

Disclosure of payments to Irish Healthcare Professionals (HCPs) and Healthcare Organisations (HCOs) by PTC during 2021

	Full Name	HCPs: City of Principal Practice HCOs: city where registered	Country of Principal Practice	Principal Practice Address	Donations and Grants to HCOs	Contribution to costs of Events			Fee for service and consultancy		TOTAL	
						Sponsorship agreements with HCOs / third parties appointed by HCOs to manage an Event	Registration Fees	Travel & Accommodation	Fees	Related expenses agreed in the contract, including travel & accommodation relevant to the contract		
HCPs	INDIVIDUAL NAMED DISCLOSURE											
												€ 0
	Aggregate amount attributable to transfer of value to HCPs									€ 1125		€ 1125
HCOs	INDIVIDUAL NAMED DISCLOSURE											
			Children's Health Ireland	Temple Street, Dublin, D01 YC67	€ 6130							€ 6130
Research & Development												€ 0

Disclosure of payments to Irish Patient Organisations by PTC during 2021

Patient Organisation disclosure template

PO name	Country	Types of the support or services provided	Description of the support or services ¹	Monetary value of financial support and of invoiced costs	Non-monetary benefit for PO ²	Fees for services paid
Rare Diseases Ireland	Ireland	Financial support	Event - Project Funding Support	10,000 euros		
Rare Diseases Ireland	Ireland	Financial support	2021 Membership Fee	3,500 euros		
Irish Paediatric Association	Ireland	Financial support	Event - 2021 Annual Meeting	1,000 euros		

¹: Add a clear description of the purpose of the support or services

²: For example, employee hours or companies facilities offered to support a Patient Organisation activity

Disclosure of payments to Irish Healthcare Professionals (HCPs) and Healthcare Organisations (HCOs) by PTC during 2022

	Full Name	HCPs: City of Principal Practice HCOs: city where registered	Country of Principal Practice	Principal Practice Address	Donations and Grants to HCOs	Contribution to costs of Events		Fee for service and consultancy		TOTAL	
						Sponsorship agreements with HCOs / third parties appointed by HCOs to manage an Event	Registration Fees	Travel & Accommodation	Fees		Related expenses agreed in the contract, including travel & accommodation relevant to the contract
HCPs	INDIVIDUAL NAMED DISCLOSURE										
											€ 0
	Aggregate amount attributable to transfer of value to HCPs										€ 0
HCOs	INDIVIDUAL NAMED DISCLOSURE										
											€0
Research & Development											€ 0

Disclosure of payments to Irish Patient Organisations by PTC during 2022

Patient Organisation disclosure template

PO name	Country	Types of the support or services provided	Description of the support or services ¹	Monetary value of financial support and of invoiced costs	Non-monetary benefit for PO ²	Fees for services paid
Irish Platform for Patients' Organisation, Science and Industry	Ireland	Financial support	Event - Project Funding Support	13,500 euros		
Rare Diseases Ireland	Ireland	Financial support	2022 Membership Fee	3,500 euros		
Muscular Dystrophy Ireland	Ireland	Financial support	MDI video with a focus on DMD	4,761 euros		
¹ : Add a clear description of the purpose of the support or services						
² : For example, employee hours or companies facilities offered to support a Patient Organisation activity						

Disclosure of payments to Irish Healthcare Professionals (HCPs) and Healthcare Organisations (HCOs) by PTC during 2023

	Full Name	HCPs: City of Principal Practice HCOs: city where registered	Country of Principal Practice	Principal Practice Address	Donations and Grants to HCOs	Contribution to costs of Events			Fee for service and consultancy		TOTAL	
						Sponsorship agreements with HCOs / third parties appointed by HCOs to manage an Event	Registration Fees	Travel & Accommodation	Fees	Related expenses agreed in the contract, including travel & accommodation relevant to the contract		
HCPs	INDIVIDUAL NAMED DISCLOSURE											
												€ 0
Aggregate amount attributable to transfer of value to HCPs												€ 0
HCOs	INDIVIDUAL NAMED DISCLOSURE											
			Irish Society of Inherited Metabolic Disorders (ISIMD)	Metabolic Unit, Children's Health Ireland at Temple Street, Dublin 1, D01 XD99, Ireland	€750							€750
			Irish Society of Human Genetics (ISHG)	c/o Tom Moore, School of Biochemistry and Cell Biology, University College Cork, Western Gateway Building, Western Road, Cork, T12 XF62, Ireland	€1050							€1050
			Irish Paediatric Association	9a Coolkill, Sandyford, Dublin 18, Ireland	€3000							€3000
Research & Development												€ 0

Disclosure of payments to Irish Patient Organisations by PTC during 2023

Patient Organisation disclosure template

PO name	Country	Types of the support or services provided	Description of the support or services ¹	Monetary value of financial support and of invoiced costs	Non-monetary benefit for PO ²	Fees for services paid
Irish Platform for Patients' Organisation, Science and Industry	Ireland	Financial support	2023 Membership fee	8,500 euros		
Rare Diseases Ireland	Ireland	Financial support	2023 Membership Fee	7,500 euros		
Muscular Dystrophy Ireland	Ireland	Financial support	Event sponsorship	3,321 euros		

¹: Add a clear description of the purpose of the support or services

²: For example, employee hours or companies facilities offered to support a Patient Organisation activity

PTC Therapeutics IPHA Disclosure (2023) Methodology

PTC Therapeutics (PTC) is committed to working in an open and transparent way both with Healthcare Professionals (HCPs), Healthcare Organisations (HCOs) and Patient Organisations (POs), in order to better serve the needs of patients. Transparency is essential to building and maintaining trust in our organisation and the pharmaceutical industry. We are working in collaboration with the Irish Pharmaceutical Healthcare Association (IPHA) in order to make sure that we continue to set high standards of ethical interaction between PTC and HCPs/HCOs/POs within Ireland. This document provides the methodological narrative to support the submission of our IPHA Disclosure Report for the year 2023.

Definitions

The term “healthcare professional” means a person of any of the following classes:

- (i) Registered medical practitioners
- (ii) Registered dentists
- (iii) Registered pharmacists
- (iv) Registered nurses

The term ‘Healthcare Organisation (HCO)’ means any healthcare, medical or scientific association or organisation such as a hospital, clinic, foundation, university or other teaching institution or learned society (except for a Patient Organisation (PO) within the scope of Annex III of the IPHA code of practice) whose business address, place of incorporation or primary place of operation is in Europe or an organisation through which one or more HCPs or other relevant decision makers provide services.

Patient organisations are defined as not-for-profit organisations (including the umbrella organisations to which they belong), mainly composed of patients and/or caregivers, that represent and/or support the needs of patients and/or caregivers.

PTC Therapeutics IPHA Disclosure (2023) Methodology

Payments

Any transfer of value from PTC to an individual HCP, HCO or PO 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. No payment is made without a signed agreement/contract. Payments to Irish HCPs, HCOs or POs are normally made in Euro. Any payments made in other currencies are made via bank transfer with appropriate exchange rate (as described in the Currency section below).

Timing

For the purpose of the 2023 Disclosure, we have taken all payments made to Irish HCPs, HCOs or POs from 3 January 2023 to 31 December 2023 inclusive.

Contracts

Any transfer of value from PTC to an individual HCP, HCO or PO 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. PTC monitor individual payments, via our internal finance system, in order to track any individual HCP, HCO or PO with a multi-year or ongoing open agreement/contract so that we are able to report payments made within each calendar year. For any ongoing agreement/contract, only where an invoice is received and paid within that calendar year will this be reported for that individual year.

Where PTC contracts indirectly with a HCP or via a third-party consultancy the total amount contracted is disclosed to the individual HCP where consent to disclose has been gained. For HCPs contracted in this way where consent has not been given, or is withdrawn, transfer of value has been aggregated.

PTC Therapeutics IPHA Disclosure (2023) Methodology

Currency

Payments to Irish HCPs, HCOs or POs are recorded within the Disclosure Report in local Euro currency. All payments during 2023 were made in Euro (EUR).

Cross-border payments

All payments made to Irish HCPs or HCOs from outside Ireland are tracked and managed centrally by our European team. All information is contained within our financial system outlining full payments made including travel and associated expenses. Contracts are also shared with the UK office containing full payment details for each engagement. The PTC Finance Team are able to track all external payments made to HCPs and HCOs within Ireland.

VAT and Tax Considerations

Where an individual HCP or HCO is VAT registered then transfers of value made to that HCP/HCO by PTC will include VAT where appropriate. All other transfers of value are exclusive of VAT. All transfers of value made by PTC to HCPs or HCOs do not include the payment of any tax. It is made clear within the agreement/contract that the individual or organisation are liable for any and all taxes on payments made to them by PTC.

PTC Therapeutics IPHA Disclosure (2023) Methodology

Definitions

PTC has defined Grants and Donations through its internal Global Standard Operating Procedure. PTC has defined Sponsorship through its internal Global Standard Operating Procedure. 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 healthcare or healthcare-related institutions or 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 – The purpose of Educational Grants must be to support either (a) specific, independent professional educational programmes (accredited or non-accredited) where the grant recipient is responsible for developing the content and for managing the event or materials, or (b) institutional fellowship or scholarship programmes. Educational Grants must not interfere with the independence of grants recipients and their associates. PTC may not control the content of the programme or the faculty, and the grant recipient controls the selection and invitation of any healthcare professionals. Fellowship or Scholarship Programmes must be open and competitive to relevant institutions or candidates in a given geographic or therapeutic area and widely communicated. The selection of subsidised fellow/scholarship holders must be solely within the discretion of the recipient receiving the grant and comply with applicable national laws, guidelines and professional codes of conduct. The purpose of educational grants may not be for general education funds. PTC may consider providing monetary support to other type of activities, for example: a) infrastructure grants to healthcare-related institutions that are in need of improving their medical infrastructure, provided the grant is enhancing patient care and it is not intended to cover the internal operating expenses of the recipient; b) grants to patients associations/organisations to increase disease awareness or to provide psycho-social support during and after diagnosis or treatment; c) grants to support advocacy or research activities regarding healthcare public policies and legislations.

PTC Therapeutics IPHA Disclosure (2023) Methodology

Donations – The purpose of a Donation is to support various initiatives, projects or non-profit organisations. Donations can only be provided to non-profit certified organisations focusing on services to patients, caregivers, and the health and well-being of the general public. This may include non-profit hospitals and foundations, medical or professional associations, disease-based research, education or patient advocacy organisations and similar non-profit organisations. If the donation is to support a fundraising activity, that should be widely publicised and solicit contributions from numerous organisations.

Sponsorship – Sponsorship to attend third party medical education meetings refers to the support that PTC provides to HCPs to attend independent third party medical education meetings. The contribution will be towards registration fees and travel expenses. These are reviewed on a case by case basis. Sponsorship could be provided to an HCP or an HCO. Sponsorship of an event refers to the financial support given by PTC for the educational aspects of said event. This would normally be by way of an exhibition stand from which PTC would distribute promotional materials relating to its products and/or disease awareness materials. Sponsorship in this case will normally be with an HCO or third party provider and not with an individual.

Consents

Effective from 10 February 2023 PTC transitioned from relying on written consent from HCPs to legitimate interests as the legal basis of processing and disclosing transfers of value data under the applicable data protection legislation (the EU General Data Protection Regulation, as supplemented in Ireland by the Irish Data Protection Act 2018).

PTC believes that the publication of transfer of value data, particularly on a named basis, serves important legitimate interests because it serves to:

- protect and instill public confidence in the integrity of the relationship between the pharmaceutical industry and HCPs;
- represent a step towards fostering greater transparency and building greater trust between the pharmaceutical industry, the medical community and society;
- enable PTC to most fully comply with its disclosure obligations, for instance under the IPHA Code of Practice disclosure requirements.

PTC Therapeutics IPHA Disclosure (2023) Methodology

To balance the legitimate interests described above against the interests, rights and freedoms of the relevant individual HCP, PTC provides HCP with information in the form of a signed agreement/contract about how and why their personal data will be processed and disclosed with specific instructions to contact ukoffice@ptcbio.com if they wish to exercise their right to object to disclosure on an identifiable basis.

Prior to 10 February 2023 consent for disclosure of information including third-party handling of personal data has been sought for all HCPs and HCOs through signed agreements/contracts in line with General Data Protection Regulation (GDPR) requirements. Where consent has been gained this has been recorded in writing and held on file by PTC. These data have been declared via the Irish Disclosure Report. Consent has been sought for each activity with each HCP or HCO.

Provided an HCP did not object to PTC processing and disclosing their personal data in this way, the total sum of all transfers of value made by PTC to the HCP was disclosed on an individual named basis.

For HCPs where consent has not been given or has been withdrawn, transfer of value has been aggregated as per instructed within the Irish Disclosure Report. If an HCP has received a number of transfer of values from PTC within the same reporting period and decides not to agree to disclosure of one or more of those transfer of values, then PTC discloses all of that individual's transfer of value in its aggregate amount.

During the period of this 2023 Disclosure, there were no individuals who still provided their consent and agreed to have some payments being disclosed individually and some in aggregate.

PTC Therapeutics IPHA Disclosure (2023) Methodology

Non-monetary Transfers of Value

During the period of this 2023 Disclosure, PTC has not provided any non-monetary transfer of value to Irish HCPs, HCOs or POs.

Cross Company Working

During the period of this 2023 Disclosure, PTC has not engaged in any cross company working in Ireland.

Collaborative Working

During the period of this 2023 Disclosure, PTC has not engaged in any collaborative working in Ireland.

Over-the-counter Transfer of Value

During the period of this 2023 Disclosure, PTC has not engaged in any over-the-counter transfer of value in Ireland.

Medical Device Transfer of Value

During the period of this 2023 Disclosure, PTC has not engaged in any medical device transfer of value in Ireland.

Transfer of Value to Patient Organisations and members of the public

Any transfer of value to a Patient Organisation and member of the public including patients and journalists will be declared on PTC's Irish website.