

#	Question	Asker Name	Asker Email	Answer	Question Time	Answered Time	Answer Name
2	"I spent over 35 years as a licensed plumber prior to my sporadic ALS diagnosis. During my career, I had chronic occupational exposure to lead fumes/melting, welding/soldering exhaust, and PVC glues and primers—which MSDS sheets explicitly warn can cause central nervous system depression, neurological damage, and severe systemic toxicity. How is the National ALS Registry currently evaluating long-term, multi-chemical occupational exposures like trades/plumbing, and is there ongoing research specifically linking heavy solvent/fume exposure to sporadic ALS risk?"	Randy Redman	rredman166@gmail.com	Randy, thank you for sharing your experience and for raising this important question. We're sorry to hear about your ALS diagnosis. Understanding whether environmental and occupational exposures may contribute to ALS is an important part of the National ALS Registry's research mission. The Registry collects information from people living with ALS through risk-factor surveys, including information about occupational history and potential workplace exposures, and funds external research to better understand possible ALS risk factors. Of particular relevance to your experience, the National ALS Registry has funded research at the University of Michigan examining occupational and environmental exposures and ALS. University of Michigan researchers have reported associations in their study populations between ALS risk and occupational exposure to metals, volatile organic compounds (VOCs), particulate matter, pesticides, combustion and diesel exhaust, as well as employment in production occupations.	8/20/2026 7:00	8/20/2026 7:04	Paul Mehta
2	"I spent over 35 years as a licensed plumber prior to my sporadic ALS diagnosis. During my career, I had chronic occupational exposure to lead fumes/melting, welding/soldering exhaust, and PVC glues and primers—which MSDS sheets explicitly warn can cause central nervous system depression, neurological damage, and severe systemic toxicity. How is the National ALS Registry currently evaluating long-term, multi-chemical occupational exposures like trades/plumbing, and is there ongoing research specifically linking heavy solvent/fume exposure to sporadic ALS risk?"	Randy Redman	rredman166@gmail.com	The Registry is also currently funding the University of Michigan's ALS CORPS (Cohort for Occupational Risk and Prevention Studies) project, led by Stephen Goutman, M.D. This research is specifically examining production-related occupations and occupational metal exposures and how a lifetime of non-genetic exposures—the “exposome”—may interact with genetic susceptibility to ALS. Other University of Michigan research supported by the National ALS Registry has examined environmental toxicants using both exposure histories and biological measurements. Researchers have found associations between certain persistent environmental pollutants and ALS, while more recent work has examined mixtures of metals measured in blood and urine and their relationship with ALS risk and survival.	8/20/2026 7:00	8/20/2026 7:04	Paul Mehta
2	"I spent over 35 years as a licensed plumber prior to my sporadic ALS diagnosis. During my career, I had chronic occupational exposure to lead fumes/melting, welding/soldering exhaust, and PVC glues and primers—which MSDS sheets explicitly warn can cause central nervous system depression, neurological damage, and severe systemic toxicity. How is the National ALS Registry currently evaluating long-term, multi-chemical occupational exposures like trades/plumbing, and is there ongoing research specifically linking heavy solvent/fume exposure to sporadic ALS risk?"	Randy Redman	rredman166@gmail.com	These findings support continued investigation of occupational exposures, but they do not establish that a particular exposure caused an individual's ALS. More research is needed to understand which exposures may contribute to ALS, at what levels and during which periods of a person's life. Your decades of experience in plumbing and your concerns about lead fumes, welding and soldering exhaust, VOCs, primers, and solvents are therefore highly relevant to the kinds of occupational exposures researchers are investigating. Participation in the National ALS Registry and completion of its risk-factor surveys help provide researchers with the information needed to continue studying these important questions.	8/20/2026 7:00	8/20/2026 7:04	Paul Mehta
2	"I spent over 35 years as a licensed plumber prior to my sporadic ALS diagnosis. During my career, I had chronic occupational exposure to lead fumes/melting, welding/soldering exhaust, and PVC glues and primers—which MSDS sheets explicitly warn can cause central nervous system depression, neurological damage, and severe systemic toxicity. How is the National ALS Registry currently evaluating long-term, multi-chemical occupational exposures like trades/plumbing, and is there ongoing research specifically linking heavy solvent/fume exposure to sporadic ALS risk?"	Randy Redman	rredman166@gmail.com	I'll hop in too. My collaborator, Stephen Goutman (who spoke yesterday), is looking at this. One of the things we're doing is looking at combinations of factors, especially in terms of environmental exposure. While the studies are ongoing, Stephen has published at least one paper on exposure mixtures: https://jnnp.bmj.com/content/95/3/241.abstract	8/20/2026 7:00	8/20/2026 7:07	Ben Murdock

2	"I spent over 35 years as a licensed plumber prior to my sporadic ALS diagnosis. During my career, I had chronic occupational exposure to lead fumes/melting, welding/soldering exhaust, and PVC glues and primers—which MSDS sheets explicitly warn can cause central nervous system depression, neurological damage, and severe systemic toxicity. How is the National ALS Registry currently evaluating long-term, multi-chemical occupational exposures like trades/plumbing, and is there ongoing research specifically linking heavy solvent/fume exposure to sporadic ALS risk?"	Randy Redman	rredman166@gmail.com	If you can't access the paper, feel free to email Stephen or myself and we can email you a copy that's not behind a paywall.	8/20/2026 7:00	8/20/2026 7:08	Ben Murdock
3	What is definition of frozen -20C -80C	Benjamin Rix Brooks	benjamin_rix.brooks@clinicaltrialsplanning.com	Those are temperatures at which samples are typically stored. -20 degrees C is the temperature you'd find in a commercial freezer (so your freezer at home is -20 C). This is typically used for short-term storage for storing experimental reagents. -80 C is long-term storage often used for storage of biomedical samples. These are massive freezers designed specifically for sample storage.	8/20/2026 7:17	8/20/2026 7:22	Ben Murdock
4	Note: -80C storage requires redundant cooling and power to ensure reliable storage of the biosamples.	Lynn Brielmaier	lynnbr2@att.net		8/20/2026 7:26		
5	Can we look at single strand DNA that is HERV specific in serum samples?	Benjamin Rix Brooks	benjamin_rix.brooks@clinicaltrialsplanning.com		8/20/2026 7:28		
6	Thank you for thoughts and answer.	Randy Redman	rredman166@gmail.com	Sure, if you have additional questions, please let us know.	8/20/2026 7:39	8/20/2026 7:59	Paul Mehta
7	1 of 2: Danielle, I couldn't agree more on the value of hearing about these valuable projects. It is important and energizing. I also hate to see us give short shrift to the original intent of the CDC ALS Registry. Perhaps it needs to be a different meeting, but there are legitimate questions about the data (and the processes that bring us to those data. Yesterday we pretty much went fast-forward through prevalence and incidence and moved on to the excitement of the results of the research grants. We heard yesterday that the CDC ALS Registry is more than counting cases, but it's also much more than these awesome research projects. We rely on the CDC ALS Registry for epidemiological data (as described in the ALS Registry Act), yet we didn't talk about timeliness of data or the challenges of turning incomplete counts into meaningful statewide data. We moved on to the outside researchers in a hurry.	M C Collet	mcollet@comcast.net	Thank you for your question. On top of the prevalence and incidence mentioned in Dr. Mehta's presentation, he also mentioned epidemiological studies recently completed or with journals currently or finalizing analysis. 2 manuscripts were linked in this morning's chat. Here is another one that was accepted earlier this year: https://www.tandfonline.com/doi/10.1080/21678421.2026.2677528?url_ver=Z39.88-2003&rft_id=ori:rid:crossref.org&rft_dat=cr_pub%20%200pubmed	8/20/2026 7:39	8/20/2026 7:45	Jaime Raymond
8	2 of 2: Today we're going to hear about incentivizing participation, yet we've not heard any concrete information on the effectiveness of the considerable money paid to partners for education and outreach. We can't assume that everything we spend money on is working. Sometimes every project needs a critical eye and some candid discussion on deliverables. And I wonder if the contracts with the partners and the significant grant monies made in a disease that is starved for grant money doesn't cause some blind spots among some. People don't want to bite the hand that feeds them. I think that the project would benefit from a spirit of continuous improvement where we measure and evaluate and use our collaborative spirit to make our cornerstone data for data on ALS in the US better. Thanks for listening.	M C Collet	mcollet@comcast.net	In Dr. Mehta's presentation, he also mentioned analyses that are currently underway, including veteran survival, a potential ALS cluster investigation in Virginia, genetic sequencing analysis done with our biorepository samples, just to name a few. Once his slides are posted, please take a look and see some of the other analyses we are doing in house to explore our risk factor data (web portal data is clean and analyzed through 2025).	8/20/2026 7:39	8/20/2026 7:47	Jaime Raymond
9	Paul, this would be a great question for Dr. Ileana Howard.	Andrea Pauls Backman	andrea@alsstrategy.com	Agree, I will reach out to her. She is on leave this week. Thanks	8/20/2026 7:40	8/20/2026 7:57	Paul Mehta
10	www.geoals.org is a series of Geographical Information Systems databases which is available to partner with researchers. https://home-geoals.hub.arcgis.com/pages/map-gallery~6fd09b6a6e8c4ce7a84444630b7d7da	Lynn Brielmaier	lynnbr2@att.net	Thanks, we have been working and collaborating with Pat Dolan who founded Geoals. He is an excellent geospatial researcher and we have shared data with him.	8/20/2026 7:55	8/20/2026 7:59	Paul Mehta

11	Should LMM model not include admission vital capacity as a co-variable?	Benjamin Rix Brooks	benjamin_rix.brooks@clinicaltrialsplanning.com	This answer is from Dr. Ostrow in the chat: @Ben Brooks - are you asking if it is possible to do, or if Alberto has done it in his study? It certainly is possible to measure HERV-K DNA in serum, and has been published in many studies. For example: https://pmc.ncbi.nlm.nih.gov/articles/PMC8788987/ and https://www.nature.com/articles/s43856-021-00060-w . The method is also been used in clinical trials, such as here: https://cdn.clinicaltrials.gov/large-docs/10/NCT02437110/Prot_SAP_001.pdf	8/20/2026 7:59	8/20/2026 8:18	Paul Mehta
11	Should LMM model not include admission vital capacity as a co-variable?	Benjamin Rix Brooks	benjamin_rix.brooks@clinicaltrialsplanning.com	My response above gave the same article link twice. Here is the other article I meant to include - https://pmc.ncbi.nlm.nih.gov/articles/PMC8009857/ . Note that HML-2 and HERV-K are two different names for the same thing	8/20/2026 7:59	8/20/2026 8:35	Lyle W. Ostrow MD PhD, Temple University
12	I hear you Randy regarding your exposure concern and ALS. Stay strong..My uncle who worked in Bharat Heavy Electrical Lmt. company in India also was diagnosed with ALS. However, his colleagues and others were unaffected..So all these rare/common chronic disease including cancer are challenging to correlate with environmental exposures and disease occurrence. I beleive it all depends on indiviual life style choices/genetics..Wish there are more studies on this perspectives for these disease which sometimes occur in children too	Sasi Aruna	sarunachal@pa.gov	This is spot on. A paper that came out about 10 years ago (https://www.thelancet.com/journals/laneur/article/PIIS1474-4422(14)70219-4/fulltext) found that ALS is likely a multi-step disease that requiries several "hits" just like cancer. The sporadic form (non-familial) is probably not due to a single source but a combination of genetic predisposition, environmental exposure, etc. That's why you have higher rates in certain occupations, but not everyone who works in the same environment gets the disease.	8/20/2026 7:59	8/20/2026 8:09	Ben Murdock
13	Thank you!	Sasi Aruna	sarunachal@pa.gov		8/20/2026 8:11		
14	Great presentation! My understanding is that most surveys focus on where people have lived but not where people worked. My assumption is that people are exposed to more toxins at work than at home. And people might work several miles away from their home, which means that they exposed to new set of toxins. Do you think having work place history could improve our understanding of what people are exposed to? And do you think work place history could be more insightful? Thanks	Patrick Dolan	phdolan@geoals.org	I think that's a great idea Pat.	8/20/2026 8:13	8/20/2026 8:16	Jaime Raymond
14	Great presentation! My understanding is that most surveys focus on where people have lived but not where people worked. My assumption is that people are exposed to more toxins at work than at home. And people might work several miles away from their home, which means that they exposed to new set of toxins. Do you think having work place history could improve our understanding of what people are exposed to? And do you think work place history could be more insightful? Thanks	Patrick Dolan	phdolan@geoals.org	Meredith didn't have a chance to go into the details, but ALS patients who enroll in the overall study at the University of Michigan fill out an exhaustive questionnaire that also covers employment and leisure activities. So one of the things we're trying to do with the stats is merge all the data together to account for multiple factors.	8/20/2026 8:13	8/20/2026 8:19	Ben Murdock
14	Great presentation! My understanding is that most surveys focus on where people have lived but not where people worked. My assumption is that people are exposed to more toxins at work than at home. And people might work several miles away from their home, which means that they exposed to new set of toxins. Do you think having work place history could improve our understanding of what people are exposed to? And do you think work place history could be more insightful? Thanks	Patrick Dolan	phdolan@geoals.org	Sorry - I'm putting my response here as well (I first posted it in the webinar chat)! Thank you for the questions! In terms or work vs home exposure, this is a great question. As you said, there are 2 factors: 1) address pollution vs your true location over time (work, shopping, etc.) and 2) address outdoor vs address indoor pollution. As you can imagine we use outdoor address pollution levels due for data availability purposes. That said, studies have found that any bias from #1 is likely small when longer-term exposures are considered. And as you said, as disease progresses concerns for #1 may decrease as people spend less time away from home. In terms of #2, most studies have found high correlations between outdoor and indoor pollution levels at the same address (especially if no home air-purification is used). So yes, these are assumptions we have to make in this type of research, but any biases from them are likely to be small.	8/20/2026 8:13	8/20/2026 8:34	Meredith Pedde
15	What is data on enclosed enviroments such as submarines and airplanes that try to control air quality exposure. eg WW2 vs nuclear vets?	Benjamin Rix Brooks	benjamin_rix.brooks@clinicaltrialsplanning.com	Great idea - not sure if anyone has looked at this, but we can try.	8/20/2026 8:15	8/20/2026 8:34	Fang Fang
16	Pat, that's a wonderful idea. I wonder if the job location is secondary and/or ancillary to the specific toxins one is exposed to?	Andrea Pauls Backman	andrea@alsstrategy.com	live answered	8/20/2026 8:19	8/20/2026 8:33	Fang Fang

17	What do we know with respect to interaction of ambient temperature and measured pollutant level on pollutant mediated disease effects?	Benjamin Rix Brooks	benjamin_rix.brooks@clinicaltrialsplanning.com	live answered	8/20/2026 8:30	8/20/2026 8:33	Fang Fang
17	What do we know with respect to interaction of ambient temperature and measured pollutant level on pollutant mediated disease effects?	Benjamin Rix Brooks	benjamin_rix.brooks@clinicaltrialsplanning.com	Thanks for this question. You're absolutely right that in short term (i.e., daily) air pollution studies that it's important to think about temperature. In "longer-term" exposures that we look at (3M and 5Y in progression, 1Y and 5Y in survival), it's generally less of a concern given the longer averaging periods and seasonality, though. That said, it is a great question and we can explore this to make sure there isn't residual confounding (by time). I will note that since our study was almost exclusively in Michigan, there isn't tremendous spatial variability in temperature, but of course there is temporal variation.	8/20/2026 8:30	8/20/2026 8:55	Meredith Pedde
18	so irrelevant; how you measure air pollution too far removed from my current condition. I'm out	Robert Cooney	robert.a.cooney@gmail.com		8/20/2026 8:39		
19	Are you looking at home indoor air pollution from gas stoves, water heaters& home heating systems?	Lynn Brielmaier	lynnbr2@att.net	no, we did not.	8/20/2026 8:41	8/20/2026 8:43	Fang Fang
20	Any data on influenza virus vaccine use on these results?	Benjamin Rix Brooks	benjamin_rix.brooks@clinicaltrialsplanning.com	Not yet - but good suggestion!	8/20/2026 8:49	8/20/2026 8:52	Fang Fang
21	Do veterans get information on how to donate their brains during ALS clinics at the VA?	Paula Garecht	paula.garecht@als.org		8/20/2026 8:59		
22	WHO has indicated that all form of tobacco/nicotine use is not safe. Is there research looking at risk/impact of vape devices (nicotine vs. nicotine-free) on ALS/neurodegenerative conditions?	Becky Wong	becky.wong@otsuka-us.com	live answered	8/20/2026 9:01	8/20/2026 12:14	Danielle Boyce
23	Did you find any differences based on military campaigns Veterans served in? For example, was there a higher rate of ALS for Veterans who served post 911 wars? Thanks	Patrick Dolan	phdolan@geoals.org	live answered	8/20/2026 9:05	8/20/2026 12:10	Danielle Boyce
24	Has anyone looked at ALS cases by proximity to coal-fired power plants vs gas-fired ... ?	M C Collet	mcollet@comcast.net	live answered	8/20/2026 9:11	8/20/2026 12:11	Danielle Boyce
25	Are nanoparticles same size as exosomes?	Benjamin Rix Brooks	benjamin_rix.brooks@clinicaltrialsplanning.com	Hi again Benjamin, they vary in size and nanoparticles could be smaller or larger than exosomes by definition.	8/20/2026 9:13	8/20/2026 9:45	Kevin Cornell
26	Are World Trade Center autopsy specimens available to CDC to compare with military specimens	Benjamin Rix Brooks	benjamin_rix.brooks@clinicaltrialsplanning.com	live answered	8/20/2026 9:18	8/20/2026 12:16	Danielle Boyce
27	Do you spinal cord data as well?	Benjamin Rix Brooks	benjamin_rix.brooks@clinicaltrialsplanning.com	Hi Benjamin, I did not look at spinal cord for the pilot experiment, but we are looking at spinal cord right now in our veteran population focused on locating toxic metals and the "metal profile" associated with it.	8/20/2026 9:27	8/20/2026 9:41	Kevin Cornell
28	What can we as advocates do to get the Registry biorepository samples available to researchers again? It seems terribly wrong that there are samples on the shelf that people donated that researchers are not able to access right now. Thanks for any thoughts.	M C Collet	mcollet@comcast.net	Hi there. I think this is one of those situations where advocacy could be helpful. I cannot speak for the CDC but I would imagine asking elected officials to help would be appropriate? The Glen Rouse Legislative Viewer is a good way to connect with your elected official. Open to other suggestions as well! Agree it is so important to be able to share samples. https://experience.arcgis.com/experience/432276c3289a4839be09c409b817ebd2	8/20/2026 10:08	8/20/2026 10:36	Danielle Boyce
29	There are big black boxes on the slides	Kuldip Dave	kuldip.dave@als.org		8/20/2026 10:34		
30	Hello, I am seeing black boxes on screen that are partially blocking the slides	Sarah Parvanta	sarah.parvanta@als.org		8/20/2026 10:34		
31	Fixed!!	Sarah Parvanta	sarah.parvanta@als.org		8/20/2026 10:35		
32	I raised this issue yesterday. ALS advocacy needs to pressure Congress not only for funding for the Registry, but staffing that allows the Registry to do its mandated work. ALS Assn, ALS United, ALS Network, MDA, Les Turner, I AM ALS, all need to get their constituents on board.	Andrea Pauls Backman	andrea@alsstrategy.com		8/20/2026 10:40		
33	@Reshma, looks like a very successful pilot project for enrollment!	Andrea Pauls Backman	andrea@alsstrategy.com	Thank you, Andrea!	8/20/2026 10:42	8/20/2026 10:46	Reshma Punjani
34	Do we know whether the 6 ALSA reps were promoting registry enrollment as enthusiastically in the months before the incentives as after?	M C Collet	mcollet@comcast.net	Hi, Collet, I understand you may be concerned with potential bias or subjectivity while promoting this project. However, ALSA has been a partner for a long time with the Registry and they are very active in patient recruitment. The integrity of the partnership and their professionalism and shared objectives/goals are strong.	8/20/2026 10:46	8/20/2026 10:58	Moon Han
35	Did anyone ask Visa, Walmart or Amazon if they would donate the gift cards to ALS Assn?	Andrea Pauls Backman	andrea@alsstrategy.com	Unfortunately, the government can't accept a service for free. It violates the Antideficiency Act. They could work directly with ALSA and donate them without our involvement.	8/20/2026 10:49	8/20/2026 11:00	Paul Mehta

36	Congrats on the huge increase in enrollment for the registry! What was different (besides the incentive) or the same in the process compared to before the pilot?	Ashley Thill	thill.ashley@gmail.com	live answered	8/20/2026 10:52	8/20/2026 11:04	Reshma Punjani
37	You said ALSA covered 800 pALS but CDC prevalence calculates to 620 How many are in CDC Registry from Texas Is there any additional data from MDA Care Centers.	Benjamin Rix Brooks	benjamin_rix.brooks@clinicaltrialsplanning.com	ALSA may have a higher number of pALS served. The Registry numbers are likely under reported.	8/20/2026 10:55	8/20/2026 10:58	Paul Mehta
38	I saw the slide but what I was referring to was the outreach/marketing, improved clinic process, etc. Sounds like nothing else changed which would assume the incentive was the difference	Ashley Thill	thill.ashley@gmail.com	live answered	8/20/2026 10:58	8/20/2026 11:04	Reshma Punjani
39	Stacy is a tremendous friend and ALS advocate!	Andrea Pauls Backman	andrea@alsstrategy.com	live answered	8/20/2026 11:09	8/20/2026 11:31	Danielle Boyce
40	I've known Shadene and Doug for years. Thank you for all you both do!	Andrea Pauls Backman	andrea@alsstrategy.com	live answered	8/20/2026 11:11	8/20/2026 11:31	Danielle Boyce
41	Let's not forget Layne Oliff, who was on the panel a couple of years ago.	Andrea Pauls Backman	andrea@alsstrategy.com	Layne was a good person and is missed.	8/20/2026 11:17	8/20/2026 11:29	Paul Mehta
42	Mara and Pat are not only phenomonal advocates, but give so much of their expertise.	Andrea Pauls Backman	andrea@alsstrategy.com	live answered	8/20/2026 11:19	8/20/2026 11:31	Danielle Boyce
43	Thank you for sharing your experiences, insights, and continued advocacy, Dr Farber, Doug, and Mara. 🐾❤️ I can relate. I was a caregiver to my dad, who passed away from sporadic ALS.	Ashley Thill	thill.ashley@gmail.com	live answered	8/20/2026 11:21	8/20/2026 12:17	Song Xue
44	I too began to feel more empowered to advocate since being diagnosed with C9 Bulbar ALS in 2025. After finding out that I carried the C9 mutation just like my mother, uncle, grandmother and great grandmother since 1881. I am now aware that I should have been able to be tracked and monitored for years before and asking if I could be tested over 15 years ago. I am involved with End the Legacy who is leading the effort to create a prevention protocol for the at risk community. I am 14 mo late .	Kristie Taddie	ssunnshyne@aol.com	Thank you for sharing your story, Kristie. We appreciate your advocacy and your commitment to raising awareness for families and communities affected by ALS. Stories like yours underscore the importance of advancing our understanding of ALS and supporting research into its causes and risk factors. The National ALS Registry is grateful to everyone who participates in the Registry and contributes to efforts to better understand ALS. We wish you and your family continued strength, and thank you for being such a dedicated advocate for the ALS community.	8/20/2026 11:21	8/20/2026 11:29	Paul Mehta
45	Why are those diagnosed with Bulbar ALS excluded from many trials?	Eric Johnson	ericjohnson47@gmail.com	live answered	8/20/2026 11:34	8/20/2026 12:11	Song Xue
46	I chosed an EAP for ten months. In the sixth month they changed the criteria. However they didn't tell me until the tenth month that I no longer qualified. To back up, EAPs are only for those who don't qualify for Clinical Trials.I found out I was too far gone for an EAP after being "in." Two years later, I'm still here!It goes to show that we still have a poor understanding of disease progression. A better understanding is crucial to better trial outcomes analysis.	Lynn Brielmaier	lynnbr2@att.net	live answered	8/20/2026 11:35	8/20/2026 11:52	Danielle Boyce
47	chased	Lynn Brielmaier	lynnbr2@att.net	live answered	8/20/2026 11:36	8/20/2026 11:52	Danielle Boyce
48	I am also a physician and I told my primary neurologist that I had ALS 4 Months before my genetic testing confirmed it . I have been told by both university of Michigan and Mayo Clinic's that I don't qualify for trials .	Kristie Taddie	ssunnshyne@aol.com	live answered	8/20/2026 11:40	8/20/2026 12:17	Song Xue
49	The answer to any question starting 'Why don't they....' is almost always, 'Money'.- Robert A. Heinlein	Lynn Brielmaier	lynnbr2@att.net		8/20/2026 12:02		
50	One thing to keep in mind is that ALS neurologist our trusted Advisor. But we have learned that they are not the best people to give advice on clinical trials. Because they focused on care and not trials. That's why pALS and cALS have to take ownership on finding the most promising treatments.	Patrick Dolan	phdolan@geoals.org	My two cents... Any neurologist or anyone else who tells you one trial is more likley to work than another is full of baloney. If we knew, we would have done a much better job over the last 30 years. What I CAN tell you about a trial - is I can explain the rationale, I can tell you the preclinical data. I can tell you about the design of the trial, and why a particular trial is designed a particular way. We can talk together about whether it is an appropriate design. But I gave up a long time ago on predicting trial results.	8/20/2026 12:08	8/20/2026 12:10	Lyle W. Ostrow MD PhD, Temple Univ.

50	One thing to keep in mind is that ALS neurologist our trusted Advisor. But we have learned that they are not the best people to give advice on clinical trials. Because they focused on care and not trials. That's why pALS and cALS have to take ownership on finding the most promising treatments.	Patrick Dolan	phdolan@geoals.org	As for advocating for drugs... as you know, I chair the DoD ALSRP. That program has grown from \$7M/year to \$40M/year since I joined it, because of YOU - beacuse of advocacy. But the greatest impact you have had has not been the \$\$, it has been the way we design and award grants. How we prioritize. Nothing about us without us. We have changed all the mechanisms to prioritize biomarker inclusion, to make sure that there are "community collaborations" in every aspect of trial design and execution - these are "Scored" components of the grants. They matter. And each year, we try to improve them. By putting these requirements into the mechanisms - we hold the purse strings. You cant get this funding without doing things the RIGHT way. Doing things together. Unfortunately, phase 3 trials still depend on funding from the same companies that are designing the drugs, because they are too expensive. I am hopeful that someday that won't be the case. That there will be other ways to fund these trials.	8/20/2026 12:08	8/20/2026 12:14	Lyle W. Ostrow MD PhD, Temple Univ.
51	I'm asking about vaping since the younger generation have preference for this. Also, if there is interest in juvenile ALS, this might be of interest.	Becky Wong	becky.wong@otsuka-us.com	live answered	8/20/2026 12:15	8/20/2026 12:17	Song Xue
52	ACT for ALS is set to expire on September 30, and Congress is running out of time to protect these critical programs.Both the House and Senate have passed bipartisan ACT for ALS reauthorization bills, but the bills are slightly different. The clearest and fastest path forward is for the House to pass the Senate-approved bill and send it to the President.The Senate bill would:Reauthorize ACT for ALS for five years through 2031 without interruption.Strengthen accountability and oversight of implementation.Preserve the important connection between expanded access and ALS research so data can continue supporting the development of new therapies.	Lynn Brielmaier	lynnbr2@att.net		8/20/2026 12:17		
53	Amen Brother! We need a unique identify	Patrick Dolan	phdolan@geoals.org		8/20/2026 12:21		
54	Thank you all for what you do. We know that you have to be fearless to do this work. Love you all!	Patrick Dolan	phdolan@geoals.org		8/20/2026 12:28		