

Disclosure of payments to UK Healthcare Professionals (HCPs) by PTC during 2021

Full Name			HCPs/ORDMs: City of Principal Practice HCOs: city where registered	Country of Principal Practice	Principal Practice Address			Collaborative Working (which includes Joint Working) (Clauses 20 & 28)		Donations and Grants to HCOs (Clauses 23 & 28)	Contribution to costs of Events (Clauses 10 & 28)			Contracted Services (Clauses 24 & 28)		TOTAL
(Clause 28)			(Clause 28)	(Clause 28)	(Clause 28)					Sponsorship agreements with HCOs / third party organisations appointed by HCOs to manage an Event (Note M)	Registration Fees	Travel & Accommodation	Fees	Expenses		
Title	First Name	Last Name	HCPs/ORDMs: City of Principal Practice HCOs: city where registered	Country of Principal Practice	Institution Name	Address Line 1	Post Code									
INDIVIDUAL NAMED DISCLOSURE - one line per HCP/ORDM (i.e. all transfers of value during a year for an individual HCP will be summed up; itemization should be available for the individual Recipient or public authorities' consultation only, as appropriate)																
Dr	Lucinda	Carr	London	United Kingdom	UCL Consultants	The Network	W1T 4TP	N/A	N/A	N/A	N/A	0	0	4250	0	4250
Dr	Gautam	Ambegaonkar	Cambridge	United Kingdom	Addenbrookes	Hills Road	CB2 0QQ	N/A	N/A	N/A	N/A	0	0	3000	0	3000
Professor	Simon	Heales	London	United Kingdom	UCL Consultants	The Network	W1T 4TP	N/A	N/A	N/A	N/A	0	0	3125	0	3125
Dr	Katrina	Räty Albert	Cambridge	United Kingdom	University of	The Old Schools,	CB2 1TN	N/A	N/A	N/A	N/A	0	0	550	0	550
Professor	Henry	Houlden	London	United Kingdom	University College	Gower Street	WC1E 6BT	N/A	N/A	N/A	N/A	0	0	1100	0	1100
Professor	Tracey	Willis	Oswestry	United Kingdom	The Robert Jones	Oswestry	SU10 7AG	N/A	N/A	N/A	N/A	0	0	3700	0	3700
Dr	Mary Imelda	Hughes	Manchester	United Kingdom	Royal Manchester	Oxford Road	M13 9WL	N/A	N/A	N/A	N/A	0	0	720	0	720
Dr	Emily	Whitehouse	Manchester	United Kingdom	Royal Manchester	Oxford Road	M13 9WL	N/A	N/A	N/A	N/A	0	0	540	0	540
Professor	Rosaline	Quinlivan	London	United Kingdom	MRC Centre for	NHNN, 8-11	WC1 3BG	N/A	N/A	N/A	N/A	150	0	1937.5	0	2087.5
Dr	Anne-Marie	Childs	Leeds	United Kingdom	Children's Hospital,	Great George	LS1 3EX	N/A	N/A	N/A	N/A	0	0	750	0	750
Professor	Francesco	Muntoni	London	United Kingdom	Great Ormond	London	WC1N 3JH	N/A	N/A	N/A	N/A	0	0	875	0	875
OTHER, NOT INCLUDED ABOVE - where information cannot be disclosed on an individual basis for legal reasons																
Aggregate amount attributable to transfers of value to such Recipients - Template & Clause 28								N/A	N/A	N/A	N/A	0	0	2300	0	2300
Number of Recipients in aggregate disclosure - Template & Clause 28								N/A	N/A	N/A	N/A	0	0	1	0	1
Number of Recipients disclosed in aggregate as a % of all Recipients (individual & aggregate disclosures) - Clause 28								N/A	N/A	N/A	N/A	0%	0%	8%	0%	8%

Disclosure of payments to Healthcare Organisations (HCOs) by PTC during 2021

Principal Practice Address			Collaborative Working (which includes Joint Working) (Clauses 20 & 28)	Donations and Grants to HCOs (Clauses 23 & 28)	Contribution to costs of Events (Clauses 10 & 28)			Contracted Services (Clauses 24 & 28)		TOTAL
(Clause 28)					Sponsorship agreements with HCOs / third party organisations appointed by HCOs to manage an Event (Note M)	Registration Fees	Travel & Accommodation	Fees	Expenses	
Institution Name	Address Line 1	Post Code								
British Paediatric Services Ltd	5-11 Theobalds Road	WC1X 8SH	0	0	5,500	0	0	0	0	5,500
British Myology Society	Box 102, National	WC1N 3BG	0	0	6,500	0	0	0	0	6,500
Alder Hey Children's NHS	Easton Road	L12 2AP	0	129	3,359	0	0	0	0	3,488
Society for the Study of Inborn	Stone King LLP, Boundary	EC1M 6HR	0	0	15,517	0	0	0	0	15,517
University Hospitals Bristol	Trust Headquarters,	BS1 3NU	0	50,000	0	0	0	0	0	50,000
ERNDIM	c/o EMQN CIC Office,	M15 6SE	0	0	4,310	0	0	0	0	4,310
Medics 4 Rare Diseases	c/o Analogue Wonderland	HP10 9RS	0	0	8,000	0	0	0	0	8,000
The Robert Jones and Agnes Hunt Royal College of General	Oswestry	SU10 7AG	0	1,810	0	0	0	0	0	1,810
	30 Euston Square	NW1 2FB	0	0	67,784	0	0	0	0	67,784
Transfers of Value re: Research & Development as defined Clause 1.20										551,075

Disclosure of payments to Patient Organisations by PTC during 2021

				Type of Support	Description of Support	Total Amount of Support
Association Name	Address Line 1	Address Line 2	Post Code			
Action Duchenne	49-51 East Road	London	N1 6AH	Grant	Helping families to make informed choices	25,000
Action Duchenne	49-51 East Road	London	N1 6AH	Event	Action Duchenne Conference	35,000
Sub Total						60,000
Pathfinders Neuromuscular Alliance	Flat 1, 80 Coley Avenue, Reading	Reading	G1 6FJ	Grant	Becoming an adult	31,755
Pathfinders Neuromuscular Alliance	Flat 1, 80 Coley Avenue, Reading	Reading	G1 6FJ	Grant	Living full lives - achieving your aims in transition to adulthood	21,800
Sub Total						53,555
Muscular Dystrophy UK	61a Great Suffolk Street	London	SE1 0BU	Consultancy	Northstar	40,412
Muscular Dystrophy UK	61a Great Suffolk Street	London	SE1 0BU	Event	MDUK Muscles Matter 2021	15,000
Muscular Dystrophy UK	61a Great Suffolk Street	London	SE1 0BU	Event	2021 Annual Neuromuscular Research Conference	5,000
Sub Total						60,412

Disclosure of payments to Patient Organisations by PTC during 2021

				Type of Support	Description of Support	Total Amount of Support
Association Name	Address Line 1	Address Line 2	Post Code			
TREAT-NMD	Time Central, 32 Gallowgate	Newcastle-upon-Tyne	NE1 4BF	Grant	TREAT-NMD Masterclass DMD	25,862
TREAT-NMD	4th Floor, The Catalyst	Newcastle-upon-Tyne	NE4 5TG	Event	TREAT-NMD Conference 2021	17,241
Sub Total						43,103
Genetic Alliance	3rd Floor, 86-90 Paul Street	London	EC2A 4NE	Grant	Rebuilding Rare Resilience Phase 2	10,000
Genetic Alliance	3rd Floor, 86-90 Paul Street	London	EC2A 4NE	Membership	RDUK Industrial support membership	12,000
Genetic Alliance	3rd Floor, 86-90 Paul Street	London	EC2A 4NE	Grant	Rare Disease Day 2021	8,000
Sub Total						30,000
Metabolic Support UK	Unit 11-12 Gwenfro Technology Park	Wrexham	LL13 7YP	Grant	Building and empowering patient communities programme	10,000
Metabolic Support UK	Unit 11-12 Gwenfro Technology Park	Wrexham	LL13 7YP	Event	Rare Thinking Festival	5,000
Sub Total						15,000
TOTAL						262,070

Disclosure of payments to UK Healthcare Professionals (HCPs) by PTC during 2022

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(Clause 28)			(Clause 28)	(Clause 28)	(Clause 28)				Sponsorship agreements with HCOs / third party organisations appointed by HCOs to manage an Event (Note M)	Registration Fees	Travel & Accommodation	Fees	Expenses			
Title	First Name	Last Name	HCPs/ORDMs: City of Principal Practice HCOs: city where registered	Country of Principal Practice	Institution Name	Address Line 1	Post Code									
INDIVIDUAL NAMED DISCLOSURE - one line per HCP/ORDM (i.e. all transfers of value during a year for an individual HCP will be summed up; itemization should be available for the individual Recipient or public authorities' consultation only, as appropriate)																
Professor	Simon	Heales	London	UK	UCL Consultants	97 Tottenham	W1T4TP	N/A	N/A	N/A	N/A	256	532.89	7600	105	8493.89
Dr	Lucinda	Carr	London	UK	UCL Consultants	97 Tottenham	W1T4TP	N/A	N/A	N/A	N/A	256	198.35	1800	49.95	2304.3
Dr	Marie	Monaghan	Bristol	UK	University	Upper Maudlin	BS2 8AE	N/A	N/A	N/A	N/A	325.04	225.47	Yearly amount	Yearly amount	550.51
Dr	Imelda	Hughes	Manchester	UK	Royal Manchester	Oxford Road	M13 9WL	N/A	N/A	N/A	N/A	Yearly amount	106.83	5312.5	Yearly amount	5419.33
Professor	Rosaline	Quinlivan	London	UK	MRC Centre for	Queen Square	WC1 3BG	N/A	N/A	N/A	N/A	256	Yearly amount	3000	Yearly amount	3256
Professor	Francesco	Muntoni	London	UK	Great Ormond	Great Ormond	WC1N 3JH	N/A	N/A	N/A	N/A	Yearly amount	Yearly amount	2125	Yearly amount	2125
Dr	Vishal	Mehta	Hull	UK	Hull Royal	Anlaby Road	HU3 2JZ	N/A	N/A	N/A	N/A	625	350	Yearly amount	Yearly amount	975
Dr	Pinki	Munot	London	UK	Great Ormond	Great Ormond	WC1N 3JH	N/A	N/A	N/A	N/A	Yearly amount	Yearly amount	2300	Yearly amount	2300
Dr	Martina	Rodie	Glasgow	UK	Royal Hospital for	1345 Govan	G51 4TF	N/A	N/A	N/A	N/A	Yearly amount	Yearly amount	500	Yearly amount	500
Dr	Sunita	Raghunathan	Birmingham	UK	Yardley Green	77 Yardley	B9 5PU	N/A	N/A	N/A	N/A	Yearly amount	Yearly amount	400	Yearly amount	400
Dr	Robin	Jones	London	UK	The Royal	Fulham Road	SW3 6JJ	N/A	N/A	N/A	N/A	Yearly amount	Yearly amount	1000	Yearly amount	1000
OTHER, NOT INCLUDED ABOVE - where information cannot be disclosed on an individual basis for legal reasons																
Aggregate amount attributable to transfers of value to such Recipients - Template & Clause 28								N/A	N/A	N/A	N/A	660	340	3750	Aggregate amount (D)	4750
Number of Recipients in aggregate disclosure - Template & Clause 28								N/A	N/A	N/A	N/A	1	1	3	Number of HCPs/ORDMs (D)	4
Number of Recipients disclosed in aggregate as a % of all Recipients (individual & aggregate disclosures) - Clause 28								N/A	N/A	N/A	N/A	17%	17%	25%	0%	26%

Disclosure of payments to Healthcare Organisations (HCOs) by PTC during 2022

Principal Practice Address <i>(Clause 28)</i>			Collaborative Working (which includes Joint Working) <i>(Clauses 20 & 28)</i>	Donations and Grants to HCOs <i>(Clauses 23 & 28)</i>	Contribution to costs of Events <i>(Clauses 10 & 28)</i>			Contracted Services <i>(Clauses 24 & 28)</i>		TOTAL
					Sponsorship agreements with HCOs / third party organisations appointed by HCOs to manage an Event <i>(Note M)</i>	Registration Fees	Travel & Accommodation	Fees	Expenses	
Institution Name	Address Line 1	Post Code								
British Paediatric Services Ltd	5-11 Theobalds Road	WC1X 8SH	0	0	28230	0	0	0	0	28230
British Paediatric Neurology	The Coach House, Rear of	BL1 4AP	0	5000	17000	0	0	0	0	22000
John Radcliffe Hospital	Headley Way	OX3 9DU	0	0	4286	0	0	0	0	4286
Society for the Study of Inborn	Stone King LLP, Boundary	EC1M 6HR	0	0	48718	0	0	0	0	48718
University Hospitals Bristol	Trust Headquarters,	BS1 3NU	0	0	4200	0	0	0	0	4200
Heartlands Hospital	Bordersley Green	B95SS	0	0	3300	0	0	0	0	3300
Medics 4 Rare Diseases	c/o Analogue Wonderland Ltd,	HP10 9RS	0	0	10000	0	0	0	0	10000
The Robert Jones and Agnes Hunt	Oswestry	SU10 7AG	0	0	552	0	0	0	0	552
Children in Scotland	Thorn House, 5 Rose Street	EH2 2PR	0	0	695	0	0	0	0	695
South Tees Hospital	Marton Road	TS4 3BW	0	0	500	0	0	0	0	500
Queen's University	University Road	BT7 1NN	0	0	0	0	0	1100	0	1100

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Principal Practice Address			Collaborative Working (which includes Joint Working) (Clauses 20 & 28)	Donations and Grants to HCOs (Clauses 23 & 28)	Contribution to costs of Events (Clauses 10 & 28)			Contracted Services (Clauses 24 & 28)		TOTAL
(Clause 28)					Sponsorship agreements with HCOs / third party organisations appointed by HCOs to manage an Event (Note M)	Registration Fees	Travel & Accommodation	Fees	Expenses	
Institution Name	Address Line 1	Post Code								
Glasgow Children's Hospital Charity	Zone 1 Office Block, 1345	G51 4TF	0	0	2400	0	0	0	0	2400
The University of Aberdeen	King's College	AB24 3FX	0	0	0	0	0	2625	0	2625
National Hospital for Neurology and	Queen Square	WC1N 3BG	0	57000	0	0	0	0	0	57000
Scottish Paediatric Society	120 Brownside Road	G72 8AF	0	0	750	0	0	0	0	750
The University of Sheffield	Firth Court, Western Bank	S10 2TN	0	0	0	0	0	750	0	750
World Muscle Society	The Old Cider Press, 5 The	TQ9 7EQ	0	0	81500	0	0	0	0	81500
Southmead Hospital	Southmead Road	BS10 5NB	0	0	1200	0	0	0	0	1200
Transfers of Value re: Research & Development as defined Clause 1.20										4069382

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

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			
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

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			
Pathfinders	Flat 1, 80 Coley Avenue	Reading	RG1 6FJ	Grant	Co-production study examining transition to adulthood for people with DMD	31,985
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			Description of Support ¹		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	Not applicable	Fees for speaking at PTC internal meeting	Not applicable	Not applicable	300
				Out of pocket expenses					0
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	Not applicable	Market research interviews	Not applicable	Not applicable	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	Not applicable	Media advisory board meeting	Not applicable	Not applicable	2834.5
				Out of pocket expenses					0

Disclosure of payments to UK Healthcare Professionals (HCPs) by PTC during 2023

Full Name			HCPs/ORDMs: City of Principal Practice HCOs: city where registered	Country of Principal Practice	Principal Practice Address			Collaborative Working (which includes Joint Working) (Clauses 20 & 28)		Donations and Grants to HCOs (Clauses 23 & 28)	Contribution to costs of Events (Clauses 10 & 28)			Contracted Services (Clauses 24 & 28)		TOTAL
(Clause 28)			(Clause 28)	(Clause 28)	(Clause 28)					Sponsorship agreements with HCOs / third party organisations appointed by HCOs to manage an Event (Note M)	Registration Fees	Travel & Accommodation	Fees	Expenses		
Title	First Name	Last Name	HCPs/ORDMs: City of Principal Practice HCOs: city where registered	Country of Principal Practice	Institution Name	Address Line 1	Post Code									
<i>INDIVIDUAL NAMED DISCLOSURE - one line per HCP/ORDM (i.e. all transfers of value during a year for an individual HCP will be summed up; itemization should be available for the individual Recipient or public authorities' consultation only, as appropriate)</i>																
Dr	Gautam	Abegaonkar	Cambridge	UK	Addenbrookes Hospital	Hill Road	CB2 0QQ	N/A	N/A	N/A	N/A	Yearly amount	1752	Yearly amount	Yearly amount	1752
Mr	Kristian	Aquilina	London	UK	UCL Consultants Ltd	90 Tottenham	W1T 4TJ	N/A	N/A	N/A	N/A	Yearly amount	652.03	1890	Yearly amount	2542.03
Dr	Lucinda	Carr	London	UK	UCL Consultants Ltd	90 Tottenham	W1T 4TJ	N/A	N/A	N/A	N/A	Yearly amount	652.07	5140	Yearly amount	5792.07
Ms	Stephanie	Cawker	London	UK	Great Ormond Street Hospital	Great Ormond	WC1N 3JH	N/A	N/A	N/A	N/A	Yearly amount	1531.45	Yearly amount	Yearly amount	1531.45
Dr	Anne-Marie	Childs	Leeds	UK	Leeds General Infirmary	Leeds	LS1 3EX	N/A	N/A	N/A	N/A	Yearly amount	443.86	1993.75	Yearly amount	2437.61
Dr	Christian	DeGoede	Preston	UK	Royal Preston Hospital	Sharoe Green	PR2 9HT	N/A	N/A	N/A	N/A	715.52	1477.79	Yearly amount	Yearly amount	2193.31
Ms	Marina	DiMarco	Glasgow	UK	Queen Elizabeth University Hospital	1345 Govan Rd	G51 4TF	N/A	N/A	N/A	N/A	Yearly amount	Yearly amount	1295	Yearly amount	1295
Dr	Paola	Giunti	London	UK	UCL Consultants Ltd	90 Tottenham	W1T 4TJ	N/A	N/A	N/A	N/A	Yearly amount	Yearly amount	1700	Yearly amount	1700
Dr	Mary Imelda	Hughes	Manchester	UK	Royal Manchester Children's Hospital	Oxford Road	M13 9WL	N/A	N/A	N/A	N/A	Yearly amount	399.38	2612.5	Yearly amount	3011.88
Ms	Lesley	Katchburian	London	UK	Great Ormond Street Hospital	Great Ormond	WC1N 3JH	N/A	N/A	N/A	N/A	Yearly amount	1603.45	750	Yearly amount	2353.45
Professor	Manju	Kurian	London	UK	UCL Consultants Ltd	90 Tottenham	W1T 4TJ	N/A	N/A	N/A	N/A	Yearly amount	Yearly amount	6077.5	Yearly amount	6077.5
Dr	Anirban	Majumdar	Bristol	UK	Bristol Royal Hospital for Children	Southmead	BS10 5NB	N/A	N/A	N/A	N/A	578.73	475.03	Yearly amount	Yearly amount	1053.76
Dr	Alisdair	McNeill	Sheffield	UK	The University of Sheffield	Firth Court,	S10 2TN	N/A	N/A	N/A	N/A	Yearly amount	Yearly amount	900	Yearly amount	900
Professor	Francesco	Muntoni	London	UK	UCL GOS Institute of Child Health	30 Guildford	WC1N 1EH	N/A	N/A	N/A	N/A	Yearly amount	1636.3	9788.75	Yearly amount	11425.05
Dr	James	Nurse	Southampton	UK	Southampton General Hospital	Tremona Road	SO16 6YD	N/A	N/A	N/A	N/A	Yearly amount	Yearly amount	675	Yearly amount	675
Dr	Manish	Prasad	Nottingham	UK	Nottingham University Hospital	Derby Road	NG7 2UH	N/A	N/A	N/A	N/A	800	744.15	Yearly amount	Yearly amount	1544.15
Professor	Rosaline	Quinlivan	London	UK	National Hospital for Neurology and Neurosurgery	Queen Square	WC1 3BG	N/A	N/A	N/A	N/A	431.03	1978.63	8333.75	Yearly amount	10743.41
Ms	Christina	Rafter	London	UK	Great Ormond Street Hospital	Great Ormond	WC1N 3JH	N/A	N/A	N/A	N/A	30	163	Yearly amount	Yearly amount	193
Dr	Marianela	Schiava	Newcastle	UK	John Walton Muscular Dystrophy Research Centre	Central Parkway	NE1 3BZ	N/A	N/A	N/A	N/A	Yearly amount	812.99	Yearly amount	Yearly amount	812.99
Dr	Handrean	Soran	Manchester	UK	Manchester University Hospitals	Oxford Road	M13 9WL	N/A	N/A	N/A	N/A	Yearly amount	Yearly amount	2245.83	Yearly amount	2245.83
Ms	Paula	Sugden	Preston	UK	Royal Preston Hospital	Sharoe Green	PR2 9HT	N/A	N/A	N/A	N/A	Yearly amount	401.45	Yearly amount	Yearly amount	401.45
Dr	Evangeline	Wassmer	Birmingham	UK	Birmingham Women and Children's Hospital	Steelhouse Lane	B4 6NH	N/A	N/A	N/A	N/A	581.9	1285.71	Yearly amount	Yearly amount	1867.61
<i>OTHER, NOT INCLUDED ABOVE - where information cannot be disclosed on an individual basis for legal reasons</i>																
Aggregate amount attributable to transfers of value to such Recipients - Template & Clause 28								N/A	N/A	N/A	N/A	191.67	2346.86	6442.5	Aggregate amount (D)	8981.03
Number of Recipients in aggregate disclosure - Template & Clause 28								N/A	N/A	N/A	N/A	1	1	6	Number of HCPs/ORDMs (D)	6
Number of Recipients disclosed in aggregate as a % of all Recipients (individual & aggregate disclosures) - Clause 28								N/A	N/A	N/A	N/A	14%	6%	32%	0%	21%

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(Clause 28)					Sponsorship agreements with HCOs / third party organisations appointed by HCOs to manage an Event (Note M)	Registration Fees	Travel & Accommodation	Fees	Expenses	
British Paediatric Neurology Association	2 St Andrews, Regents Park	NW1 4LB	Payment Amount	Payment Amount	13500	Payment Amount	Payment Amount	Payment Amount	Payment Amount	13500
British Paediatric Services Ltd	5-11 Theobald Road	Wc1X 8SH	Payment Amount	Payment Amount	7752	Payment Amount	Payment Amount	Payment Amount	Payment Amount	7752
Manchester University NHS Foundation Trust	Oxford Road	M13 9WL	Payment Amount	Payment Amount	400	Payment Amount	Payment Amount	Payment Amount	Payment Amount	400
National Hospital for Neurology and Neurosurgery	Queen Square	WC1N 3 BG	Payment Amount	62700	Payment Amount	Payment Amount	Payment Amount	Payment Amount	Payment Amount	62700
John Radcliffe Hospital	Headley Way	OX3 9DU	Payment Amount	Payment Amount	2000	Payment Amount	Payment Amount	Payment Amount	Payment Amount	2000
Queen's University	University Road	BT7 1NN	Payment Amount	Payment Amount	Payment Amount	Payment Amount	Payment Amount	300	Payment Amount	300
Robert Jones & Agnes Hunt Orthopaedic Hospital	Gobowen	SY10 7AG	Payment Amount	Payment Amount	1146.3	Payment Amount	Payment Amount	Payment Amount	Payment Amount	1146.3
Scottish Association for Child Health	12 Queen Street	EH2 1JE	Payment Amount	Payment Amount	550	Payment Amount	Payment Amount	Payment Amount	Payment Amount	550
Scottish Paediatric Society	120 Brownside Road	G72 8AF	Payment Amount	Payment Amount	450	Payment Amount	Payment Amount	Payment Amount	Payment Amount	450
Society for the Study of Inborn Errors of Metabolism	Boundary House, 91	EC1M 6HR	Payment Amount	Payment Amount	85344.83	Payment Amount	Payment Amount	Payment Amount	Payment Amount	85344.83
North Bristol NHS Trust	Southmead Road	BS10 5NB	Payment Amount	Payment Amount	1200	Payment Amount	Payment Amount	Payment Amount	Payment Amount	1200
South Tees Hospitals NHS Foundation Trust	Marlon Road	TS4 3BW	Payment Amount	Payment Amount	400	Payment Amount	Payment Amount	Payment Amount	Payment Amount	400
British Academy of Childhood Disability (BACD)	5 Theobalds Road	WC1X 8SH	Payment Amount	Payment Amount	500	Payment Amount	Payment Amount	Payment Amount	Payment Amount	500
Royal College of General Practitioners	30 Euston Square	NW1 2FB	Payment Amount	Payment Amount	10000	Payment Amount	Payment Amount	Payment Amount	Payment Amount	10000
Medics4RareDiseases	c/o Analogue Wonderland,	HP10 9RS	Payment Amount	Payment Amount	15000	Payment Amount	Payment Amount	Payment Amount	Payment Amount	15000
The University of Sheffield	Firth Court, Western Bank	S10 2TN	Payment Amount	Payment Amount	Payment Amount	Payment Amount	Payment Amount	1500	Payment Amount	1500
World Muscle Society	The Old Cider Press, 5 The	TQ9 7EQ	Payment Amount	Payment Amount	140750	Payment Amount	Payment Amount	Payment Amount	Payment Amount	140750
Transfer of value re: Research & Development as defined Clause 1.20										631943.3

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

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				
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%

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				
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			Description of Support ¹		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	Not applicable	ITN/Genetic Alliance interview for Rare Disease Day	Not applicable	Not applicable	200
				Out of pocket expenses					0
Patients and carers	1	UK	Contracted Services (Fees and expenses should be disclosed separately) add a line for each different service provided	Fees	Not applicable	PTC University panel discussion to mark World Duchenne Awareness Day	Not applicable	Not applicable	100
				Out of pocket expenses					0

PTC Therapeutics, Ltd Patient Organisation and Members of the Public Disclosure (2023) 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, in order 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) in order 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 2023.

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 organizations.
2. Indirect payments made through an intermediary (third party) on behalf of PTC for the benefit of patient organizations and where the organization can be clearly identified.
3. In-kind: any significant non-monetary support provided to benefitting patient organizations.
4. Cross-border ToV: ToV to a patient organization 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 purpose of the 2023 Disclosure, we have taken all payments made to UK patient organisations or members of the public from 2 January 2023 to 31 December 2023 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.

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 2023 of £1=EUR 1.16 and = \$1.24 USD and applied this to all EUR or USD payments made during 2023. This rate has been taken from yearly average rates from OFX.com accessed on 20 March 2024 (<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.

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.