



2020 Transparency Reporting

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Healthcare professionals and organizations:

UK: Report & Methodology Notes

Germany: Report and Methodology Notes

Netherlands

Belgium

France

Patient Organizations:

UK, Germany, Italy and France



**Association of the British Pharmaceutical Industry
Disclosure Methodology
2020**



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1) Definitions

a) Recipients

i) Definition of an HCP.

The term “healthcare professional” includes members of the medical, pharmacy and nursing professions and any other persons who in the course of their professional activities may administer, prescribe, purchase, recommend or supply a bluebird bio medicine.

ii) Definition of an HCO.

The term “healthcare organisation” means either a healthcare, medical or scientific association or organisation such as a hospital, clinic, foundation, university or other teaching institution or learned society whose business address, place of incorporation or primary place of operation is in the UK or an organisation through which one or more healthcare professionals or ORDMs provides services.

b) Kind of ToVs

i) Donations, Sponsorships and Grants

Bluebird bio provides financial or non-financial ToVs to organisations that provide medical or scientific education, research or advances in health or healthcare systems. This support may be in the form of sponsorship or grant support, donations to non-profit or public sector healthcare organisations to support their charitable mission and activities. Grants may be made to patient organisations are subject to separate disclosure requirements and thus are excluded here.

ii) Fees for service and consultancy and related expenses

Bluebird bio engages qualified with HCP/HCOs for appropriate services representing genuine and legitimate business needs paid through a fee representing fair market value. These services may include such activities as data analytics, advisory board participation and feedback, retrospective non-interventional study services or market research where bluebird knows the identity of the participants. Service agreements provide for reimbursement of reasonable associated expenses provided adequate receipt is given to bluebird for payment.

iii) Research and Development

Clinical trial expenses including those provided by contract research organisations on behalf of bluebird bio are considered research and development ToVs and are reported on an aggregate basis. If a retrospective or non-interventional study is non submitted to authorities as per local law, then these expenses do not fall under



research and development activities and the ToVs are reported as a fee for service under the name of the individual recipient.

2) Scope of disclosure

a) Excluded ToVs

Hospitality costs to individuals are not disclosable if in conformance with national association limits, which limits bluebird bio follows. Sponsorship amounts for events or congresses may include hospitality costs integrated into the overall amounts, which then are includable as part of the sponsorship ToV. Reasonable and appropriate logistical costs related to meetings hosted by bluebird bio are not considered ToVs and are not disclosed. Donations to charitable and patient organisations are out of scope and are separately reported as required by local law.

b) Date of ToVs

Payments to reportable recipients are reported as of the date of the payment, not the date of the engagement. These ToVs are disclosed at the individual level unless the consent to disclose is not obtained, which would result in the disclosure on an aggregate level. For contracts or agreements with services that span multiple periods, bluebird used the date of payment as the ToV date.

c) Direct and Indirect ToVs

The holder of the bank account where a ToV is made is the recipient for whom the ToV is disclosed. Those payments made to third parties who pay HCPs or HCOs on behalf of bluebird bio are disclosed against the HCP or HCO, as applicable and in accordance with consent obtained in the case of HCP payments.

d) Cross-Border Interactions

For HCPs/ORDMs and HCOs, bluebird bio will disclose based on the principal practice address of the identified recipient regardless of where the payment is made.

3) Data Privacy

a) Consent for Publication of Data

bluebird bio is requesting consent from all Healthcare Professional (HCPs) and Other Relevant Decision Makers (ORDMs) before declaring a Transfer of Value (ToV) to the individual concerned. If consent is not granted, bluebird will publish the ToV in the aggregated section of the report.



b) Data Privacy – Partial Consent for Publication of Data

If an HCP/ORDM receives several transfers of value from bluebird bio and decides not to agree to disclosure of one or more of those transfers of value, bluebird bio will disclose all that individual's transfers of value in its aggregate amount.

c) Data Privacy – Declaration of Consent

HCPs/ORDMs are informed about the purpose of the ABPI Disclosure Code and the required data processing. The option is provided to HCPs/ORDMs to grant consent for at least one full reporting period or to dissent to the publication of data.

4) Duration of Publication

bluebird bio's report will be available for a period of three years. The report will be amended accordingly, if required, for specific reasons, e.g. legal, etc.

5) Currency

All payments and transfers of value will be disclosed in local currency per guidance from EFPIA. If a payment is captured in another currency, it will be converted into local country currency based on the daily exchange rate at 12/31 of the corresponding year of the payment.

6) VAT

VAT is excluded for direct payments and included for in kind transfers of value.

7) Reconciliation of the Data

On an annual basis, bluebird bio will complete a full year reconciliation to identify any transactions that were submitted post data validation or post publication and update the reports accordingly to support the principles of full transparency.

Mustervorlage für die Datenerfassung (bluebird bio)											Tag der Veröffentlichung: Tag der Veröffentlichung: 28-06-21	
	Vollständiger Name	Praxis- oder Geschäftssadresse			Lebenslange Arztnummer (falls vorhanden)	Geld-/Sachspenden und andere einseitige Geld- oder Sachleistungen	Geldwerte Leistungen im Zusammenhang mit Fortbildungsveranstaltungen (§ 7 Abs. 2 Nr. 1 a) (I) und (II); & § 7 Abs. 2 Nr. 2 b) (I), (II) und (III))			Dienstleistungs- und Beratungshonorare § 7 Abs. 2 Nr. 1 b); Abs 2 Nr. 2 c)	Gesamt Optional	
		Stadt	Land	Anschrift								
	§8 Abs. 1 Nr. 1	§8 Abs. 1 Nr. 2	§8 Abs. 1 Nr. 2	§8 Abs. 1 Nr. 2	§8 Abs. 1 Nr. 3	§7 Abs. 2 Nr. 2 a	Sponsoringverträge mit HCOs oder von diesen mit der Durchführung der Veranstaltung beauftragte Dritte	Tagungs- und Teilnahmegebühren	Reise- und Übernachtungskosten	Honorare	Erstattung von Auslagen	
Individualisierte Offenlegung bei Angehörigen der Fachkreise – eine Zeile pro HCP d.h. für das gesamte Jahr sind alle geldwerten Leistungen an den jeweiligen HCP zusammenzurechnen: Einzelauflistungen sollen für Anfragen des jeweiligen Empfängers oder für Anfragen von Behörden vorgehalten werden)												
HCP	Ferras Alashkar	Essen	Deutschland	Ladenspelderstraße 62	n/a	n/a			4.400 €		4.400 €	
	Andrea Jarisch	Frankfurt	Deutschland	In der Romerstadt 5	n/a	n/a			2.875 €		2.875 €	
	Alfred Laengler	Herdecke	Deutschland	Gemeinschaftskrankenhaus Herdecke	n/a	n/a			800 €		800 €	
	Benjamin Becker	Siegen	Deutschland	Wellersbergstr. 60, DRK-Kinderklinik	n/a	n/a			800 €		800 €	
	Dirk Reinhardt	Essen	Deutschland	Hufelandstrasse 55, Universitätsklinikum Essen	n/a	n/a			4.893 €		4.893 €	
	Holger Cario	Ulm	Deutschland	Otto-Lilienthal-Weg 73	n/a	n/a			4.500 €		4.500 €	
	Irene Schmid	München	Deutschland	Lindwurmstr. 4, Haunersche Kinderklinik, Pädiatrische Hämatologie,	n/a	n/a			700 €		700 €	
	Janine Boell	Köln	Deutschland	Kerpener Str. 62, Universitätsklinikum Köln, Innere Medizin 1	n/a	n/a			600 €		600 €	
	Lars Bullinger	Berlin	Deutschland	Husemannstr. 11	n/a	n/a			1.500 €		1.500 €	
	Magdalena Sokalska-Duhme	Stuttgart	Deutschland	Kriegsbergsstraße 62, Klinikum Stuttgart	n/a	n/a			420 €		420 €	
	Markus Thalheimer	Heidelberg	Deutschland	Vangerowstr. 20, Universitätsklinikum Heidelberg	n/a	n/a			1.543 €		1.543 €	
	Nael Alakel	Dresden	Deutschland	Fetscherstr. 74, Universitätsklinikum Carl Gustav Carus Medizinische Klinik I	n/a	n/a			700 €		700 €	
	Nina Kristin Steckel	Essen	Deutschland	Hufelandstrasse 55, Universitätsklinikum Essen, Klinik für Onkologie und Rheumatologie	n/a	n/a			800 €		800 €	
	Paul-Gerhardt Schlegel	Würzburg	Deutschland	Josef-Schneider-Straße 2, Universitätsklinikum Würzburg	n/a	n/a			875 €		875 €	
	Regine Grosse	München	Deutschland	Josephsplatz 15	n/a	n/a			1.058 €		1.058 €	
	Stephan Lobitz	Koblenz	Deutschland	Koblenzer Str. 115-155,	n/a	n/a			1.500 €		1.500 €	
	Udo Kontny	Aachen	Deutschland	Pauweliusstraße 30, Universitätsklinikum Aachen	n/a	n/a			1.000 €		1.000 €	
	Veronika Lenz	Essen	Deutschland	Hufelandstrasse 55, Universitätsklinikum Essen	n/a	n/a			950 €		950 €	
	Volker Ulrich	Bayreuth	Deutschland	Lehrstuhl VWL III, Universität Bayreuth	n/a	n/a			2.517 €		2.517 €	
Gesamtbetrag zurechenbarer geldwerte Leistungen in dieser Kategorie – §7 Abs. 6				n/a	n/a			19.003 €	266 €	19.269 €		
Gesamtzahl der Empfänger geldwerte Leistungen in dieser Kategorie – §7 Abs. 6				n/a	n/a			11	1	12		
Prozentualer Anteil im Verhältnis zu allen Empfängern geldwerten Leistungen in dieser Kategorie – §7 Abs. 6				n/a	n/a					38.7%		
HCOs	DGHO Service GmbH	Berlin	Deutschland	Alexanderplatz 1			40.000 €				40.000 €	
	Congress Support International GmbH	Kassel	Deutschland	Kuhbergstrasse 28				1.336 €			1.336 €	
	CONVENTUS Congressmanagement &	Jena	Deutschland	Carl-Pufendorf-Str. 1			7.500 €				7.500 €	
	CSi Hamburg GmbH	Hamburg	Deutschland	Goernerstraße 30			5.000 €				5.000 €	
	GPOH gGmbH	Berlin	Deutschland	Chausseestraße 128/129			6.000 €				6.000 €	
	Universitätsklinikum Heidelberg	Heidelberg	Deutschland	Innere Medizin 5, Hämatologie, Onkologie und Rheumatologie			8.000 €		82.880 €		90.880 €	
	Charite-Universitätsmedizin Berlin	Berlin	Deutschland	Augustenburger Platz 1			2.000 €				2.000 €	
	Universitätsklinikum Ulm	Ulm	Deutschland	Albert-Einstein-Allee 29			1.000 €				1.000 €	
	Gemeinschaftsklinik Mittelhein gGmbH	Koblenz	Deutschland	Koblenzer Straße 115-155			1.500 €				1.500 €	
	Kinderklinik München Schwabing	München	Deutschland	Kolner Platz 1, Eingang Parivalstr 16			1.000 €				1.000 €	
	ALS Automated Lab Solutions GmbH	Jena	Deutschland	Gewerbegebiet Jena-Göschwitz, Ernst-Ruska-Ring 11				1.294 €			1.294 €	
	ClinSol Research GmbH	Würzburg	Deutschland	Kanistrasse 26				14.603 €			14.603 €	
	Gemeinsamer Bundesausschuss	Berlin	Deutschland	Wegelystr. 8				5.000 €			5.000 €	
	GeneWerk GmbH	Heidelberg	Deutschland	Im Neuenheimer Feld 582				24.000 €			24.000 €	
	IKTZ Heidelberg GmbH	Heidelberg	Deutschland	Stammzellabor, Im Neuenheimer Feld 582				720 €			720 €	
	Mnaris Regenerative Medicine GmbH	Ottobrunn	Deutschland	Haidgraben 5				9.723.671 €			9.723.671 €	
	Paul-Ehrlich-Institut	Langen	Deutschland	Straße 51-59				587 €			587 €	
	Pietrek Associates GmbH	Weinheim	Deutschland	Rosenbrunnenstraße 8				121.173 €			121.173 €	
	Xcenda GmbH	Hannover	Deutschland	Lange Laube 31				134.399 €			134.399 €	
Sonstiges, oben nicht genannt – wenn Informationen aus rechtlichen Gründen nicht offenlegen dürfen												
R&D	Gesamtbetrag zurechenbarer geldwerte Leistungen in dieser Kategorie – §7 Abs. 6							1.000 €			1.000 €	
	Gesamtzahl der Empfänger geldwerte Leistungen in dieser Kategorie – §7 Abs. 6							1			1	
	% -ualer Anteil im Verhältnis zu allen Empfängern geldwerten Leistungen in dieser Kategorie – §7 Abs. 6										5.0%	
	Gesamte Offenlegung											
	Geldwerte Leistungen im Zusammenhang mit Forschung & Entwicklung §7 Abs. 5									Gesamtbetrag	2.976.602 €	
	Die in Bezug genommenen Vorschriften sind solche des FSA-Transparenzkodex · HCP = Angehörige der Fachkreise im Sinne des §2 Abs. 1 FSA-Transparenzkodex · HCO = Organisation im Sinne des §2 Abs. 2 FSA-Transparenzkodex											



**Arzneimittel und Kooperation im
Gesundheitswesen AKG e.V.**

**Deutschland
Methodik der Offenlegung
2020**

Inhaltsübersicht

1. Datenschutz - Zustimmung zur Veröffentlichung von Daten
2. Datenschutz - Teilweise Zustimmung zur Veröffentlichung von Daten
3. Datenschutz - Einwilligungserklärung
4. Dauer der Veröffentlichung
5. Grenzüberschreitende Interaktionen
6. Währung
7. Umsatzsteuer
8. Datum der Wertübertragung
9. Abgleich der Daten

1. Datenschutz – Zustimmung zur Veröffentlichung der Daten

bluebird bio bittet alle medizinischen Fachkräfte (HCPs), medizinische Organisationen (HCOs) und andere relevante Entscheidungsträger (ORDMs) um ihr Einverständnis, bevor eine Wertübertragung (ToV) an die betroffene Person deklariert wird. Sollte diese Zustimmung nicht erteilt werden, wird bluebird bio die Wertübertragung im aggregierten Teil des Berichts veröffentlichen.

2. Datenschutz – Teilweise Zustimmung zur Veröffentlichung der Daten

Wenn ein HCP/HCO/ORDM mehrere Werttransfers von bluebird bio erhält und sich entscheidet, der Offenlegung eines oder mehrerer dieser Werttransfers nicht zuzustimmen, wird bluebird bio alle Werttransfers dieser Person in ihrer Gesamtsumme offenlegen.

3. Datenschutz - Einwilligungserklärung

HCPs/HCOs/ORDMs werden über den Zweck des AKG Offenlegungscodes und die erforderliche Datenverarbeitung informiert. Den HCPs/HCOs/ORDMs wird die Möglichkeit gegeben, die Zustimmung für mindestens einen vollen Berichtszeitraum zu erteilen oder der Veröffentlichung der Daten zu widersprechen.

4. Dauer der Veröffentlichung

Der Bericht von bluebird bio wird für einen Zeitraum von drei Jahren verfügbar sein. Der Bericht wird entsprechend geändert, wenn dies aus bestimmten Gründen, z. B. aus rechtlichen Gründen, erforderlich ist.

5. Grenzüberschreitende Interaktionen

Für HCPs/HCOs und ORDMs wird bluebird bio auf Basis der Hauptpraxisadresse des identifizierten Empfängers offenlegen, unabhängig davon, wo die Zahlung erfolgt.

6. Währung

Alle Zahlungen und Werttransfers werden in der lokalen Währung angegeben. Wenn eine Zahlung in einer anderen Währung erfasst wird, wird der Umrechnungskurs vom 31. Dezember 2020 verwendet.

7. Umsatzsteuer

Die Mehrwertsteuer ist bei Direktzahlungen ausgeschlossen und bei Wertübertragungen mit Aufwandsentschädigung enthalten.

8. Datum der Wertübertragung



bluebird bio verwendete das Zahlungsdatum für direkte gebührenpflichtige Dienste und andere Zahlungen für Aktivitäten innerhalb des Berichtszeitraums, einschließlich der Erstattung von Reise- und Unterkunftskosten. Für Verträge oder Vereinbarungen mit Leistungen, die sich über mehrere Perioden erstrecken, verwendete bluebird bio das Datum der Zahlung als ToV-Datum.

9. Abgleich der Daten

Jährlich wird bluebird bio einen Jahresabgleich durchführen, um alle Transaktionen zu identifizieren, die nach der Datenvälidierung oder nach der Veröffentlichung eingereicht wurden und die Berichte entsprechend aktualisieren, um die Prinzipien der vollständigen Transparenz zu unterstützen.

Transparency Reporting in the Netherlands – 2020

Sponsor ID	Sponsor Key	KvK Nummer	BIG Nummer	E-mailadres Ontvanger	Type	Jaar	Bedrag	Additionele Informatie
1155	v!fyZ&n	24334797		sponsorship@ehaweb.org	21	2020	25000	
1155	v!fyZ&n	24334797		sponsorship@ehaweb.org	21	2020	35300	
1155	v!fyZ&n	24334797		sponsorship@ehaweb.org	21	2020	75000	
1155	v!fyZ&n	24334797		sponsorship@ehaweb.org	21	2020	8000	
1155	v!fyZ&n	41166105		sponsorship@ebmt.org	21	2020	25000	
1155	v!fyZ&n	41166105		sponsorship@ebmt.org	21	2020	13571	
1155	v!fyZ&n	41166105		sponsorship@ebmt.org	21	2020	18095	
1155	v!fyZ&n	41166105		sponsorship@ebmt.org	21	2020	10000	
1155	v!fyZ&n	41166105		sponsorship@ebmt.org	21	2020	15000	
1155	v!fyZ&n	41166105		sponsorship@ebmt.org	21	2020	1000	
1155	v!fyZ&n	41166105		sponsorship@ebmt.org	21	2020	25000	
1155	v!fyZ&n	41166105		sponsorship@ebmt.org	21	2020	88800	
1155	v!fyZ&n	41166105		sponsorship@ebmt.org	21	2020	88800	

Transparency Reporting in Belgium - 2020

Type of beneficiary of premium and benefit	Name	Postal Code	Profession (HCP)	Entreprise number (HCO, PO)	NiHDI number (HCP)	National Register number (HCP)	Identifier communicated by betreueponent.be (HCP, HCO, PO)	Donations and grants that support healthcare	Sponsorship agreements with (third parties appointed by) HCOs to manage a scientific event	Registration fees for a scientific event	Travel and accommodation in the frame of a scientific event	Fees for services and consultancy	Payments/reimbursements of expenses for service and consultancy (including travel & accommodation)	Financial supports to patient organisations	Other supports to patient organisations	Scientific Research
HCO	ASSOCIATION HOSPITALIERE DE	1020		0260238627				0.00	0.00	0.00	0.00	800.00	0.00	0.00	0.00	0.00
HCO	HOPITAL ERASME - CLINIQUES UNIVERSITAIRES	1070		0941792893				0.00	0.00	0.00	0.00	800.00	0.00	0.00	0.00	0.00
PO	HICT	9000		0866039556				0.00	0.00	0.00	0.00	0.00	0.00	12,500.00	0.00	0.00

France - Contracts Transparency Report Submission (February, 2021)

ENTREPRISE_IDENTIFIANT LINEE_IDENTIFIANT LINEE_ACTION LINEE_DEMANDE_RECTIFICATION BENEF_CATEGORIE BENEF_NOM BENEF_PRENOM BENEF_QUALITE BENEF_ADRESSE1 BENEF_ADRESSE2 BENEF_ADRESSE3 BENEF_ADRESSE4 BENEF_CODEPOSTAL BENEF_VILLE BENEF_PAYS BENEF_TITRE BENEF_SPECIALE BENEF_IDENTIFIANT_TYPE BENEF_IDENTIFIANT_VALEUR BENEF_ETABLISSEMENT BENEF_ETABLISSEMENT_CODEPOSTAL BENEF_ETABLISSEMENT_VILLE BENEF_DENOMINATIONSOCIALE BENEF_OBJETSOCIAL LINE_TYPE CONV_DATE_SIGNATURE CONV_OBJET CONV_OBJET_AUTRE CONV_DATE_DEBUT CONV_DATE_FIN CONV_MONTANT_TTC CONV_EVENEMENT_DATE CONV_EVENEMENT_NOM CONV_EVENEMENT_LIEU CONV_EVENEMENT_ORGANISEUR AVANT_SOCIAL AVANT_MONTANT_TTC AVANT_NATURE AVANT_CONVENTION_LIE REMU_DATE REMU_MONTANT_TTC REMU_CONVENTION_LIEE
GHURNQVW CONTRACTID32748_0 [C][N][P]RS[Gauthier-Vasserot Alexandra [10] 1 place Joseph Renaut [69008 yon [FR]] [RPPS]10100826030 [C][09/09/2020][CIM] /[09/09/2020 GHURNQVW CONTRACTID29847_0 [C][N][P]RS[Habili - Khosrowshahi Anoosha [10] 51 ave du Marchal de Latte de Tassigny [49000 Cetrel [FR]] [RPPS]10002996873 [C][12/11/2019][CES] /[12/11/2019 GHURNQVW CONTRACTID32807_0 [C][N][P]RS[Thuret Dr. Isabelle [10] Hôpital de la Timone Service Hématologie Pédiatrique [13005 Marseille [FR]] [RPPS]10001406585 [C][09/09/2020][CIM] /[09/09/2020 BIZLDYTN CONTRACTID3336_0 [C][N][P]RS[De Montalembert Dr. Marianne [10] 458 Boulevard du Commandant Charcot [92200 Neuilly [FR]] [RPPS]1000034183 [C][05/11/2020][CES] /[05/11/2020 GHURNQVW CONTRACTID32739_0 [C][N][P]RS[Galacteros Frederic [10] 7 Rue de la Driessene [94440 Sateny [FR]] [RPPS]1000127705 [C][11/09/2020][CIM] /[11/09/2020 BIZLDYTN CONTRACTID33379_0 [C][N][P]RS[De Luna Gonzalo [10] 51 Avenue du Maréchal de Latte de Tassigny [94010 Cetrel [FR]] [RPPS]10100661817 [C][06/11/2020][CES] /[06/11/2020 BIZLDYTN CONTRACTID32730_0 [C][N][P]RS[Dalle Jean-Hugues [10] 17 Rue Jaurès [93210 Saint-Denis [FR]] [RPPS]1000127705 [C][11/09/2020][CIM] /[11/09/2020 BIZLDYTN CONTRACTID33418_0 [C][N][P]RS[Dalle Jean-Hugues [10] 8 Route de la Jonelière [BP31222 [44312 Nantes [FR]] [SIREN]351265121 Audencia ORGANISME DE FORMATION [C][16/12/2019][FOR] /[16/12/2019 GHURNQVW CONTRACTID32730_0 [C][N][P]RS[Dalle Jean-Hugues [10] 257 rue Paul Doumer [75116 Paris [FR]] [SIREN]813221231 Biodimed Conseils CONSULTANT [C][22/07/2020][CES] /[22/07/2020 GHURNQVW CONTRACTID33481_0 [C][N][P]RS[Dalle Jean-Hugues [10] 257 rue Paul Doumer [75116 Paris [FR]] [SIREN]813221231 Biodimed Conseils CONSULTANT [C][16/10/2020][CES] /[16/10/2020 GHURNQVW BBB100148FR_0 [C][N][P]MS [12 AX Victor Hugo [75116 Paris [FR]] [SIREN]9950577262 Communication Globale Santé ORGANISME DE FORMATION [C][20/07/2020][FOR] /[20/07/2020 GHURNQVW CONTRACTID33359_0 [C][N][P]S [1 A place des orphelins [67000 Strasbourg [FR]] [SIREN]339193013 DORYS ASSOCIATION DE PROFESSIONNELS DE SANTE [C][05/11/2020][ACES] /[05/11/2020 BIZLDYTN CONTRACTID33105_0 [C][N][P]ON [211 C Rue de Chantepleie [10] 0281 Preversin Moens [FR]] [SIREN]751897241 Eur Henr Villemagne CONSULTANT [C][14/10/2020][CES] /[14/10/2020 BIZLDYTN CONTRACTID33106_0 [C][N][P]ON [211 C Rue de Chantepleie [10] 0282 Preversin Moens [FR]] [SIREN]751897241 Eur Henr Villemagne CONSULTANT [C][14/10/2020][CES] /[14/10/2020 GHURNQVW CONTRACTID32737_0 [C][N][P]ON [allées Jean Jaurès [10] 31015 Toulouse [FR]] [SIREN]342066727 Europa Group ORGANISATEUR CONGRES [C][11/09/2020][ACES] /[11/09/2020 GHURNQVW CONTRACTID33191_0 [C][N][P]ON [30 rue Molliens [75015 Paris [FR]] [SIREN]438820078 FB Conseil CONSULTANT [C][26/05/2020][CES] /[26/05/2020 GHURNQVW CONTRACTID33767_0 [C][N][P]US [196 rue didot [75014 Paris [FR]] [SIREN]393995964 Federation SOS Glob ASSOCIATION OF PATIENTS [C][08/12/2020][ACES] /[08/12/2020 GHURNQVW CONTRACTID32683_0 [C][N][P]ON [196 rue didot [75014 Paris [FR]] [SIREN]751931445 FONDATION MALADIES RARES FONDATION [C][24/06/2020][ACES] /[24/06/2020 GHURNQVW BBB100133FR_0 [C][N][P]MS [15 rue Rieux [75217 Boulogne Billancourt cdx [FR]] [SIREN]78823964 IFIS ORGANISME DE FORMATION [C][29/03/2020][FOR] /[29/03/2020 GHURNQVW BBB100155FR_0 [C][N][P]MS [15 rue Rieux [75217 Boulogne Billancourt cdx [FR]] [SIREN]78823964 IFIS ORGANISME DE FORMATION [C][07/09/2020][FOR] /[07/09/2020 GHURNQVW BBB100160FR_0 [C][N][P]MS [15 rue Rieux [75217 Boulogne Billancourt cdx [FR]] [SIREN]78823964 IFIS ORGANISME DE FORMATION [C][08/10/2020][FOR] /[08/10/2020 GHURNQVW CONTRACTID33296_0 [C][N][P]ON [15001 PARIS [FR]] [SIREN]534497791 KALYTERA CONSULTANT [C][20/10/2020][CES] /[20/10/2020 BIZLDYTN CONTRACTIDCONV3296_0 [C][N][P]ON [30 rue Narcisse Bertholey [69600 Oullins [FR]] [SIREN]4888197721 Stev Consultants CONSULTANT [C][01/06/2020][CES] /[01/06/2020 GHURNQVW CONTRACTID33100_0 [C][N][P]ON [30 rue Narcisse 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France - Renumerations and Benefits Transparency Report Submission (February, 2021)

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ENTREPRISE_IDENTIFIANT LIGNE_IDENTIFIANT LIGNE_ACTION LIGNE_DEMANDE RECTIFICATION BENEF_CATEGORIE BENEF_NOMBENEF_PRENOM BENEF_QUALITE BENEF_ADRESSE1 BENEF_ADRESSE2 BENEF_CODEPOSTAL BENEF_VILLE BENEF_PAYBENEF_TITRE BENEF_SPECIALENT BENEF_IDENTIFIANT BENEF_TYPE BENEF_IDENTIFIER VALUER BENEF_ETABLISSEMENT CONV_OBJET CONV_DATE_DEBUT CONV_DATE_FIN CONV_MONTANT_TTC CONV_EVENEMENT_DATE CONV_EVENEMENT_NOM CONV_EVENEMENT_LIEU CONV_EVENEMENT_ORGANISATEUR AVANT_DATE AVANT_MONTANT_TTC AVANT_NATURE AVANT_CONVENTION_LIE REMU_DATE REMU_MONTANT_TTC REMU_CONVENTION_LIEE															
BIZLDYTN BBB1000827R_2021_1_1[C][N][P] Bernaudin Françoise [10] 20 rue de Couiniers [FR][SIREN 1000187946 [1] [R] 10/06/2021 1500 CONTRACTID29522_1															
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BIZLDYTN BBB128028US_2021_1_4[C][N][FONI 3 rue des Longs Pres [92100 Boulogne [FR][SIREN 41440867 Voisin Consulting CONSULTANT [R] 29/03/2021 3332 CONTRACTID28631_0															
BIZLDYTN BBB128028US_2021_1_5[C][N][FONI 3 rue des Longs Pres [92100 Boulogne [FR][SIREN 41440867 Voisin Consulting CONSULTANT [R] 11/05/2021 1725 CONTRACTID28631_0															
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BIZLDYTN BBB135828US_2021_1_15[C][N][FONI 3 rue des Longs Pres [92100 Boulogne [FR][SIREN 41440867 Voisin Consulting CONSULTANT [R] 27/04/2021 1428 CONTRACTID30686_0															
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BIZLDYTN BBB139869US_2021_1_20[C][N][FONI 3 rue des Longs Pres [92100 Boulogne [FR][SIREN 41440867 Voisin Consulting CONSULTANT [R] 10/03/2021 2551 CONTRACTID30686_0															
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BIZLDYTN BBB139869US_2021_1_24[C][N][FONI 3 rue des Longs Pres [92100 Boulogne [FR][SIREN 41440867 Voisin Consulting CONSULTANT [R] 10/03/2021 2152 CONTRACTID32918_0															
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BIZLDYTN BBB139869US_2021_1_28[C][N][FONI 3 rue des Longs Pres [92100 Boulogne [FR][SIREN 41440867 Voisin Consulting CONSULTANT [R] 10/03/2021 2159 CONTRACTID32918_0															
BIZLDYTN BBB139869US_2021_1_29[C][N][FONI 3 rue des Longs Pres [92100 Boulogne [FR][SIREN 41440867 Voisin Consulting CONSULTANT [

France - Renumerations and Benefits Transparency Report Submission (August, 2021)

<u>Year</u>	<u>Therapeutic Area</u>	<u>Name of the Beneficiary Institution</u>	<u>Program/Project Description</u>	<u>Support Type</u>	<u>Country</u>	<u>Currency</u>	<u>Individual Payment Amount</u>	<u>Approved</u>
2020	ALD	Alex, The Leukodystrophy Charity	Alex TLC 2020 Activities	Financial Support	United Kingdom	GBP	32,500.00	Yes
2020	Rare Diseases	Genetic Alliance UK	Genetic Alliance UK - Rare Disease Film Festival	Financial Support	United Kingdom	GBP	2,000.00	Yes
2020	Thalassemia	Genetic Alliance UK	UKGA20020 Annual subscription to Rare Diseases UK	Financial Support	United Kingdom	GBP	12,000.00	Yes
2020	ALD	International Patient Organisation for Primary Immunodeficiencies (IPOPI)	EU Rare Diseases Newborn Screening Campaign Programme 2020	Financial Support	United Kingdom	EUR	20,000.00	Yes
2020	Rare Diseases	Metabolic Support UK	Metabolic Support UK - Program supporting patients with access to treatments and specialist services	Financial Support	United Kingdom	GBP	5,000.00	Yes
2020	Sickle	The Sickle Cell Society	HQPA20015 Sickle Cell Society Grant for SCTAPPG 2020 funding	Financial Support	United Kingdom	GBP	7,500.00	Yes
2020	Thalassemia	UK Thalassaemia Society	UKTS - Patient Support Program and UKTS Magazine	Financial Support	United Kingdom	GBP	15,000.00	Yes
2020	Thalassemia	SAM Deutschland	Grants & Sponsorships. HGB-Commercial (Thal). HQPA20008 - SAM e.V. Germany	Financial Support	Germany	Euro	8,000.00	Yes
2020	Thalassemia	Fondazione Franco e Piera Cutino Onlus	CHMA19120-Prof. Maggio speaker honorarium at EU MAPA meeting in Palermo Sep 2019	Financial Support	Italy	Euro	520.00	Yes
2020	Thalassemia	Fondazione Franco e Piera Cutino Onlus	HQMA20027 Sponsored Research Prof. Maggio	Financial Support	Italy	Euro	13,500.00	Yes

2020	Thalassemia	Fondazione per la Ricerca sulle Anemie ed Emoglobinopatie In Italia	Fondazione per la Ricerca Sulle Anemie, Data Use Agreement THAL-C	Financial Support	Italy	Euro	60,000.00	Yes
2020	Thalassemia	Drepagreffe Association	LentiGlobin (Thal) - Grant Donation Award	Financial Support	France	Euro	10,000.00	Yes
2020	Thalassemia	Drepagreffe Association	LentiGlobin (Thal) - Grants and Sponsorships	Financial Support	France	Euro	6,000.00	Yes
2020	Thalassemia	EURORDIS	LentiGlobin (Thal) - Emerald Membership 2020	Financial Support	France	Euro	10,000.00	Yes
2020	Thalassemia	Federation SOS Globi	LentiGlobin (Thal) - Grants & Sponsorships	Financial Support	France	Euro	10,000.00	Yes
2020	Thalassemia	Federation SOS Globi	AdBoard	Financial Support	France	Euro	694.30	Yes