

ICMJE DISCLOSURE FORM

Date: 25-102024

Your Name: Janneke Langendonk

Manuscript Title: Erfelijke metabole ziekten bij volwassenen: meer patiënten, nieuwe diagnoses en nieuwe behandelingen

Manuscript Number (if known): [Click or tap here to enter text.](#)

In the interest of transparency, we ask you to disclose all relationships/activities/interests listed below that are related to the content of your manuscript. “Related” means any relation with for-profit or not-for-profit third parties whose interests may be affected by the content of the manuscript. Disclosure represents a commitment to transparency and does not necessarily indicate a bias. If you are in doubt about whether to list a relationship/activity/interest, it is preferable that you do so.

The author’s relationships/activities/interests should be defined broadly. For example, if your manuscript pertains to the epidemiology of hypertension, you should declare all relationships with manufacturers of antihypertensive medication, even if that medication is not mentioned in the manuscript.

In item #1 below, report all support for the work reported in this manuscript without time limit. For all other items, the time frame for disclosure is the past 36 months.

		Name all entities with whom you have this relationship or indicate none (add rows as needed)	Specifications/Comments (e.g., if payments were made to you or to your institution)						
Time frame: Since the initial planning of the work									
1	All support for the present manuscript (e.g., funding, provision of study materials, medical writing, article processing charges, etc.) No time limit for this item.	☒ None <table border="1" style="width: 100%; border-collapse: collapse; margin-top: 5px;"> <tr><td style="height: 20px;"></td><td style="height: 20px;"></td></tr> <tr><td style="height: 20px;"></td><td style="height: 20px;"></td></tr> <tr><td style="height: 20px;"></td><td style="height: 20px;"></td></tr> </table>							
Time frame: past 36 months									
2	Grants or contracts from any entity (if not indicated in item #1 above).	☐ None <table border="1" style="width: 100%; border-collapse: collapse; margin-top: 5px;"> <tr> <td style="width: 60%;">Contract studies (Phase I-IV) with Alnylam, Clinuvel, Mitsubishi Tanabe, and Ultragenyx, all unrelated to this study.</td> <td style="width: 40%;"></td> </tr> <tr> <td>Unrestricted research grant from Clinuvel 2024-2028; unrelated to this study</td> <td></td> </tr> <tr><td style="height: 20px;"></td><td style="height: 20px;"></td></tr> </table>		Contract studies (Phase I-IV) with Alnylam, Clinuvel, Mitsubishi Tanabe, and Ultragenyx, all unrelated to this study.		Unrestricted research grant from Clinuvel 2024-2028; unrelated to this study			
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3	Royalties or licenses	☒ None <table border="1" style="width: 100%; border-collapse: collapse; margin-top: 5px;"> <tr><td style="height: 20px;"></td><td style="height: 20px;"></td></tr> <tr><td style="height: 20px;"></td><td style="height: 20px;"></td></tr> <tr><td style="height: 20px;"></td><td style="height: 20px;"></td></tr> </table>							

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4	Consulting fees	☒ None <table border="1"> <tr><td></td><td></td></tr> <tr><td></td><td></td></tr> <tr><td></td><td></td></tr> <tr><td></td><td></td></tr> </table>									
5	Payment or honoraria for lectures, presentations, speakers bureaus, manuscript writing or educational events	☒ None <table border="1"> <tr><td></td><td></td></tr> <tr><td></td><td></td></tr> <tr><td></td><td></td></tr> </table>									
6	Payment for expert testimony	☒ None <table border="1"> <tr><td></td><td></td></tr> <tr><td></td><td></td></tr> <tr><td></td><td></td></tr> </table>									
7	Support for attending meetings and/or travel	☐ None <table border="1"> <tr> <td>As board member and invited speaker for ICPP meetings, by Ipnet and local organisers, unrelated to this study.</td> <td>Ipnet and the local organisers are non-profit organisations for the studies on Porphyrias.</td> </tr> <tr><td></td><td></td></tr> <tr><td></td><td></td></tr> </table>		As board member and invited speaker for ICPP meetings, by Ipnet and local organisers, unrelated to this study.	Ipnet and the local organisers are non-profit organisations for the studies on Porphyrias.						
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8	Patents planned, issued or pending	☒ None <table border="1"> <tr><td></td><td></td></tr> <tr><td></td><td></td></tr> <tr><td></td><td></td></tr> </table>									
9	Participation on a Data Safety Monitoring Board or Advisory Board	☒ None <table border="1"> <tr><td></td><td></td></tr> <tr><td></td><td></td></tr> <tr><td></td><td></td></tr> </table>									
10	Leadership or fiduciary role in other board, society, committee or advocacy group, paid or unpaid	☐ None <table border="1"> <tr> <td>Treasurer in the executive board of Ipnet, International non profit porphyria network</td> <td></td> </tr> <tr><td></td><td></td></tr> <tr><td></td><td></td></tr> </table>		Treasurer in the executive board of Ipnet, International non profit porphyria network							
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11	Stock or stock options	☒ None <table border="1" style="width: 100%; margin-top: 5px;"> <tr><td></td><td></td></tr> <tr><td></td><td></td></tr> <tr><td></td><td></td></tr> </table>							
12	Receipt of equipment, materials, drugs, medical writing, gifts or other services	☒ None <table border="1" style="width: 100%; margin-top: 5px;"> <tr><td></td><td></td></tr> <tr><td></td><td></td></tr> <tr><td></td><td></td></tr> </table>							
13	Other financial or non-financial interests	☒ None <table border="1" style="width: 100%; margin-top: 5px;"> <tr><td></td><td></td></tr> <tr><td></td><td></td></tr> <tr><td></td><td></td></tr> </table>							

Please place an "X" next to the following statement to indicate your agreement:

☒ I certify that I have answered every question and have not altered the wording of any of the questions on this form.