a line for each different service provided	Fees		PTC University panel discussion to mark World Duchenne Awareness Day			100
				Out of pocket expenses					

Disclosure of payments to Patient Organisations by PTC during 2024

Principal Address				Type of Support	Description of Support	Total Amount of Support	As a % of turnover*
Association Name	Address Line 1	Address Line 2	Post Code				
Action Duchenne Ltd	Wellesley House, Duke of Wellington Avenue	London	SE18 6SS	Event	Annual conference	15,000	
Sub Total						15,000	2
Ataxia UK	12 Broadbent Close	London	N6 5JW	Event	International Congress for Ataxia Research	19,531	
Sub Total						19,531	1
Euro Ataxia	12 Broadbent Close	London	N6 5JW	Event	Euro-ataxia research conference 2024	2,542	
Sub Total						2,542	12
Genetic Alliance	Creative Works, 7 Blackhorse Lane	London	E17 6DS	Membership	RDUK membership 2024	15,000	
Genetic Alliance	Creative Works, 7 Blackhorse Lane	London	E17 6DS	Grant	Rare Disease Day 2024	5,000	
Sub Total						20,000	3
Muscular Dystrophy UK	61A Great Suffolk Street	London	SE1 0BU	Event	2023 UK Neuromuscular Translational Research Meeting	19,200	
Sub Total						19,200	>1%

Disclosure of payments to Patient Organisations by PTC during 2024

Principal Address				Type of Support	Description of Support	Total Amount of Support	As a % of turnover*
Association Name	Address Line 1	Address Line 2	Post Code				
Metabolic Support	Centurion House, 129 Deansgate	Manchester	M3 3WR	Event	2024 Annual Community Conference	10,000	
Metabolic Support	Centurion House, 129 Deansgate	Manchester	M3 3WR	Grant	Living Well Symposium	10,000	
Sub Total						20,000	9
Motor Neurone Disease Association (MND)	Francis Crick House, Summerhouse Road, Moulton Park	Northampton	NN3 6BJ	Event	35th International Symposium on ALS/MND	14,000	
Sub Total						14,000	>1%

Disclosure of payments to Members of the Public by PTC during 2024

- There were no payments made by PTC to members of the public or journalists during 2024

PTC Therapeutics, Ltd Patient Organisation and Members of the Public Disclosure (2024)

Methodology

PTC Therapeutics, Ltd (PTC) is committed to working in an open and transparent way both with patient organisations and members of the public including but not limited to patients, carers and journalists, to better serve the needs of patients. Transparency is essential to building and maintaining trust in our organisation and the pharmaceutical industry. PTC is working in collaboration with the Association of the British Pharmaceutical Industry (ABPI) to make sure that it continues to set high standards of ethical interaction between the company and patient organisations as well as other members of the public in the UK. This document provides the methodological narrative to support PTC's Disclosure Report for the year 2024.

Transfer of value (ToV)

The following types of transfer of value are included in this report:

1. Direct payments, made directly by PTC to the benefitting patient organisations.
2. Indirect payments made through an intermediary (third party) on behalf of PTC for the benefit of patient organisations and where the organization can be clearly identified.
3. In-kind: any significant non-monetary support provided to benefitting patient organisations.
4. Cross-border ToV: ToV to a patient organisation where a non-UK PTC entity or intermediary on behalf of PTC has provided the funding and the patient organisation is registered at an address in the UK.
5. ToV to an individual patient, who does not represent or is not hired through a patient organization, is disclosed in aggregate together with other members of the public including carers and journalists, for example.

Timing

For the 2024 Disclosure, we have taken all payments made to UK patient organisations and members of the public from 2 January 2024 to 31 December 2024 inclusive.

Contracts

Any transfer of value from PTC to a patient organisation registered in the UK requires development and return of a signed agreement/contract setting out the purpose of, and terms of, the funding. Each agreement/contract and total transfer of value for the calendar year are recorded and kept securely by PTC. Where contracts are valid for more than one year, the corresponding ToV is disclosed in the reportable disclosure period.

Currency

Payments to patient organisations and members of the public are recorded within the Disclosure Report in local GBP currency. Most payments made are in GBP, however some payments may be made in other currencies. With limited ability to track exact exchange rates on any given day of monetary transfer we have taken an average exchange rate for 2024 of £1=EUR 1.18, = 4.79 SAR and also = \$1.28 USD and applied this to all EUR, SAR or USD payments made during 2024. This rate has been taken from yearly average rates from OFX.com accessed on 17 February 2025.

(<https://www.ofx.com/en-gb/forex-news/historical-exchange-rates/yearly-average-rates/>).

Cross-border payments

All payments made to UK registered patient organisations from outside the UK are tracked and managed centrally by PTC Global Finance. All information is contained within PTC's financial system outlining full payments made including travel and associated expenses. Contracts are also shared and approved by the PTC UK office containing full payment details for each engagement. PTC Global Finance is able to track all external payments made to patient organisations and individual members of the public within the UK.

VAT

The ToV reported is the total amount paid by PTC including VAT where applicable.

Definitions

PTC has defined Grants and Donations through its internal Global Standard Operating Procedure and in line with the ABPI Code of Practice. PTC has defined Sponsorship through its internal Global Standard Operating Procedure and in line with the ABPI Code of Practice. These Procedures supplement and do not replace external requirements including local laws and regulations, HCP professional codes of conduct, industry codes and standards. If there is a conflict or inconsistency between these Procedures and any external requirements, the more stringent rule shall apply. Grants and Donations can only be provided to reputable patient organisations and not to individuals. Grants and Donations must be provided without agreement or intent to receive a tangible return in exchange, and they must not have the promotion of products as their purpose. Grants and Donations must be based upon an unsolicited request. The outline of these is included below.

Grants and Donations – Donations and grants are funds, benefits-in-kind or services freely given for the purpose of supporting healthcare, scientific research or education, with no consequent obligation on the recipient organisation, institution and the like to provide goods or services to the benefit of PTC in return. In general, donations are physical items, services or benefits-in-kind which may be offered or requested. Grants are the provision of funds.

Sponsorship - Sponsorship of an event normally refers to the financial support given by PTC for the educational aspects of said event where PTC receives a tangible benefit, for example space for an appropriate exhibition stand. Sponsorship will be with a patient association directly or third-party provider and not with an individual.

Patient: someone who is under medical care or treatment

Caregiver/carer: someone who looks after another person (usually family member, partner or friend) who needs help because of their illness, frailty, disability, a mental health problem or an addiction and cannot cope without their support.

Patient organisation (PO): A non-profit legal entity, mainly composed of patients and/or caregivers, that represents, supports and advocates for the needs and rights of patients and/or caregivers. These may be registered charities or incorporated as companies.

PO representative: A person responsible to represent and express the collective views of a PO on a specific issue or disease area.

Journalist: A person engaged in the collection, writing, editing and presentation of news or other material intended for dissemination through a range of media (TV, radio, magazines, newspapers etc) to the public.

Influencer: An individual – often a celebrity – who has a significant online audience of members of the public and uses digital platforms to influence public opinion or behaviour.

Public service provider: someone who is not a healthcare professional who provides services for the purpose of supporting healthcare, research or (medical) education.

Health Economist: an expert in the application of economics to healthcare markets, healthcare programmes, public health policies and healthcare interventions.

Members of the public

Any ToV made directly by PTC or via a third party on its behalf to members of the public including individual patients, carers and journalists is disclosed in aggregate on PTC's corporate website annually.