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.

		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 Marcus Program in Precision Medicine Innovation (MPPMI) - ELSI in Precision Medicine Initiative 2019	Click the tab key to add additional rows.
		Time frame: past 36 months	S
2	Grants or contracts from any entity (if not indicated in item #1 above).	[⊠] None	
3	Royalties or licenses	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)
4	Consulting fees	☑ None	
5	Payment or honoraria for lectures, presentations, speakers bureaus, manuscript writing or educational events	☑ None	
6	Payment for expert testimony	⊠ None	
7	Support for attending meetings and/or travel	⊠ None	
8	Patents planned, issued or pending	⊠ None	
9	Participation on a Data Safety Monitoring Board or Advisory Board	⊠ None	
10	Leadership or fiduciary role in other board, society, committee or advocacy group, paid or unpaid	⊠ 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)
11	Stock or stock options	⊠ None □ □ □ □ □ □ □ □	
12	Receipt of equipment, materials, drugs, medical writing, gifts or other services	⊠ None □ □ □ □ □ □	
13	Other financial or non-financial interests	None	
Plea	Please place an "X" next to the following statement to indicate your agreement:		

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

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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.

		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
	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 ☑	Click the tab key to add additional rows.
		Time frame: past 36 month	IS
2	Grants or contracts from any entity (if not indicated in item #1 above).	☑ None	
3	Royalties or licenses	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)
4	Consulting fees	☑ None	
5	Payment or honoraria for lectures, presentations, speakers bureaus, manuscript writing or educational events	☑ None	
6	Payment for expert testimony	⊠ None	
7	Support for attending meetings and/or travel	⊠ None	
8	Patents planned, issued or pending	⊠ None □ □ □ □ □ □	
9	Participation on a Data Safety Monitoring Board or Advisory Board	⊠ None	
10	Leadership or fiduciary role in other board, society, committee or advocacy group, paid or unpaid	⊠ 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)
11	Stock or stock options	⊠ None □ □ □ □ □ □ □ □	
12	Receipt of equipment, materials, drugs, medical writing, gifts or other services	⊠ None □ □ □ □ □ □	
13	Other financial or non-financial interests	None	
Plea	Please place an "X" next to the following statement to indicate your agreement:		

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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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.

		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
	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 ☑	Click the tab key to add additional rows.
		Time frame: past 36 month	IS
2	Grants or contracts from any entity (if not indicated in item #1 above).	⊠ None	
3	Royalties or licenses	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)
4	Consulting fees	☑ None	
5	Payment or honoraria for lectures, presentations, speakers bureaus, manuscript writing or educational events	☑ None	
6	Payment for expert testimony	⊠ None	
7	Support for attending meetings and/or travel	⊠ None	
8	Patents planned, issued or pending	⊠ None □ □ □ □ □ □	
9	Participation on a Data Safety Monitoring Board or Advisory Board	⊠ None	
10	Leadership or fiduciary role in other board, society, committee or advocacy group, paid or unpaid	⊠ 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)
11	Stock or stock options	⊠ None □ □ □ □ □ □ □ □	
12	Receipt of equipment, materials, drugs, medical writing, gifts or other services	 □ □	
13	Other financial or non-financial interests	None	
Plea	Please place an "X" next to the following statement to indicate your agreement:		

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

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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.

		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 o	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.	□	Click the tab key to add additional rows.
		Time frame: past 36 months	3
2	Grants or contracts from any entity (if not indicated in item #1 above).	 None I am CEO of The Assn for Frontotemporal Degeneration (AFTD), a 501c3 nonprofit that operates in the FTD space. We receive philanthropic support from a large number of donors: individuals, foundations, corporations. But none of these were related to the issues in this paper. 	

		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	☑ None □ □ □ □	
4	Consulting fees	☑ None	
5	Payment or honoraria for lectures, presentations, speakers bureaus, manuscript writing or educational events	☑ None	
6	Payment for expert testimony	[⊠] None [
7	Support for attending meetings and/or travel	⊠ None	
8	Patents planned, issued or pending	⊠ None	
9	Participation on a Data Safety Monitoring Board or Advisory Board	⊠ None	
10	Leadership or fiduciary role in other board,	□ 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)
	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
11	Stock or stock options	None	
12	Receipt of equipment, materials, drugs, medical writing, gifts or other services	⊠ None	
13	Other financial or non-financial interests	⊠ None	
Plea	Please place an "X" next to the following statement to indicate your agreement:		

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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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.

		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
	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	Click the tab key to add additional rows.
		Time frame: past 36 month	IS
2	Grants or contracts from any entity (if not indicated in item #1 above).	⊠ None	
3	Royalties or licenses	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)
4	Consulting fees	☑ None □ □ □ □ □ □ □ □	
5	Payment or honoraria for lectures, presentations, speakers bureaus, manuscript writing or educational events	None	
6	Payment for expert testimony	⊠ None	
7	Support for attending meetings and/or travel	⊠ None	
8	Patents planned, issued or pending	□ None	
9	Participation on a Data Safety Monitoring Board or Advisory Board	⊠ None	
10	Leadership or fiduciary role in other board, society, committee or advocacy group, paid or unpaid	⊠ 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)
11	Stock or stock options	⊠ None □ □ □ □ □ □ □ □	
12	Receipt of equipment, materials, drugs, medical writing, gifts or other services	 □ □	
13	Other financial or non-financial interests	None	
Plea	Please place an "X" next to the following statement to indicate your agreement:		

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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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.

		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
2	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. Grants or contracts from any entity (if not indicated in item #1 above).	 None 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. Time frame: past 36 month None National Institute on Aging/ NIH (grants are made to my institution) 	Click the tab key to add additional rows.
3	Royalties or	⊠ None	
	licenses		

		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	☑ None □ □ □ □ □ □	
5	Payment or honoraria for lectures, presentations, speakers bureaus, manuscript writing or educational events	None	
6	Payment for expert testimony	⊠ None	
7	Support for attending meetings and/or travel	None All travel paid for by the Alzheimer's Association	
8	Patents planned, issued or pending	⊠ None	
9	Participation on a Data Safety Monitoring Board or Advisory Board	EAB for Discovery (NINDS funded), unpaid	
10	Leadership or fiduciary role in other board, society, committee or advocacy group, paid or unpaid	 None Chair, Programmatic Review for the CDMRP AD/ADRD and TBI Program, unpaid Chair and Immediate Past Chair for Health Research Alliance, unpaid Member, FHS Advisory Investigators Committee, unpaid 	Research Committee, American Heart Association, 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)
11	Stock or stock options	⊠ None	
12	Receipt of equipment, materials, drugs, medical writing, gifts or other services	[⊠] None	
13	Other financial or non-financial interests	 None Partner is a full time employee of Abbott Labs in an unrelated field. HS is a full time employee of the Alzheimer's Association 	
Plea	Please place an "X" next to the following statement to indicate your agreement:		

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

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		Time frame: past 36 month	IS
2	Grants or contracts from any entity (if not indicated in item #1 above).	⊠ None	
3	Royalties or licenses	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)
4	Consulting fees	☑ None	
5	Payment or honoraria for lectures, presentations, speakers bureaus, manuscript writing or educational events	☑ None	
6	Payment for expert testimony	⊠ None	
7	Support for attending meetings and/or travel	⊠ None	
8	Patents planned, issued or pending	⊠ None □ □ □ □ □ □	
9	Participation on a Data Safety Monitoring Board or Advisory Board	⊠ None	
10	Leadership or fiduciary role in other board, society, committee or advocacy group, paid or unpaid	⊠ 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)
11	Stock or stock options	⊠ None □ □ □ □ □ □ □ □	
12	Receipt of equipment, materials, drugs, medical writing, gifts or other services	⊠ None □ □ □ □ □ □	
13	Other financial or non-financial interests	None	
Plea	Please place an "X" next to the following statement to indicate your agreement:		

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

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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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		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 ☑ □ □ □ □ □	Click the tab key to add additional rows.
		Time frame: past 36 months	S
2	Grants or contracts from any entity (if not indicated in item #1 above).	None *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	

		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	None	
4	Consulting fees	☑ None □ □ □ □ □ □ □ □	
5	Payment or honoraria for lectures, presentations, speakers bureaus, manuscript writing or educational events	☑ None	
6	Payment for expert testimony	⊠ None	
7	Support for attending meetings and/or travel	None	
8	Patents planned, issued or pending	⊠ None	
9	Participation on a Data Safety Monitoring Board or Advisory Board	US POINTER Study DSMB	
10	Leadership or fiduciary role in other board,	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
11	Stock or stock options	⊠ None	
12	Receipt of equipment, materials, drugs, medical writing, gifts or other services	⊠ None □ □ □ □ □ □	
13	Other financial or non-financial interests	None	
Plea	Please place an "X" next to the following statement to indicate your agreement:		

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

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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)
		Time frame: Since the initial planning o	of the work
	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 NIH grant (Jalayne Arias, PI)	As disclosed on Dr. Arias's COI form Click the tab key to add additional rows.
		Time frame: past 36 months	5
2	Grants or contracts from any entity (if not indicated in item #1 above).	⊠ None	
3	Royalties or licenses	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)
4	Consulting fees	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,	D None	Honorarium for participating in a scholarly
	presentations, speakers bureaus, manuscript writing or educational events		working group on data ethics.
6	Payment for expert testimony	⊠ None	
7	Support for attending meetings and/or travel	⊠ None	
8	Patents planned, issued or pending	⊠ None	
9	Participation on a Data Safety Monitoring Board or Advisory Board	None	
10	Leadership or fiduciary role in other board, society, committee or advocacy group, paid or unpaid	⊠ 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)
11	Stock or stock options	⊠ None □ □ □ □ □ □ □ □	
12	Receipt of equipment, materials, drugs, medical writing, gifts or other services	⊠ None □ □ □ □ □ □	
13	Other financial or non-financial interests	None	
Plea	Please place an "X" next to the following statement to indicate your agreement:		

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	

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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.

		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 NIH Rainwater Charitable Foundation Alzheimer's Association Global Brain Health Institute Mary Oakley Foundation	Institution (NIH-NIA R01 AG062588, R01 AG057234, P30 AG062422; NIH-NINDS U54 NS123985, NIH-NIDA 75N95022C00031, NIH-NIA U19AG079774) Institution Institution Institution Institution	
		Time frame: past 36 months		
2	Grants or contracts from any entity (if not indicated in item #1 above).	⊠ None		
3	Royalties or licenses	☑ 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)
4	Consulting fees	⊠ None	
5	Payment or honoraria for lectures,	None Lecture: "Immune Contributions to	Payment to JSY directly
	presentations, speakers bureaus, manuscript writing or	Frontotemporal Dementia," Knight Initiative Symposium: Frontotemporal Dementia, Knight Initiative for Brain Resilience, Wu Tsai Neurosciences Institute, Stanford University, November 28, 2023	
	educational events	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	[⊠] None	
7	Support for attending meetings and/or	⊠ None	
	travel		
8	Patents planned, issued or	⊠ None	
	pending		
9	Participation on a Data Safety Image: None		
	Monitoring Board or Advisory Board	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)	
10	Leadership or fiduciary role in other board, society, committee or advocacy group, paid or unpaid	⊠ None □ □ □ □ □ □		
11	Stock or stock options	⊠ None		
12	Receipt of equipment, materials, drugs, medical writing, gifts or other services	⊠ None		
13	Other financial or non-financial interests	Image: None		
Plea	Please place an "X" next to the following statement to indicate your agreement:			