

## ICMJE DISCLOSURE FORM

**Date:** 12/21/2023

**Your Name:** Jalayne J Arias

**Manuscript Title:** Data Stewardship in FTLD Research: Investigator and Research Participant Views

**Manuscript Number (if known):** ADJ-D-23-01340

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								
<b>1</b>	All support for the present manuscript (e.g., funding, provision of study materials, medical writing, article processing charges, etc.) <b>No time limit for this item.</b>	<input type="checkbox"/> None  <table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 60%; padding: 5px;"><b>Marcus Program in Precision Medicine Innovation (MPPMI) - ELSI in Precision Medicine Initiative 2019</b></td> <td style="width: 40%;"></td> </tr> <tr> <td style="height: 20px;"></td> <td></td> </tr> <tr> <td style="height: 20px;"></td> <td style="text-align: right; font-size: small;">Click the tab key to add additional rows.</td> </tr> </table>	<b>Marcus Program in Precision Medicine Innovation (MPPMI) - ELSI in Precision Medicine Initiative 2019</b>					Click the tab key to add additional rows.
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Time frame: past 36 months								
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11	Stock or stock options	<input checked="" type="checkbox"/> None	
12	Receipt of equipment, materials, drugs, medical writing, gifts or other services	<input checked="" type="checkbox"/> None	
13	Other financial or non-financial interests	<input checked="" type="checkbox"/> None	

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.

## ICMJE DISCLOSURE FORM

**Date:** 12/21/2023

**Your Name:** Laura M. Beskow

**Manuscript Title:** Data Stewardship in FTLD Research: Investigator and Research Participant Views

**Manuscript Number (if known):** ADJ-D-23-01340

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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.

## ICMJE DISCLOSURE FORM

**Date:** 12/19/2023

**Your Name:** Susan L-J Dickinson

**Manuscript Title:** Data Stewardship in FTLD Research: Investigator and Research Participant Views

**Manuscript Number (if known):** ADJ-D-23-01340

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.

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10	Leadership or fiduciary role in other board,	<input type="checkbox"/> <b>None</b>							



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	society, committee or advocacy group, paid or unpaid	CEO, The Association for Frontotemporal Degeneration	
		Partner, FTD Disorders Registry LLC (AFTD is the partner, I'm the official rep)	The Bluefield Project (a nonprofit org) is our partner in the LLC
<b>11</b>	Stock or stock options	<input checked="" type="checkbox"/> <b>None</b>	
<b>12</b>	Receipt of equipment, materials, drugs, medical writing, gifts or other services	<input checked="" type="checkbox"/> <b>None</b>	
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Please place an "X" next to the following statement to indicate your agreement:

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## ICMJE DISCLOSURE FORM

**Date:** 12/18/2023

**Your Name:** Jill Goldman

**Manuscript Title:** Data Stewardship in FTLD Research: Investigator and Research Participant Views

**Manuscript Number (if known):** ADJ-D-23-01340

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# ICMJE DISCLOSURE FORM

**Date:** 12/18/2023

**Your Name:** Heather M. Snyder

**Manuscript Title:** Data Stewardship in FTLD Research: Investigator and Research Participant Views

**Manuscript Number (if known):** ADJ-D-23-01340

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<b>1</b>	All support for the present manuscript (e.g., funding, provision of study materials, medical writing, article processing charges, etc.) <b>No time limit for this item.</b>	<input type="checkbox"/> <b>None</b>  <table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 60%;">I am a full time employee of the Alzheimer's Association. Any time spent on this effort and supporting this manuscript preparation was supported through my employer.</td> <td style="width: 40%;"></td> </tr> <tr> <td> </td> <td> </td> </tr> <tr> <td colspan="2" style="text-align: right; font-size: small;">Click the tab key to add additional rows.</td> </tr> </table>	I am a full time employee of the Alzheimer's Association. Any time spent on this effort and supporting this manuscript preparation was supported through my employer.				Click the tab key to add additional rows.	
I am a full time employee of the Alzheimer's Association. Any time spent on this effort and supporting this manuscript preparation was supported through my employer.								
Click the tab key to add additional rows.								
Time frame: past 36 months								
<b>2</b>	Grants or contracts from any entity (if not indicated in item #1 above).	<input type="checkbox"/> <b>None</b>  <table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 60%;">National Institute on Aging/ NIH (grants are made to my institution)</td> <td style="width: 40%;"></td> </tr> <tr> <td> </td> <td> </td> </tr> </table>	National Institute on Aging/ NIH (grants are made to my institution)					
National Institute on Aging/ NIH (grants are made to my institution)								
<b>3</b>	Royalties or licenses	<input checked="" type="checkbox"/> <b>None</b>  <table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 60%;"></td> <td style="width: 40%;"></td> </tr> <tr> <td> </td> <td> </td> </tr> </table>						

		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)
4	Consulting fees	<input checked="" type="checkbox"/> None	
5	Payment or honoraria for lectures, presentations, speakers bureaus, manuscript writing or educational events	<input checked="" type="checkbox"/> None	
6	Payment for expert testimony	<input checked="" type="checkbox"/> None	
7	Support for attending meetings and/or travel	<input checked="" type="checkbox"/> None	
		All travel paid for by the Alzheimer's Association	
8	Patents planned, issued or pending	<input checked="" type="checkbox"/> None	
9	Participation on a Data Safety Monitoring Board or Advisory Board	<input type="checkbox"/> None	
		EAB for Discovery (NINDS funded), unpaid	
10	Leadership or fiduciary role in other board, society, committee or advocacy group, paid or unpaid	<input type="checkbox"/> None	
		Chair, Programmatic Review for the CDMRP AD/ADRD and TBI Program, unpaid	Research Committee, American Heart Association, unpaid
		Chair and Immediate Past Chair for Health Research Alliance, unpaid	
		Member, FHS Advisory Investigators Committee, unpaid	

		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)
<b>11</b>	Stock or stock options	<input checked="" type="checkbox"/> <b>None</b>	
<b>12</b>	Receipt of equipment, materials, drugs, medical writing, gifts or other services	<input checked="" type="checkbox"/> <b>None</b>	
<b>13</b>	Other financial or non-financial interests	<input type="checkbox"/> <b>None</b>	
		Partner is a full time employee of Abbott Labs in an unrelated field.	
		HS is a full time employee of the Alzheimer's Association	

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.

# ICMJE DISCLOSURE FORM

**Date:** 12/21/2023

**Your Name:** Mary A. Majumder

**Manuscript Title:** Data Stewardship in FTLD Research: Investigator and Research Participant Views

**Manuscript Number (if known):** ADJ-D-23-01340

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)						
<b>Time frame: Since the initial planning of the work</b>									
<b>1</b>	All support for the present manuscript (e.g., funding, provision of study materials, medical writing, article processing charges, etc.) <b>No time limit for this item.</b>	<input checked="" type="checkbox"/> <b>None</b> <table border="1" style="width: 100%; height: 40px; margin-top: 5px;"> <tr><td style="width: 60%;"></td><td></td></tr> <tr><td></td><td></td></tr> <tr><td></td><td></td></tr> </table>							<div style="border: 1px solid black; padding: 2px; font-size: small;">Click the tab key to add additional rows.</div>
<b>Time frame: past 36 months</b>									
<b>2</b>	Grants or contracts from any entity (if not indicated in item #1 above).	<input checked="" type="checkbox"/> <b>None</b> <table border="1" style="width: 100%; height: 40px; margin-top: 5px;"> <tr><td style="width: 60%;"></td><td></td></tr> <tr><td></td><td></td></tr> <tr><td></td><td></td></tr> </table>							
<b>3</b>	Royalties or licenses	<input checked="" type="checkbox"/> <b>None</b> <table border="1" style="width: 100%; height: 40px; margin-top: 5px;"> <tr><td style="width: 60%;"></td><td></td></tr> <tr><td></td><td></td></tr> <tr><td></td><td></td></tr> </table>							



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4	Consulting fees	<input checked="" type="checkbox"/> <b>None</b> <table border="1" style="width: 100%; border-collapse: collapse;"> <tr><td style="width: 50%; height: 15px;"></td><td style="width: 50%;"></td></tr> <tr><td style="height: 15px;"></td><td></td></tr> <tr><td style="height: 15px;"></td><td></td></tr> <tr><td style="height: 15px;"></td><td></td></tr> </table>									
5	Payment or honoraria for lectures, presentations, speakers bureaus, manuscript writing or educational events	<input checked="" type="checkbox"/> <b>None</b> <table border="1" style="width: 100%; border-collapse: collapse;"> <tr><td style="width: 50%; height: 15px;"></td><td style="width: 50%;"></td></tr> <tr><td style="height: 15px;"></td><td></td></tr> <tr><td style="height: 15px;"></td><td></td></tr> </table>									
6	Payment for expert testimony	<input checked="" type="checkbox"/> <b>None</b> <table border="1" style="width: 100%; border-collapse: collapse;"> <tr><td style="width: 50%; height: 15px;"></td><td style="width: 50%;"></td></tr> <tr><td style="height: 15px;"></td><td></td></tr> <tr><td style="height: 15px;"></td><td></td></tr> </table>									
7	Support for attending meetings and/or travel	<input checked="" type="checkbox"/> <b>None</b> <table border="1" style="width: 100%; border-collapse: collapse;"> <tr><td style="width: 50%; height: 15px;"></td><td style="width: 50%;"></td></tr> <tr><td style="height: 15px;"></td><td></td></tr> <tr><td style="height: 15px;"></td><td></td></tr> </table>									
8	Patents planned, issued or pending	<input checked="" type="checkbox"/> <b>None</b> <table border="1" style="width: 100%; border-collapse: collapse;"> <tr><td style="width: 50%; height: 15px;"></td><td style="width: 50%;"></td></tr> <tr><td style="height: 15px;"></td><td></td></tr> <tr><td style="height: 15px;"></td><td></td></tr> </table>									
9	Participation on a Data Safety Monitoring Board or Advisory Board	<input checked="" type="checkbox"/> <b>None</b> <table border="1" style="width: 100%; border-collapse: collapse;"> <tr><td style="width: 50%; height: 15px;"></td><td style="width: 50%;"></td></tr> <tr><td style="height: 15px;"></td><td></td></tr> <tr><td style="height: 15px;"></td><td></td></tr> </table>									
10	Leadership or fiduciary role in other board, society, committee or advocacy group, paid or unpaid	<input checked="" type="checkbox"/> <b>None</b> <table border="1" style="width: 100%; border-collapse: collapse;"> <tr><td style="width: 50%; height: 15px;"></td><td style="width: 50%;"></td></tr> <tr><td style="height: 15px;"></td><td></td></tr> <tr><td style="height: 15px;"></td><td></td></tr> </table>									

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<b>11</b>	Stock or stock options	<input checked="" type="checkbox"/> <b>None</b> <table border="1" style="width: 100%; border-collapse: collapse;"> <tr><td style="width: 50%; height: 20px;"></td><td style="width: 50%;"></td></tr> <tr><td style="height: 20px;"></td><td></td></tr> <tr><td style="height: 20px;"></td><td></td></tr> </table>							
<b>12</b>	Receipt of equipment, materials, drugs, medical writing, gifts or other services	<input checked="" type="checkbox"/> <b>None</b> <table border="1" style="width: 100%; border-collapse: collapse;"> <tr><td style="width: 50%; height: 20px;"></td><td style="width: 50%;"></td></tr> <tr><td style="height: 20px;"></td><td></td></tr> <tr><td style="height: 20px;"></td><td></td></tr> </table>							
<b>13</b>	Other financial or non-financial interests	<input checked="" type="checkbox"/> <b>None</b> <table border="1" style="width: 100%; border-collapse: collapse;"> <tr><td style="width: 50%; height: 20px;"></td><td style="width: 50%;"></td></tr> <tr><td style="height: 20px;"></td><td></td></tr> <tr><td style="height: 20px;"></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.

# ICMJE DISCLOSURE FORM

**Date:** 12/19/2023

**Your Name:** Maria C Carrillo

**Manuscript Title:** Data Stewardship in FTLD Research: Investigator and Research Participant Views

**Manuscript Number (if known):** ADJ-D-23-01340

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								
<b>1</b>	All support for the present manuscript (e.g., funding, provision of study materials, medical writing, article processing charges, etc.) <b>No time limit for this item.</b>	<input checked="" type="checkbox"/> <b>None</b> <table border="1" style="width: 100%; height: 40px; margin-top: 5px;"> <tr><td style="width: 60%;"></td><td style="width: 40%;"></td></tr> <tr><td></td><td></td></tr> <tr><td></td><td></td></tr> </table> <p style="font-size: small; text-align: right; margin-top: 5px;">Click the tab key to add additional rows.</p>						
Time frame: past 36 months								
<b>2</b>	Grants or contracts from any entity (if not indicated in item #1 above).	<input type="checkbox"/> <b>None</b> <table border="1" style="width: 100%; height: 150px; margin-top: 5px;"> <tr> <td style="width: 60%; padding: 5px;">           *Title: LINC-AD: Leveraging an Interdisciplinary Consortium to Improve Care and Outcomes for Persons Living with Alzheimer's and Dementia            Major Goals: The goal is to create an international consortium of researchers and stakeholders that will review existing measures, identify and address gaps, and disseminate these results via permanent online repositories of recommended measures and shareable data. *Status of Support: Active 0.1 Mo/yr         </td> <td style="width: 40%;"></td> </tr> <tr><td></td><td></td></tr> <tr><td></td><td></td></tr> </table>	*Title: LINC-AD: Leveraging an Interdisciplinary Consortium to Improve Care and Outcomes for Persons Living with Alzheimer's and Dementia Major Goals: The goal is to create an international consortium of researchers and stakeholders that will review existing measures, identify and address gaps, and disseminate these results via permanent online repositories of recommended measures and shareable data. *Status of Support: Active 0.1 Mo/yr					
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		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)						
3	Royalties or licenses	<input checked="" type="checkbox"/> <b>None</b> <table border="1" style="width: 100%; border-collapse: collapse;"> <tr><td style="width: 50%; height: 15px;"></td><td style="width: 50%;"></td></tr> <tr><td style="height: 15px;"></td><td></td></tr> <tr><td style="height: 15px;"></td><td></td></tr> </table>							
4	Consulting fees	<input checked="" type="checkbox"/> <b>None</b> <table border="1" style="width: 100%; border-collapse: collapse;"> <tr><td style="width: 50%; height: 15px;"></td><td style="width: 50%;"></td></tr> <tr><td style="height: 15px;"></td><td></td></tr> <tr><td style="height: 15px;"></td><td></td></tr> </table>							
5	Payment or honoraria for lectures, presentations, speakers bureaus, manuscript writing or educational events	<input checked="" type="checkbox"/> <b>None</b> <table border="1" style="width: 100%; border-collapse: collapse;"> <tr><td style="width: 50%; height: 15px;"></td><td style="width: 50%;"></td></tr> <tr><td style="height: 15px;"></td><td></td></tr> <tr><td style="height: 15px;"></td><td></td></tr> </table>							
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7	Support for attending meetings and/or travel	<input checked="" type="checkbox"/> <b>None</b> <table border="1" style="width: 100%; border-collapse: collapse;"> <tr><td style="width: 50%; height: 15px;"></td><td style="width: 50%;"></td></tr> <tr><td style="height: 15px;"></td><td></td></tr> <tr><td style="height: 15px;"></td><td></td></tr> </table>							
8	Patents planned, issued or pending	<input checked="" type="checkbox"/> <b>None</b> <table border="1" style="width: 100%; border-collapse: collapse;"> <tr><td style="width: 50%; height: 15px;"></td><td style="width: 50%;"></td></tr> <tr><td style="height: 15px;"></td><td></td></tr> <tr><td style="height: 15px;"></td><td></td></tr> </table>							
9	Participation on a Data Safety Monitoring Board or Advisory Board	<input type="checkbox"/> <b>None</b> <table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 50%; height: 15px;">US POINTER Study DSMB</td> <td style="width: 50%;"></td> </tr> <tr> <td style="height: 15px;"></td> <td></td> </tr> <tr> <td style="height: 15px;"></td> <td></td> </tr> </table>	US POINTER Study DSMB						
US POINTER Study DSMB									
10	Leadership or fiduciary role in other board,	<input checked="" type="checkbox"/> <b>None</b> <table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 50%; height: 15px;">GHR Foundatoin Member of BOD</td> <td style="width: 50%;">Unpaid</td> </tr> </table>	GHR Foundatoin Member of BOD	Unpaid					
GHR Foundatoin Member of BOD	Unpaid								

		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)
	society, committee or advocacy group, paid or unpaid	International Brain Bee, Member BOD	Unpaid
<b>11</b>	Stock or stock options	<input checked="" type="checkbox"/> <b>None</b>	
<b>12</b>	Receipt of equipment, materials, drugs, medical writing, gifts or other services	<input checked="" type="checkbox"/> <b>None</b>	
<b>13</b>	Other financial or non-financial interests	<input checked="" type="checkbox"/> <b>None</b>	

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.

## ICMJE DISCLOSURE FORM

**Date:** 12/18/2023

**Your Name:** Michelle Mello

**Manuscript Title:** Data Stewardship in FTLD Research: Investigator and Research Participant Views

**Manuscript Number (if known):** ADJ-D-23-01340

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									
<b>1</b>	All support for the present manuscript (e.g., funding, provision of study materials, medical writing, article processing charges, etc.) <b>No time limit for this item.</b>	<input type="checkbox"/> <b>None</b>  <table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 55%;">NIH grant (Jalayne Arias, PI)</td> <td style="width: 45%;">As disclosed on Dr. Arias's COI form</td> </tr> <tr> <td> </td> <td> </td> </tr> <tr> <td colspan="2" style="text-align: center; font-size: small;">Click the tab key to add additional rows.</td> </tr> </table>	NIH grant (Jalayne Arias, PI)	As disclosed on Dr. Arias's COI form			Click the tab key to add additional rows.		
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Click the tab key to add additional rows.									
Time frame: past 36 months									
<b>2</b>	Grants or contracts from any entity (if not indicated in item #1 above).	<input checked="" type="checkbox"/> <b>None</b>  <table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 55%;"> </td> <td style="width: 45%;"> </td> </tr> <tr> <td> </td> <td> </td> </tr> </table>							
<b>3</b>	Royalties or licenses	<input checked="" type="checkbox"/> <b>None</b>  <table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 55%;"> </td> <td style="width: 45%;"> </td> </tr> <tr> <td> </td> <td> </td> </tr> </table>							

		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)
4	Consulting fees	<input type="checkbox"/> None	
		Verily Life Sciences, LLC	Personal fees for serving as an advisor on a product designed to facilitate safe return to work and school during COVID-19
5	Payment or honoraria for lectures, presentations, speakers bureaus, manuscript writing or educational events	<input type="checkbox"/> None	
		University of Pennsylvania	Honorarium for participating in a scholarly working group on data ethics.
6	Payment for expert testimony	<input checked="" type="checkbox"/> None	
7	Support for attending meetings and/or travel	<input checked="" type="checkbox"/> None	
8	Patents planned, issued or pending	<input checked="" type="checkbox"/> None	
9	Participation on a Data Safety Monitoring Board or Advisory Board	<input checked="" type="checkbox"/> None	
10	Leadership or fiduciary role in other board, society, committee or advocacy group, paid or unpaid	<input checked="" type="checkbox"/> None	

		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)						
<b>11</b>	Stock or stock options	<input checked="" type="checkbox"/> <b>None</b> <table border="1" style="width: 100%; border-collapse: collapse;"> <tr><td style="width: 50%; height: 20px;"></td><td style="width: 50%;"></td></tr> <tr><td style="height: 20px;"></td><td></td></tr> <tr><td style="height: 20px;"></td><td></td></tr> </table>							
<b>12</b>	Receipt of equipment, materials, drugs, medical writing, gifts or other services	<input checked="" type="checkbox"/> <b>None</b> <table border="1" style="width: 100%; border-collapse: collapse;"> <tr><td style="width: 50%; height: 20px;"></td><td style="width: 50%;"></td></tr> <tr><td style="height: 20px;"></td><td></td></tr> <tr><td style="height: 20px;"></td><td></td></tr> </table>							
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I certify that I have answered every question and have not altered the wording of any of the questions on this form.



## ICMJE DISCLOSURE FORM

**Date:** 12/20/2023

**Your Name:** Ana M. Tyler

**Manuscript Title:** Data Stewardship in FTLD Research: Investigator and Research Participant Views

**Manuscript Number (if known):** ADJ-D-23-01340

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.

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	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)						
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<b>3</b>	Royalties or licenses	<input checked="" type="checkbox"/> <b>None</b> <table border="1" style="width: 100%; border-collapse: collapse; margin-top: 5px;"> <tr><td style="width: 60%; height: 20px;"></td><td style="width: 40%;"></td></tr> <tr><td style="height: 20px;"></td><td></td></tr> <tr><td style="height: 20px;"></td><td></td></tr> </table>						

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4	Consulting fees	<input checked="" type="checkbox"/> <b>None</b> <table border="1" style="width: 100%; border-collapse: collapse;"> <tr><td style="width: 50%; height: 15px;"></td><td style="width: 50%;"></td></tr> <tr><td style="height: 15px;"></td><td></td></tr> <tr><td style="height: 15px;"></td><td></td></tr> <tr><td style="height: 15px;"></td><td></td></tr> </table>									
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10	Leadership or fiduciary role in other board, society, committee or advocacy group, paid or unpaid	<input checked="" type="checkbox"/> <b>None</b> <table border="1" style="width: 100%; border-collapse: collapse;"> <tr><td style="width: 50%; height: 15px;"></td><td style="width: 50%;"></td></tr> <tr><td style="height: 15px;"></td><td></td></tr> <tr><td style="height: 15px;"></td><td></td></tr> </table>									

		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)
11	Stock or stock options	<input checked="" type="checkbox"/> None	
12	Receipt of equipment, materials, drugs, medical writing, gifts or other services	<input checked="" type="checkbox"/> None	
13	Other financial or non-financial interests	<input checked="" type="checkbox"/> None	

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.

## ICMJE DISCLOSURE FORM

**Date:** 12/20/2023

**Your Name:** Jennifer S. Yokoyama

**Manuscript Title:** Data Stewardship in FTLD Research: Investigator and Research Participant Views

**Manuscript Number (if known):** ADJ-D-23-01340

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.

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		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)										
<b>Time frame: Since the initial planning of the work</b>													
<b>1</b>	All support for the present manuscript (e.g., funding, provision of study materials, medical writing, article processing charges, etc.) <b>No time limit for this item.</b>	<input type="checkbox"/> <b>None</b>	<table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 50%; padding: 2px;">NIH</td> <td style="width: 50%; padding: 2px;">Institution (NIH-NIA R01 AG062588, R01 AG057234, P30 AG062422; NIH-NINDS U54 NS123985, NIH-NIDA 75N95022C00031, NIH-NIA U19AG079774)</td> </tr> <tr> <td style="padding: 2px;">Rainwater Charitable Foundation</td> <td style="padding: 2px;">Institution</td> </tr> <tr> <td style="padding: 2px;">Alzheimer's Association</td> <td style="padding: 2px;">Institution</td> </tr> <tr> <td style="padding: 2px;">Global Brain Health Institute</td> <td style="padding: 2px;">Institution</td> </tr> <tr> <td style="padding: 2px;">Mary Oakley Foundation</td> <td style="padding: 2px;">Institution</td> </tr> </table>	NIH	Institution (NIH-NIA R01 AG062588, R01 AG057234, P30 AG062422; NIH-NINDS U54 NS123985, NIH-NIDA 75N95022C00031, NIH-NIA U19AG079774)	Rainwater Charitable Foundation	Institution	Alzheimer's Association	Institution	Global Brain Health Institute	Institution	Mary Oakley Foundation	Institution
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<b>2</b>	Grants or contracts from any entity (if not indicated in item #1 above).	<input checked="" type="checkbox"/> <b>None</b>	<table border="1" style="width: 100%; border-collapse: collapse;"> <tr><td style="width: 50%; height: 20px;"></td><td style="width: 50%;"></td></tr> <tr><td style="height: 20px;"></td><td></td></tr> <tr><td style="height: 20px;"></td><td></td></tr> </table>										
<b>3</b>	Royalties or licenses	<input checked="" type="checkbox"/> <b>None</b>	<table border="1" style="width: 100%; border-collapse: collapse;"> <tr><td style="width: 50%; height: 20px;"></td><td style="width: 50%;"></td></tr> <tr><td style="height: 20px;"></td><td></td></tr> <tr><td style="height: 20px;"></td><td></td></tr> </table>										

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5	Payment or honoraria for lectures, presentations, speakers bureaus, manuscript writing or educational events	<input type="checkbox"/> <b>None</b>	
		Lecture: "Immune Contributions to Frontotemporal Dementia," Knight Initiative Symposium: Frontotemporal Dementia, Knight Initiative for Brain Resilience, Wu Tsai Neurosciences Institute, Stanford University, November 28, 2023	Payment to JSY directly
		Lecture: "Immune Contributors to Neurodegenerative Disease," Washington University in St. Louis School of Medicine NeuroGenomics and Informatics Center, August 18, 2022	Payment to JSY directly
		Lecture: Immune Contributors to Neurodegeneration," North Central Florida Society for Neuroscience Chapter Conference, January 28, 2022	Payment to JSY directly
		Lecture: "Genetic Characterization of Neurodegenerative Diseases," The Ohio State University Inaugural Neurogenetics Symposium, September 24, 2021.	Payment to JSY directly
6	Payment for expert testimony	<input checked="" type="checkbox"/> <b>None</b>	
7	Support for attending meetings and/or travel	<input checked="" type="checkbox"/> <b>None</b>	
8	Patents planned, issued or pending	<input checked="" type="checkbox"/> <b>None</b>	
9	Participation on a Data Safety Monitoring Board or Advisory Board	<input type="checkbox"/> <b>None</b>	
		Epstein Family Alzheimer's Collaboration, University of California San Diego	Scientific Advisory Board member—payment made to institution

		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)
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