

Public Declaration of Interests and Confidentiality Undertaking of European Medicines Agency (EMA)

SCIENTIFIC COMMITTEE MEMBERS AND EXPERTS

I, Patricia Felgueiras Seabra Durao

Organisation/Company: European Organisation For Rare Diseases

Country: France

Declare on my honour that, to the best of my knowledge, the only direct or indirect interests I have in the pharmaceutical companies and in medical device companies are those listed below:

Pharmaceutical company interests

1.1 Employment

No interest declared

1.2 Consultancy

No interest declared

1.3 Strategic advisory role

No interest declared

1.4 Financial interests

No interest declared

1.5 Principal investigator

No interest declared

1.6 Investigator

No interest declared

1.7 Grant / Funding to organisation /institution

Name of pharmaceutical company	Subject Matter
Sanofi; Azafaros BV	Sponsorship of Conference
Sanofi; Azafaros BV	Sponsorship for Diagnosis Packs
Azafaros BV	Sponsorship for project: Clinician Tool for GM2

1.8 Close family member interest

Name of pharmaceutical company	Type of interest declared	Other comments
Pulse Inframe - based in Canada and USA	Consultancy	Consultant for this company, an RWE platform

1.9 Repurposing of a medicinal product

No interest declared

1.10 Any other interests or facts

I am a co-founder and full-time salaried employee of the CATS Foundation. My salary is not paid by the pharmaceutical industry. I am EURORDIS volunteer. EURORDIS funding below and link here:
Black Pearl 2022: Alexion Services Europe; Alnylam Netherlands BV; Biogen (Czech Republic) s.r.o.; Chiesi; CSL BEHRING; Cytokinetics, Inc.; Foundation Bertarelli; Horizon Therapeutics; JANSSEN - a J&J company; Novartis Gene Therapies Switzerland GmbH; Orphalan; Recordati Rare Diseases; Roche; Swedish Orphan Biovitrum BVBA; Takeda Pharmaceuticals International AG; Vertex Pharmaceuticals; Vifor Pharma Group; VOZ Advisors
European Conference on Rare Diseases 2022: Biogen (Czech Republic) s.r.o.; Chiesi; CSL BEHRING; Horizon Therapeutics; JANSSEN - a J&J company; Orchard Therapeutics; PTC Therapeutics; Roche; Takeda Pharmaceuticals International AG; Ultragenyx Europe GmbH
European Round Table of Companies Restricted Membership 2022: Aeglea Biotherapeutics; Alira Health SAS; Amgen (Europe) GmbH; Amicus Therapeutics UK Ltd; AVROBIO; Blueprint Medicines; Gilead Sciences Belux; Mereo BioPharma Group plc; Novo Nordisk HQ; OpenApp; Passage Bio; Sarepta Therapeutics; Sciensus International B.V.; Takeda Pharmaceuticals International AG; Ultragenyx Europe GmbH; Vertex Pharmaceuticals; VOZ Advisors; Zambon S.p.A.
European Round Table of Companies Unrestricted Membership 2022: Alexion Services Europe; Alnylam Netherlands BV; Biogen (Czech Republic) s.r.o.; Bristol-Myers Squibb (BMS); Camurus AB; Chiesi; CSL BEHRING; GRIFOLS S.A.; Healx Ltd.; Horizon Therapeutics; Illumina Cambridge Ltd.; Insmid Ireland Ltd.; JANSSEN - a J&J company; Neurogene Inc.; Orchard Therapeutics; Ovid Therapeutics Inc.; Parexel International; PTC Therapeutics; REGENXBIO Inc.; Roche; Saniona; SANOFI; Santen Pharmaceutical; Swedish Orphan Biovitrum BVBA; Vifor Pharma Group.
EURORDIS International Initiatives: Bristol-Myers Squibb (BMS); Chiesi; Horizon Therapeutics; PTC Therapeutics; Recordati Rare Diseases; Roche; Takeda Pharmaceuticals International AG.
Rare Barometer 2022: Bristol-Myers Squibb (BMS); CSL BEHRING; EveryLife Foundation for Rare Diseases; JANSSEN - a J&J company; Swedish Orphan Biovitrum BVBA; Vifor Pharma Group
Project Development 2022: CSL BEHRING; Roche; Swedish Orphan Biovitrum BVBA
Unsolicited: BioAgilytix Labs, LLC

1.11 Committee for Advanced Therapies (CAT) member or alternate

Not a CAT member or alternate

Medical device company interests

2.1 Employment

No interest declared

2.2 Consultancy

No interest declared

2.3 Strategic advisory role

No interest declared

2.4 Financial interests

No interest declared

2.5 Principal investigator

No interest declared

2.6 Investigator

No interest declared

2.7 Grant / Funding to organisation /institution

No interest declared

2.8 Close family member interest

No interest declared

2.9 Any other interests or facts

No interest declared

CONFIDENTIALITY UNDERTAKING

In view of the following definitions:

"EMA Activities" encompass any meeting (including meeting preparation and follow-up, associated discussion or any other related activity) of the European Medicines Agency's Management Board, Committees, Working Parties, Expert Groups, or any other such meeting; work as an expert on assessments; work as an expert on guidance development.

"Confidential Information" means all information, facts, data and any other matters of which I acquire knowledge, either directly or indirectly, as a result of my EMA Activities.

"Confidential Documents" mean all drafts, preparatory information, documents and any other material, together with any information contained therein, to which I have access, either directly or indirectly, as a result of my participation in EMA Activities. Furthermore, any records or notes made by me relating to Confidential Information or Confidential Documents shall be treated as Confidential Documents.

I understand that I may be invited to participate either directly or indirectly in certain EMA activities and hereby undertake:

- To treat all Confidential Information and Confidential Documents under conditions of strict confidentiality as long as the information or document has not been made public/is not in the public domain.
- Not to disclose (or authorise any other person to disclose) in any way to any third party ¹ any Confidential Information or Confidential Document.
- Not to use (or authorise any other person to use) any Confidential Information or Confidential Document other than for the purposes of my work in connection with EMA activities.
- To dispose of Confidential Documents as confidential material as soon as I have no further use for them.
- When expressing views to indicate clearly that the views are my own if acting in my own capacity or those of the EMA, Management Board, Committee, Working Party, Expert Group or other group if acting on behalf of that group.
- Not to disclose any commercially confidential information.

This undertaking shall not be limited in time, but shall not apply to any document or information that I can reasonably prove was known to me before the date of this undertaking or which becomes public knowledge other than as a result of a breach of any of the above undertakings.

I confirm the information declared on this form is accurate and complete to the best of my knowledge and I acknowledge that my information will be stored electronically and published on the EMA website.

1. *Third party does not include employees of the National Competent Authorities who either have employment contracts that provide confidentiality obligations or are encompassed by confidentiality obligations under national legislation on professional secrecy.*

Full Name:	Patricia Felgueiras Seabra Durao
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Date:	2024-02-22
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For definitions of activities etc, refer to the policy on handling of competing interests.