

#	Question	Asker Name	Asker Email	Answer	Question Time	Answered Time	Answer Name
1	Where can we access th full agenda fo the meeting?	Radhika Sudhir Joshi	rjoshi@als.net	live answered	8/19/2026 6:55	8/19/2026 6:55	Samer Khan (she/her)
1	Where can we access th full agenda fo the meeting?	Radhika Sudhir Joshi	rjoshi@als.net	I can email you the agenda, Radhika	8/19/2026 6:55	8/19/2026 6:55	Samer Khan (she/her)
3	Good to see you, Danielle! Looking forward to the meeting.	Andrea Pauls Backman	andrea@alsstrategy.com	live answered	8/19/2026 6:57	8/19/2026 6:58	Danielle Boyce
3	Good to see you, Danielle! Looking forward to the meeting.	Andrea Pauls Backman	andrea@alsstrategy.com	THANK YOU!	8/19/2026 6:57	8/19/2026 6:58	Danielle Boyce
4	Hi, I am assuming that we are all muted and have our cameras off by design.	Christina Wolfson	christina.wolfson@mcgill.ca	live answered	8/19/2026 6:58	8/19/2026 6:59	Samer Khan (she/her)
5	Hello from McGill University in Montreal.	Christina Wolfson	christina.wolfson@mcgill.ca		8/19/2026 7:00		
6	Amy, ALS Association in Iowa	Amy Orban	amy.orban@als.org		8/19/2026 7:00		
7	Hello - Sarah Embro from ALS United of Georgia	Sarah Embro	sarah@alsgeorgia.org	Here!	8/19/2026 7:01	8/19/2026 7:02	Danielle Boyce
8	Good morning from Andrea Pauls Backman of ALS Strategy Consulting in Chicago.	Andrea Pauls Backman	andrea@alsstrategy.com		8/19/2026 7:03		
9	So glad you are Back Danielle!	Greg Zarus	greg.zarus@our1world.org	Good to see you Greg	8/19/2026 7:03	8/19/2026 7:06	Moon Han
10	Will recording of this webinar will be shared? Sorry if missed listening to this info	Sasi Aruna	sarunachal@pa.gov	A summary of the meeting will be shared before the end of the year.	8/19/2026 7:05	8/19/2026 7:07	Samer Khan (she/her)
11	Is the most recent year of actually reported cases still 2018? Thanks.	M C Collet	mcollet@comcast.net	Yes	8/19/2026 7:21	8/19/2026 7:25	Jaime Raymond
11	Is the most recent year of actually reported cases still 2018? Thanks.	M C Collet	mcollet@comcast.net	We have been working with CMS to get data through 2023 and hopes to increase our estimates in the near future.	8/19/2026 7:21	8/19/2026 7:29	Jaime Raymond
12	Could a state's higher incidence merely be because of better self-enrollment? And likewise, could low incidence states in your reporting be states that have poor sekl enrollment? Thanks.	M C Collet	mcollet@comcast.net	For state level incidence, we combined data from our web portal as well as administrative datasets from Veterans Affairs and Medicare. All datasets are combined/matched and de-duplicated. If a patient is not receiving care from Medicare or the VA, then yes, we would get their data from the web portal.	8/19/2026 7:25	8/19/2026 7:27	Jaime Raymond
13	Thanks, Jaime. My concern is (and has been) that reference to "incidence" by state really may be reflecting differences in how well the registry finds cases in states rather than the actual cases.	M C Collet	mcollet@comcast.net	Understand. Adding the CMS and VA data helps get a more holistic approach.	8/19/2026 7:29	8/19/2026 7:32	Jaime Raymond
14	Jaime, do you know approximately what percent of enrollees are from the portal and not on the administrative data sets? Thanks.	M C Collet	mcollet@comcast.net	We have published on this previously. Let me find the link	8/19/2026 7:33	8/19/2026 7:34	Jaime Raymond
14	Jaime, do you know approximately what percent of enrollees are from the portal and not on the administrative data sets? Thanks.	M C Collet	mcollet@comcast.net	https://karger.com/ned/article/56/2/104/825234/Evaluation-of-the-Completeness-of-ALS-Case	8/19/2026 7:33	8/19/2026 7:38	Jaime Raymond
15	Jaime, is it still true that the CMS and VA data contribute about 80% of the case data and self-reported portal contributes about 20%?	Andrea Pauls Backman	andrea@alsstrategy.com	Yes, at least.	8/19/2026 7:34	8/19/2026 7:35	Jaime Raymond
16	So samples from the biorepsotory are not being sent out due to the vendor hold?	Andrea Pauls Backman	andrea@alsstrategy.com	Samples have not been available for researchers and blood collection from patients has been halted due to recent changes to the government activities. We are working to resume as soon as possible.	8/19/2026 7:38	8/19/2026 7:43	Moon Han
17	So do I understand that at the moment you are not collecting biosamples and you are not currently distributing biosamples?	M C Collet	mcollet@comcast.net	Both activities have been paused at this moment.	8/19/2026 7:38	8/19/2026 7:44	Moon Han

17	So do I understand that at the moment you are not collecting biosamples and you are not currently distributing biosamples?	M C Collet	mcollet@comcast.net	The contracts staf were RIF'd. The remaining staf are serving all of CDC. Due to this, we were not able to get the Biorepository funded. Unfortunately. this was out of our control.	8/19/2026 7:38	8/19/2026 7:59	Paul Mehta
18	I know you will be sharing a summary, but will the slide decks be available after the meeting? Thank you	Cynthia Melde	cynthiamelde@gmail.com		8/19/2026 7:44		
19	Moon, this sounds like an advocacy opportunity to push Congress to compel the agencies to allow the registry to do its mandated work.	Andrea Pauls Backman	andrea@alsstrategy.com	You are absolutely correct. We have so much potential to work with biorepository samples and support ALS research community. We have been getting numerous external inquiries but have not been able to fulfill the demand for support.	8/19/2026 7:46	8/19/2026 7:49	Moon Han
20	Of the 21,000 patients in the portal, how many are still alive?	Stephen Finger	stephenfinger@yahoo.com	12,000-13,000	8/19/2026 7:49	8/19/2026 7:53	Jaime Raymond
21	Are there currently any formal collaborations between the US National Registry with ALS registries elsewhere in the world?	Christina Wolfson	christina.wolfson@mcgill.ca	We have had conversations with a few other registries in Canada and Europe, but we don't have any formal collaborations currently.	8/19/2026 7:50	8/19/2026 7:56	Jaime Raymond
21	Are there currently any formal collaborations between the US National Registry with ALS registries elsewhere in the world?	Christina Wolfson	christina.wolfson@mcgill.ca	But are open to collaborate!	8/19/2026 7:50	8/19/2026 8:04	Paul Mehta
22	Any chance CDC might put together data from the various "hot spots" being identified around the US- ex VCU, Alabama, Puerto Rico- to see if there are comonalities in them	Antoinette Harrison	toni.harrison@shionogi.com	Possibly. A lot depends on how much detail we can get from the state and local health departments	8/19/2026 7:50	8/19/2026 7:51	Jaime Raymond
23	Any chance states could be funded to collect statewide registries?	Beth Anderson	andersonb@michigan.gov	live answered	8/19/2026 7:50	8/19/2026 8:10	Samer Khan (she/her)
24	common characteristics	Antoinette Harrison	toni.harrison@shionogi.com	Yes, if we can get that kind of detail, absolutely.	8/19/2026 7:51	8/19/2026 7:55	Jaime Raymond
25	ALS clusters in the past were studied through the EIS. Is the process now to go directly to the ALS Registry section?	Anonymous Attendee		No, it still goes to the EIS Office but the National ALS Registry is usually brought in as SME's.	8/19/2026 8:00	8/19/2026 8:05	Jaime Raymond
25	ALS clusters in the past were studied through the EIS. Is the process now to go directly to the ALS Registry section?	Anonymous Attendee		The EpiAid office was consulted for the Virgiinia investigation.	8/19/2026 8:00	8/19/2026 8:39	Paul Mehta
26	How much do you pay the "partner organizations" snnually? How do you measure their performance, results in self-enrollment?	M C Collet	mcollet@comcast.net	live answered	8/19/2026 8:02	8/19/2026 8:12	Samer Khan (she/her)
26	How much do you pay the "partner organizations" snnually? How do you measure their performance, results in self-enrollment?	M C Collet	mcollet@comcast.net	Partners received between 550K to 880K in total funding in FY24 and FY25.	8/19/2026 8:02	8/19/2026 9:03	Paul Mehta
27	How about a clinic bonus based on percentage enrolled pALS	Anonymous Attendee		live answered	8/19/2026 8:04	8/19/2026 8:13	Samer Khan (she/her)
28	If 80% of patients come from the administrative data and the C/R paper cited having 5,400 patients in the portal, how do you now have 12,000 patients living with ALS patients?	Stephen Finger	stephenfinger@yahoo.com	Some of the 12,000 patients are also in our administrative datasets so they overlap.	8/19/2026 8:05	8/19/2026 8:09	Jaime Raymond
29	Will presenter slides be made available?	Peter Munoz	peter.munoz@cdph.ca.gov	live answered	8/19/2026 8:07	8/19/2026 8:13	Samer Khan (she/her)
31	New York and New Jersey both passed legislaion for a state registry.	tiffany card	tcard@als-ny.org		8/19/2026 8:10		

32	Note from Lynn in Houston, Registry member since 2019: I just provided my 4th quarterly biosamples to the ALL ALS Observational Study. I also previously helped ALS-TDI source a vendor of in-home blood collection.	Lynn Brielmaier	lynnbr2@att.net	Hi, Lynn, Thank you so much for your active participation in providing biosamples. Longitudinal collection is very valuable to researchers!	8/19/2026 8:10	8/19/2026 8:13	Moon Han
33	What's the total payout to partners?	M C Collet	mcollet@comcast.net	Partners received between 550K to 880K in total funding in FY24 and FY25.	8/19/2026 8:11	8/19/2026 9:07	Paul Mehta
34	Will you publish a list of each study funded, what researchers and most importantly, what they actually concluded and how it advances ALS research?	Anonymous Attendee		https://www.cdc.gov/als/hcp/aboutalsregistryresearchapplicationinfo/external-research.html	8/19/2026 8:14	8/19/2026 8:15	Paul Mehta
34	Will you publish a list of each study funded, what researchers and most importantly, what they actually concluded and how it advances ALS research?	Anonymous Attendee		https://www.cdc.gov/als/php/abstracts-publications-reports/index.html	8/19/2026 8:14	8/19/2026 8:15	Paul Mehta
34	Will you publish a list of each study funded, what researchers and most importantly, what they actually concluded and how it advances ALS research?	Anonymous Attendee		live answered	8/19/2026 8:14	8/19/2026 8:16	Samer Khan (she/her)
35	What is the proportion of rural population in USA in ALS Registry by percentage of rural cases by region?	Anonymous Attendee		Currently, our analyses are limited to state level only from our OMB requirements/limitations. We only collect data at the state level for our web portal data.	8/19/2026 8:15	8/19/2026 8:21	Jaime Raymond
36	We need an AFTER ACTION REVIEW of what was accomplished not just a list of studies and rating the impact for the ALS community not just a list of links	Anonymous Attendee		The impact of the funded studies can be found on our publication pages.	8/19/2026 8:17	8/19/2026 9:09	Paul Mehta
37	Does Les turner get any state government support?	Anonymous Attendee		The Les Turner ALS Foundation advocated for a \$300K state appropriation. FY27 was the first year that we were included in the state budget. So grateful to everyone who helped advocate.	8/19/2026 8:26	8/19/2026 8:39	Lauren Webb, Les Turner ALS Foundation
38	Ms Webb, do you offer print material for offices?	Jessica Allsmiller	jessica.allsmiller@uoflhealth.org	To order registry materials: https://www.cdc.gov/als/hcp/alsmaterials/index.html and if you would like printed guides from the Foundation. Please email, education@lesturnerals.org	8/19/2026 8:34	8/19/2026 8:43	Lauren Webb, Les Turner ALS Foundation
39	What is the average ALSFRS-R of pALS who enter patient portal?	Anonymous Attendee		The average ALSFRS-R total score varies and this can be found in previous publications (Raymond et al., Han et al.,) that reports some clinical characteristics of the web-portal enrollees.	8/19/2026 8:35	8/19/2026 8:47	Moon Han
40	Is there a report of how many registry enrollees result from each of the partner organizations versus how much they are paid? i.e. assessing their productivity per government dollars spent?	Anonymous Attendee		The registry doesn't track which portal enrollees have been referred by what organization	8/19/2026 8:37	8/19/2026 8:45	Kevin Horton
41	Will you save and post (or distribute) the Q and A from this meeting, please?	M C Collet	mcollet@comcast.net	Our meeting summary will include these	8/19/2026 9:11	8/19/2026 9:15	Kevin Horton
43	Paul, some of us on the West Coast missed your presentation. Will you post your slides so we can see the updated data that was presented this year?	Michelle Lorenz	als.cdmresearch@gmail.com	We can provide the slides in the chat at the end of the day and we will have it uploaded on our Annual Meetings page on the National ALS Registry site shortly after the meeting is done.	8/19/2026 9:26	8/19/2026 11:05	Song Xue
44	Do people now not believe the Guam epidemic was not caused by seeds from cycad trees?	Stephen Finger	stephenfinger@yahoo.com	live answered	8/19/2026 9:32	8/19/2026 10:19	Lyle W. Ostrow MD PhD, Temple LKSOM

44	Do people now not believe the Guam epidemic was not caused by seeds from cycad trees?	Stephen Finger	stephenfinger@yahoo.com	Stephen - there are many reasons that people are increasingly rejecting the cycad hypothesis. I'm happy to chat about it if you like, and to provide references, etc. Send me an email. Lyle.Ostrow@tuhs.temple.edu	8/19/2026 9:32	8/19/2026 10:21	Lyle W. Ostrow MD PhD, Temple LKSOM
45	Fascinating Guamanian research Lyle. So happy to see ALS Clusters being studied. Please fund more research like this!	Michelle Lorenz	als.cdmresearch@gmail.com		8/19/2026 9:34		
46	Dr. Ostrow, this is amazingly painstaking work - kudos! The value of the tissue of those who phenoconverted, as well as those who did not, has ramifications today as we look at controls and at-risk tissue donations.	Andrea Pauls Backman	andrea@alsstrategy.com		8/19/2026 9:36		
47	Has MG53 found to be similarly elevated in other ALS studies or just in the Guamanian population? Is there a gene that controls how MG53 responds?	Michelle Lorenz	als.cdmresearch@gmail.com	MG53 is not specific to ALS. It is a protein involved in muscle membrane repair. It appears that this process may be deficient in ALS, but it is not a "cause" - Its sort of like if you have a drafty house, you can fix the leaky window, or you can turn up the heat. MG53 is turning up the heat. It helps muscle membranes repair faster. In the mice - there is some suggestion that it may allow ALS mice who exercise to have gains. Normally, if an ALS mouse runs on a treadmill, their diaphragm muscle damage is accelerated. With MG53 on board, this wasn't the case. So maybe there is a chance it will allow ALS patients to get benefit from exercise. Who knows? Lots of work still to do. Very preliminary. The reason I personally became a collaborator on that project is that the research team didn't have ALS expertise. Without our core, they never would have had access to the samples. They had had prior grant proposals rejected saying "demonstrate in human tissue" which is why they originally approached us.	8/19/2026 9:38	8/19/2026 10:17	Lyle W. Ostrow MD PhD, Temple LKSOM
47	Has MG53 found to be similarly elevated in other ALS studies or just in the Guamanian population? Is there a gene that controls how MG53 responds?	Michelle Lorenz	als.cdmresearch@gmail.com	We helped design the experiments in human postmortem muscle. When the data was promising, we helped design the next steps. They then asked me to collaborate because they didn't have expertise in ALS. We still are working together. The only reason I ran some Guam samples with that ELISA is that we are using the same ELISAs presently on modern ALS serum samples - trying to find how levels change with disease, and whether we can tell who might be most likely to respond to a therapy targeting this system, and how we can track the response.	8/19/2026 9:38	8/19/2026 10:19	Lyle W. Ostrow MD PhD, Temple LKSOM
49	Is there a difference in how much MG53 is elevated in ALS vs Parkinsonism patients?	Michelle Lorenz	als.cdmresearch@gmail.com	We have just starting looking at this in the	8/19/2026 9:57	8/19/2026 10:11	Lyle W. Ostrow MD PhD, Temple LKSOM

49	Is there a difference in how much MG53 is elevated in ALS vs Parkinsonism patients?	Michelle Lorenz	als.cdmresearch@gmail.com	We have just started looking at this in the Guam samples. In the pilot sample set, it was even higher in the PDC samples than the ALS ones, but this is just a small pilot. Don't know what it means at all. Very early days. Those experiments were mostly done so we could see if we got reliable and reproducible ELISA data assaying for a specific protein - ie, we are working to sort what sort of substrates the samples can be tested for with good QC.	8/19/2026 9:57	8/19/2026 10:12	Lyle W. Ostrow MD PhD, Temple LKSOM
50	"We're entering an era where the organoids are going to be really instrumental for empowering new ways of developing therapeutics for diseases of the central nervous system," https://www.statnews.com/2026/08/19/brain-organoids-alive-5-years-neuroscience-research-harvard/?utm_source=Sailthru&utm_medium=email&utm_campaign=Issue:%202026-08-19%20BioPharma%20Dive%20%5Bissue:88302%5D&utm_term=BioPharma%20Dive	Lynn Brielmaier	lynnbr2@att.net	Lynn - maybe we should review this paper and the press release for one of our Citizen Research zoom meetings. Their science is fascinating and impressive, but I disagree that it is going to be a boon for drug development. Email me and I'll explain!	8/19/2026 10:02	8/19/2026 10:30	Lyle W. Ostrow MD PhD, Temple LKSOM
51	Is the registry collecting data on pediatric ALS cases yet? I know it wasn't previously but you were trying to fix this several years ago.	Michelle Lorenz	als.cdmresearch@gmail.com	Our current requirements are that ALS participants must be 18 years or old. We did complete a brief report on juvenile ALS which is symptom onset before age 25 - https://www.tandfonline.com/doi/full/10.1080/21678421.2023.2264922	8/19/2026 10:06	8/19/2026 10:52	Jaime Raymond
52	hi Lyle, as an engineer, I hope to change your mind.	Lynn Brielmaier	lynnbr2@att.net	There are very specific ways I feel this way. It worked well for prion disease and a few other things, but for late onset proteinopathies, what's been found is phenotypes attributable to mutatinos, not disease. iPSC reprogramming resets cellular age - and the resulting tissue corresponds molecularly and electrophysiologically to fetal or early developmental stages. In that paper, the had 34 organoids sampled every 3-6 months for 18 months, then annually for 5 yrs. The finding was that organoids transcriptionall age w cell-type specificity across those years, and whole genome methylation profiling shows predicted epigenomic age. The most elegant part is the chimera experiment - neurons moved from older into younger organoids kept progressing on their original schedule - what they called a "Cell intrinsic clock." Beautiful developmental biology! But bad news for disease modeling. If the tempo is cell-intrinsic and epigenetically enforced - resistant even to being dropped into a younger environment... (cont)	8/19/2026 10:54	8/19/2026 10:58	Lyle W. Ostrow MD PhD, Temple LKSOM

52	hi Lyle, as an engineer, I hope to change your mind.	Lynn Brielmaier	lynnbr2@att.net	then you can't media-cheat your way to an aged human cortex. The maturation gap won't close by optimizing culture, which is the assumption the therapeutics rhetoric depends on. They had 34 organoids over 5 years. Whatever this is, it is not a platform for developing drugs. No CNS program has a 5-year lead time just to generate the assay substrate.	8/19/2026 10:54	8/19/2026 10:59	Lyle W. Ostrow MD PhD, Temple LKSOM
53	Did the neutrophil change in women differ in pre- vs post-menopausal women with ALS where estrogen levels were drastically different? Was there a difference in men vs post-menopausal women?	Michelle Lorenz	als.cdmresearch@gmail.com	Sorry, I just saw this one, so sorry for the late response. We found that the associations with neutrophils were specific for women over 55 and not really seen in men. Now, whether or not it's specific to pre- versus post-menopausal women we couldn't determine mainly due to lack of statistical power: most people who get ALS are older and tend to be men. So doing stats on young women is hard, because there tend to be so few individuals in the overall cohort. However, we have definitely found that several sex hormones do associate with ALS risk and survival.	8/19/2026 10:54	8/19/2026 12:11	Ben Murdock
54	Dr. Murdock- what are your thoughts on NLR as a biomarker for ALS?	Antoinette Harrison	toni.harrison@shionogi.com		8/19/2026 10:54		
55	Neutrophils have remarkable responses to vit B12 in PA What are Vit B12 levels and hormone levels in females	Benjamin Rix Brooks	benjamin_rix.brooks@clinicaltrialsplanning.com	I'm not entirely sure about B12 levels in women versus men in ALS. I know a number of studies have been done associating B12 with ALS and finding that B12 is likely protective, but I don't know if anyone has stratified the data based on sex. In our own studies we have found that several sex hormones are associated with ALS risk and survival, including several of the estrogens and 11-keto-testosterone. We're currently examining the association between these hormones and immune activation in ALS patients.	8/19/2026 10:56	8/19/2026 11:26	Ben Murdock
56	neutrophil to lymphocyte ratio	Antoinette Harrison	toni.harrison@shionogi.com	live answered	8/19/2026 10:56	8/19/2026 11:17	Danielle Boyce
58	Thank you Pat and ALS-TDI for doing this important geospatial mapping! You are heroes! Are you tracking where people lived historically as well as where they may have had possible in utero exposure too?	Michelle Lorenz	als.cdmresearch@gmail.com	we are tracking where people have lived and when. One of the challenges is the resolution of that tracking. We don't have specific addresses. More city level data. We have not gone so far back to ask about in utero, but we do have city of birth for many participants.	8/19/2026 11:19	8/19/2026 11:48	Fernando Vieira
59	Dr. Viera, what do you mean by saying military service is an open question? Do you have data that casts doubt on the correlations previously found? Can you clarify?	Andrea Pauls Backman	andrea@alsstrategy.com	It is an open question for our data! Not in general.	8/19/2026 11:22	8/19/2026 11:28	Fernando Vieira
59	Dr. Viera, what do you mean by saying military service is an open question? Do you have data that casts doubt on the correlations previously found? Can you clarify?	Andrea Pauls Backman	andrea@alsstrategy.com	We are convinced by the incredibly robust dataset linkages that have come from other studies.	8/19/2026 11:22	8/19/2026 11:29	Fernando Vieira

60	With tretment for some of these autoimmune disease is National ALS Registry capable to pick up rates of ALS in subjects with treated autoimmune diseases?	Benjamin Rix Brooks	benjamin_rix.brooks@clinicaltrialsplanning.com		8/19/2026 11:24		
61	I Spoke with one CALS in India, same building 4 families lived, like quarters, all four the ladies developed ALS after several years. The sad part is that there are not more. none of the children or male family members got any symptoms. just wanted to share.	Satvinder Kaur	alscasindia@gmail.com	Interesting...we have also heard about these kinds of cases in other locales.	8/19/2026 11:28	8/19/2026 12:05	Paul Mehta
62	Would you consider adding grant amounts to the list at https://www.cdc.gov/als/abouttheregistrymain/active-alsclinicalresearchnotification.html , please. I think it helps us all to understand the cost and value of studies. Thank you.	M C Collet	mcollet@comcast.net	Hi, Collet. We list our grant RFA on grants.gov and includes the award amount and number of awards expected to be awarded for that particular funding announcement. In parallel, we also list study description of grantees on our website too. Collectively, these inform the public of our support for the incredible studies as being described today and their overall impact. Hope this helps.	8/19/2026 11:30	8/19/2026 12:18	Moon Han
63	Is Dr. Weisskopf collecting data from healthy controls in the same units as people wth ALS? We've seen some clusters in C-130 pilots, and other post 9/11 units with multiple people dx'd with ALS.	Michelle Lorenz	als.cdmresearch@gmail.com	We are hoping to do exactly this kind of thing. Looking at veternas who did and did not have certain jobs—like being a pilot. It has turned out to be harder to get that military occupation data than had been suggested to us originally, but we're hopeful!	8/19/2026 11:34	8/19/2026 12:03	Marc Weisskopf
64	Dr W, at one time there was a theory that the military connection had something to do with people who flew. Thoughts?	M C Collet	mcollet@comcast.net	Yes. I think that is still a very interesting possibility. If we can get the military occupation data (this has proven harder than we thought), we can address this much more directly.	8/19/2026 11:43	8/19/2026 12:06	Marc Weisskopf
65	Remote Kurtzke study suggested large bone fracture had increased risk for ALS. Did you look at the fracture rate in the younger ALS by cohort?	Benjamin Rix Brooks	benjamin_rix.brooks@clinicaltrialsplanning.com	We have not done that in the VA syatem (yet!), but potentially could. We have looked at that in the past in the Danish population (Seals et al.)	8/19/2026 11:43	8/19/2026 12:03	Marc Weisskopf
66	Dr. W, is the Million Veteran Project data of any help in your work? Thank you.	M C Collet	mcollet@comcast.net	live answered	8/19/2026 11:45	8/19/2026 11:54	Danielle Boyce
67	VW2 studies fround more polio in officers. Does this bring virus back into the fray?	Benjamin Rix Brooks	benjamin_rix.brooks@clinicaltrialsplanning.com	Interesting! Not sure. Alberto Ascherio is presenting tomorrow on work lookingat the virome and ALS. Maybe he has thoughts.	8/19/2026 11:45	8/19/2026 12:04	Marc Weisskopf
68	Has anyone designed a study looking at the stressors and inflammation during the military recruitment period? We know the boot camp period is extremely stressful on the system. Could a research team partner with DOD to start gathering/analyzing the blood work before boot camp, DURING boot camp, and follow-up three years after boot camp? [Or at least zero-target the specific military divisions with the highest prevalence of ALS.]	Tiffani Davis	tiffani.m.davis@gmail.com	I need to get together with Dr. Ascherio about this because he has been using a military blood repository for other work. If we could combine that with connecting to our VA data, we could do exactly that kind of thing. But it has been very hard to work across the VA and DOD. All sorts of hurdle get thrown up. But we keep trying!	8/19/2026 11:53	8/19/2026 12:05	Marc Weisskopf
69	I think it wuld be interesting (and possibly valuable) to run suh a prediction model on people who were never dx'd w ALS and who died with other causes of death. We might find some people who may well have died from ALS but were never dx'd.	M C Collet	mcollet@comcast.net	live answered	8/19/2026 12:45	8/19/2026 13:04	Danielle Boyce

70	Dr. Song, I'm very surprised that respiratory intervention in MDT care did not improve survival.	Andrea Pauls Backman	andrea@alsstrategy.com	live answered	8/19/2026 12:54	8/19/2026 13:04	Danielle Boyce
71	Any NFL levels studied in veterans with ALS?	Michelle Lorenz	als.cdmresearch@gmail.com	live answered	8/19/2026 13:09	8/19/2026 13:13	Danielle Boyce
72	Dr Murdock, Have you reached out to the young women in HERALStory to study neutrophils in these women dx'd before 35?	Michelle Lorenz	als.cdmresearch@gmail.com	live answered	8/19/2026 13:11	8/19/2026 13:13	Danielle Boyce
73	This question is for all the researchers, what are the top three data sets you wished you had? For example, a complete ALS census. Thanks	Patrick Dolan	phdolan@geoals.org	live answered	8/19/2026 13:12	8/19/2026 13:23	Danielle Boyce
74	Is there any genetic data on neutrophil lymphocyte ratio response to various toxic, infection, autoimmune exposures?	Benjamin Rix Brooks	benjamin_rix.brooks@clinicaltrialsplanning.com	live answered	8/19/2026 13:17	8/19/2026 13:23	Danielle Boyce
75	wish we would start collecting zip codes for in utero exposure. I think we are missing significant exposome data.	Michelle Lorenz	als.cdmresearch@gmail.com	address information for moms may be obtained from EHR or medicaid claims	8/19/2026 13:23	8/19/2026 13:25	Xing Song
76	If we look at the list of environmental exposures etc for ALS ,remove military history, what overlap is there for AD, PD, LBD FTD etc?	Benjamin Rix Brooks	benjamin_rix.brooks@clinicaltrialsplanning.com		8/19/2026 13:24		
77	Friendly reminder to all researchers, you have an army of pALS , cALS, and advocates who will do anything to advance the science of ALS. So, put us to work. if you need data, tell us what you need and the barriers to getting it. If you need organizations to do something, tell us who they are and what the issues are. Thanks	Patrick Dolan	phdolan@geoals.org		8/19/2026 13:27		
78	Can you speak on modifiable risk factors for ALS	Becky Wong	becky.wong@otsuka-us.com		8/19/2026 13:29		
79	We see work in ALZ dementia and was curious if there is work in this area for ALS	Becky Wong	becky.wong@otsuka-us.com		8/19/2026 13:30		