

2023 National ALS Registry Annual Meeting August, 30th - Day 2 Questions and Answers Transcript

*Note this is only a transcript of the questions asked during the webinar, questions submitted during registration were answered separately and will be provided elsewhere

Time	Question	Asker Name	Answer	Answered By
9:07	Brooke & Sunny, as former athletes, how many cumulative Traumatic Brain Injury events do you think you might have had in your lives?	Lynn Brielmaier	live answered	Andrea Pauls Backman (Moderator)
9:30	What s being done to address the back log?	Stephen Fray	We are working with CMS to try to get the data as soon as it is available. CMS is typically not available for 2 years after the end of the calendar year and the data request is time consuming.	Jaime S. Raymond (ATSDR)
9:30	I found the National ALS Registry when I wen on a tear, researching clinical trials. I filled out the surveys, but now new things come to mind. There is no append/ update option.		Thank you for this information. The only survey/information that is made available to be updated is the Disease progression survey for which the email get sent out as reminder to update at certain interval. We will discuss your input of considering update/append option to other surveys beyond post-submission of the information in the future.	Moon Han (ATSDR)
9:38	Would you put a status meter on the website to continuously show us where we are in acquiring and processing and reporting on the next year's data, please?	M. C. Collet	Yes, we can provide an informational page on what data are received and being analyzed. Perhaps, we can say what year is currently being analyzed on the Registry Dashboard.	Paul Mehta (ATSDR)
9:38	The CDC refused to meet with last year's stakeholder group after our presentation at the meeting and ignored the majority of our action items. How will the new sessions be different?	Stephen Finger	We have never refused to meet with the stakeholder group. The action items were listed on my talk yesterday and many of the recommendations were implemented.	Paul Mehta (ATSDR)

9:38	The CDC refused to meet with last year's stakeholder group after our presentation at the meeting and ignored the majority of our action items. How will the new sessions be different?	Stephen Finger	As it was briefly addressed yesterday, the plan to meet with Stakeholders is in place. The exact detail is tentative, however. We value insights from different arms of ALS community so we are also seeking people of various experience, profession, and other attributes for diverse input. We continually address our limitations and this often takes actions of other agencies outside the Registry. We value the immediate need and call for change, and we will continuously put our effort in addressing them.	Moon Han (ATSDR)
9:38	The CDC refused to meet with last year's stakeholder group after our presentation at the meeting and ignored the majority of our action items. How will the new sessions be different?	Stephen Finger	We met with the first stakeholder group for months last year to get feedback on how to improve the registry. Further, we implemented many of the suggestions that were given to us as was discussed by Dr. Mehta in yesterday's talk. To say that we ignored the majority of the action items is, at best, disingenuous. Additionally, we feel it's important to broaden these stakeholder engagements to hear ideas from other groups (e.g., healthcare professionals). Regardless, any stakeholder may reach out to us at any time to discuss additional ways that we can make the Registry better. Any suggestion that we feel is reasonable and feasible, we do our best to implement.	Kevin Horton (ATSDR)
9:40	Hello what mobile applications are really helpful for ALS and why?	Vitaliy Hrynychshyn	All of our webpages are responsive to mobile and tablets. We have made improvements on the interface and will be making more. At this time, we do not have an app for registering.	Paul Mehta (ATSDR)
9:40	'@Brooke - was the information about the provided within the registry as a single line within the paperwork, or as a stand-alone brochure?	Michelle Schmitz	live answered	Andrea Pauls Backman (Moderator)
9:42	that's question from me as senior developer from Ukraine. My uncle have that and he cannot talk, so preparing app which can use text to speech interface...		Thank you, utilizing technology is very important for persons with ALS.	Paul Mehta (ATSDR)

9:42	In addition to the 2024 public engagement sessions, building an ongoing feedback mechanism would be great to continue to learn from the community. That way updates can be more timely and responsive to the community's needs.	Aditi Narayan Minkoff	live answered	Andrea Pauls Backman (Moderator)
9:42	In addition to the 2024 public engagement sessions, building an ongoing feedback mechanism would be great to continue to learn from the community. That way updates can be more timely and responsive to the community's needs.	Aditi Narayan Minkoff	Hi Aditi, we always welcome feedback. Our email address is als@cdc.gov where feedback can be sent. Thanks	Paul Mehta (ATSDR)
9:42	Last year we asked about when we would be able to register pediatric patients. Has any progress been made on this as we have so many people with juvenile onset under the age of 18 yrs old & their data isn't being captured.	Michelle Lorenz	We are currently looking into the requirements to include patients less than 18 years. We just recently analyzed juvenile ALS cases in our database (18-24 years). We hope it will be published soon.	Jaime S. Raymond (ATSDR)
9:42	Can you talk more about what user friendly means to the community? It would be super helpful to create a document that uses "technical spec/requirements" to provide the Registry with actionable steps to go through approval processes. The approval process takes time and phases would be helpful. I'll reach-out after the meeting.	Lauren Webb	live answered	Andrea Pauls Backman (Moderator)
9:47	yes to status meter (as someone who helps others complete the surveys)!!	Anne Supplee	Thank you for your feedback.	Paul Mehta (ATSDR)
10:06	What does FoB stand for?	Antoinette Harrison	live answered	Andrea Pauls Backman (Moderator)
10:14	How have the RFAs for ALS research coming from registry funds changed over time?	Neil Thakur	Neil, the team can answer this live at the end of day wrap up. Thank you.	Andrea Pauls Backman (Moderator)
10:14	How have the RFAs for ALS research coming from registry funds changed over time?	Neil Thakur	Most notably, I believe it was two years ago that they started a new mechanism to fund novel ideas / pilot projects in the early stages as opposed to only R01-level projects.	Lyle Ostrow (Temple University)

10:14	How have the RFAs for ALS research coming from registry funds changed over time?	Neil Thakur	I just looked it up. It is "Option B" - "intended to support novel ALS risk factor research... exploratory and development in nature." Scroll down to "additional information" - https://www.grants.gov/web/grants/view-opportunity.html?oppld=343085	Lyle Ostrow (Temple University)
10:14	How have the RFAs for ALS research coming from registry funds changed over time?	Neil Thakur	Further, I believe another *change* was not to the RFA language itself, but rather to the number of proposals they received. Prior to a couple years ago, my impression is that many ALS researchers were not aware of these funding mechanisms. Continued vigilance to promote these opportunities is important!	Lyle Ostrow (Temple University)
10:15	Dr. Fang, higher BMI is also associated with slower progression?	Lynn Brielmaier	live answered	Andrea Pauls Backman (Moderator)
10:15	Estimated peak incidence age for ALS continues to increase, do you believe that you will see an even later peak with your detailed methodology?	Bjorn Oskarsson	live answered	Andrea Pauls Backman (Moderator)
10:20	Is anyone collecting data on those patients who are diagnosed as not having ALS	Benjamin Rix Brooks MD	live answered	Andrea Pauls Backman (Moderator)
10:23	Thank you everyone.	Nitesh Sanghai		
10:40	Do you have detailed history of previous immunizations at time of entry to military Is there a relationship to results	Benjamin Rix Brooks MD	live answered	Andrea Pauls Backman (Moderator)
10:42	Does your data indicate a particular branch of service with a higher incidence of ALS?	Juliet pierce	live answered	Andrea Pauls Backman (Moderator)
10:48	Dr. Bjornevik, this DoDSR study does not include VA data?	Lynn Brielmaier	live answered	Andrea Pauls Backman (Moderator)
10:58	Will your research also assess if Veterans with ALS are living longer? If so, is there a commonality that points to their longevity?	Juliet pierce	live answered	Andrea Pauls Backman (Moderator)
11:12	Is there comparable data for mercury?	Benjamin Rix Brooks MD	live answered	Andrea Pauls Backman (Moderator)

11:17	How specific was the location of ALS mortality cases... zip code? Thank you,	M. C. Collet	live answered	Andrea Pauls Backman (Moderator)
11:17	Do you have any data on reports of Pb intoxication in these areas ie non ALS Pb intoxication	Benjamin Rix Brooks MD	live answered	Andrea Pauls Backman (Moderator)
11:18	Do you know if anyone has studied lead in dishes and ALS? Thank you.	M. C. Collet	live answered	Andrea Pauls Backman (Moderator)
11:19	Why would airborne lead be more significant in rural areas? is it more likely to be well water?	Jonathan Guest	live answered	Andrea Pauls Backman (Moderator)
11:20	What about shaving lead fishing weights?	Lynn Brielmaier	live answered	Andrea Pauls Backman (Moderator)
11:21	Is your research published already? Would love to read more.	Adriana Martinez	live answered	Andrea Pauls Backman (Moderator)
11:21	Data for child ALS and it's links to SPTLC2?	Lakeia Nard	live answered	Andrea Pauls Backman (Moderator)
11:23	Has there been any studies in the age of the housing (older homes have lead paint) and ALS and blood lead levels?	Brian Kaplan	live answered	Andrea Pauls Backman (Moderator)
11:24	Older homes may also have lead water lines.	Brian Kaplan	live answered	Andrea Pauls Backman (Moderator)
11:29	ATSDR has done an extensive review of lead sources and I recommend they be consulted. There are a number of lead sources that are not necessarily captured in TRI data. Some of these sources include old forgotten mines and former military training sites.	Brian Kaplan	live answered	Andrea Pauls Backman (Moderator)
11:31	Data rising in child ALS link to SPTLC2 in people of color?	Lakeia Nard	live answered	Andrea Pauls Backman (Moderator)
1:12	So as to not to conflict with HIPA and OMB confidentiality rules, can a map be shown for ALS counts by County using the ALS registry?	Evelyn E Talbott	We do not have county level data, just city for this survey.	Jaime S. Raymond (ATSDR)
1:25	Is there any effort to translate the questions into other languages like Spanish? Somali?	Anne Supplee	live answered	Andrea Pauls Backman (Moderator)

1:25	Is there any effort to translate the questions into other languages like Spanish? Somali?	Anne Supplee	We do have survey questions in Spanish. That is the only other language to date.	Jaime S. Raymond (ATSDR)
1:28	thanks, Jaime , I was about to email you, as we have county of blood draw for the study , I don't believe county is considered a HIPA prohibitive descriptor, can a map be used in our NATA paper to show where teh 260 cases and controls are located (we were asked to do a spatial analysis with Morans I as part of the revision, do you see a problem with that or should I also ask Wendy this questions? I can send you the map to take a look, Thanks evelyn	Evelyn E Talbott	Yes, let's talk offline.	Jaime S. Raymond (ATSDR)
1:28	Fantastic, where does one access that? Could send the link?	Anne Supplee	https://www.cdc.gov/als/ALSJoinALSRegistry_Spanish.html	Jaime S. Raymond (ATSDR)
1:31	yes	Evelyn E Talbott		
1:35	Could this analysis be done at a street address level instead of city level?	Stephen Finger	The survey only asks for city, not county nor street level.	Jaime S. Raymond (ATSDR)
1:37	How long has the particular survey used here been live?	M. C. Collet	live answered	Andrea Pauls Backman (Moderator)
1:41	Great work Pat, Earl, Danielle and Earl. Thank you for doing work this in addition to your day jobs.	Diane Hoey	live answered	Danielle Boyce (Johns Hopkins University)
1:42	^ Opps thanks Clare.	Diane Hoey	Thank you for coming and for your kind words, Diane!	Danielle Boyce (Johns Hopkins University)
1:43	We heard two anecdotes that clinic education and outreach amounted to brochures in a "welcome to ALS" packet. How can ATSDR raise the bar on what ALSA, MDA, LTALS are paid to do? How are their results being measured?	M. C. Collet	We are working on a new approach which will allow us to see how Registry information is actually going out. We hope to see if this approach is more effective.	Jaime S. Raymond (ATSDR)
1:45	What does it mean that ALS clinics are linked to you? Is there actually any of specific data transmitted to you? It seems there are so many different researchers/databases that just don't communicate with each other. So disheartening.	Myra Taksa	We have no direct links to the clinics, but the organizations such as ALSA, MDA, and Les Turner who have staff members at these facilities.	Paul Mehta (ATSDR)

1:46	Mda, Itals, and ALS association here been paid to market the registry for the past decade. Which efforts have they found most effective to increase enrollments? How do will build upon these efforts?	Stephen Finger	All of these groups have been instrumental in getting the word out to persons with ALS and caregivers. They have direct contact at the clinic and support level. Without their efforts, outreach and awareness would be very difficult, if not possible. We don't have the resources to have "boots on the grounds" as these groups do.	Paul Mehta (ATSDR)
1:47	"Stepping on toes"???? Politics are killing us pALS			
1:49	Also, paying attention to the person and not just their ALSFRS scale and loss of speech. Folks often say that they get depressed by going to clinic.	Anne Supplee		
1:50	People stop going to Clinic due to futility. Once you are > 24 months post Dx, you are excluded from clinical.	Lynn Brielmaier		
1:51	excluded from clinical trials.	Lynn Brielmaier		
1:58	Not a question, but to add to what Layne just said, we need to remember - "You can't fix what you don't measure."	M. C. Collet	live answered	Andrea Pauls Backman (Moderator)
1:58	great question!	rene rivera-serra		
2:00	Last year when we surveyed people w ALS on what would motivate them to take surveys, they clearly ranked an incentive very low. The big motivators were to see the results and importance of their participation!	M. C. Collet		
2:01	What metrics are you using to measure the effectiveness of marketing efforts?	Stephen Finger	live answered	Andrea Pauls Backman (Moderator)
2:02	Which efforts have partners found most effective to increase enrollments? How do will build upon these efforts?	Stephen Finger	live answered	Andrea Pauls Backman (Moderator)
2:04	When we asked "What might motivate you to self-enroll?" responses were 79% More info about what my data would contribute 33% More results from the registry 30% More timely reporting of results < 10% An incentive like a gift card	M. C. Collet	Yes, we have heard that as well. In the past, we have made our manuscripts Open Access but we have realized that is not enough. We are now working on creating "bite size" information that highlights the manuscripts that utilize the survey data.	Jaime S. Raymond (ATSDR)

2:05	The name is also confusing because people say "I've already registered" but it's with their local ALS organization, not THE Registry!	Anne Supplee	live answered	Andrea Pauls Backman (Moderator)
2:07	How do you measure the effectiveness of these efforts?	Stephen Finger	Each organization sends us reports on a monthly basis regarding persons with ALS contacted at the clinic or support group level. Since we cannot force anyone to join, these data are important, but not exhaustive.	Paul Mehta (ATSDR)
2:09	My question is why you are so focused on an incentive when we had a strong signal that an incentive is not an important motivator to people with ALS???	M. C. Collet	Incentives have been used in research in the past. If the pilot program, when launched, does not show to be effective, we would not pursue this effort and shift gears.	Paul Mehta (ATSDR)
2:09	How cancer does it, including quarterly updates: Cancer Prevention Study-3 (CPS-3): https://www.cancer.org/research/cps3-cancer-prevention-study-3.html	Lynn Brielmaier	Thank you for the information. As it is common to learn from a strong study model as such as cancer study, we also continuously learn from literatures. One difference to note is that ALS is not notifiable disease as cancer is. This makes it challenging to estimate concrete disease burden.	Moon Han (ATSDR)
2:09	How long does a name stay in the registry? When I die will you erase my info?		live answered	Andrea Pauls Backman (Moderator)
2:10	Les Turner ALS Foundation has a dedicated Registry person and provide one on one assistance. We do need help in doing outreach in communities most impacted by health disparities. I'll be reaching out to the ALS Geospatial group to inform our outreach efforts	Lauren Webb	live answered	Andrea Pauls Backman (Moderator)
2:11	Do people from CMS and VA databases get GUIDs, or only those who self-register?	Michelle Lorenz	Good question. Only those who self register accept to have a GUID created for them will receive a GUID.	Jaime S. Raymond (ATSDR)
2:13	What would each ALS patient consider as something that they thought that the ALS Registry would help them with their ALS journey and was this that they saw has been accomplished?	Benjamin Rix Brooks MD	live answered	Andrea Pauls Backman (Moderator)
2:14	What year was the last year that registry names were compared to the NDI? If someone died in 2020 are they still receiving emails?	Stephen Finger	For NDI analysis, through 2018 about to complete the match for 2019.	Jaime S. Raymond (ATSDR)
2:14	Why not make it international?	Gudjon Sigurdsson	live answered	Andrea Pauls Backman (Moderator)

2:17	Does what I just read about NDI mean that families of people who died in 2020, 2021, 2022 are still getting emails and clinical trial notification?	M. C. Collet	We have implemented measures to allow the caregivers who would receive information/notification to unsubscribe from further communications. As we do not know the passing of the registrants unless the family member or caregiver contacts us directly, we rely on NDI to confirm the passing of the registrant. It is then, that we indicate in the database to remove them from further communications.	Moon Han (ATSDR)
2:20	The ALS community wants a way to report hot spots of possible ALS clusters to investigate. When we have asked about it previously, we were told that should be done at the state level. But states don't have the revenue and often have political reasons for not pursuing investigations. We need to be able to correlate Pat's GIS data with the CDC registry and need ATSDR to investigate. How do we work together to make that happen?	Michelle Lorenz	live answered	Andrea Pauls Backman (Moderator)
2:22	5 years delay is far too long. Must find a way to speed this up asap. Make this simpler "We are on the ALS clock"	Gudjon Sigurdsson	live answered	Andrea Pauls Backman (Moderator)
2:23	An easy way to increase URM community enrollment is by outreach to the 102 HBCUs and especially at the HBCU med schools. Pat has mapped these HBCUs and very few have clinics or clinical trials are in these locations.	Michelle Lorenz	live answered	Andrea Pauls Backman (Moderator)
2:27	The ALS Association is launching a trained volunteer ALS Registry enrollment program (similar to Les Turner's one-on-one approach) to provide direct assistance when requested. We're also working on a pilot to increase community-based outreach to people living with ALS who stop attending clinic because of language or cultural barriers. In addition, we are planning a workshop focused on developing an ALS diagnostic referral line to reduce the time to diagnosis and increase access to multi-disciplinary care, genetic testing, treatments and the Registry.	Patricia Stanco	live answered	Andrea Pauls Backman (Moderator)

2:30	what's the name of the WhatsApp group	Myra Taksa	It is through Her ALS Story.	Andrea Pauls Backman (Moderator)
2:31	Has CDC ALS Registry considered developing an ALS Caregiver's Form to expand the information available across the different geographies/ economical levels for those who are impacted by the disease ALS?	Benjamin Rix Brooks MD	live answered	Andrea Pauls Backman (Moderator)
2:31	Has CDC ALS Registry considered developing an ALS Caregiver's Form to expand the information available across the different geographies/ economical levels for those who are impacted by the disease ALS?	Benjamin Rix Brooks MD	This is a great recommendation. We will discuss internally.	Paul Mehta (ATSDR)
2:32	How could ALS advocacy groups be informed so they could mobilize to put pressure on local governments to cooperate with the CDC, if they are not being responsive about investigating specific potential hotspots like the one in Alabama?	Kathleen Wilsbach	live answered	Andrea Pauls Backman (Moderator)
2:41	A bit off topic and not really a question but more of an ask. I was only able to listen to a little bit of yesterday's webinar, so this comment pertains to yesterday discussion because I didn't get a chance to comment! Some of the discussion centered around a lack of diversity in the registry numbers. Because capturing diversity seems to be a big issue maybe an invitation to a member of the I AM ALS group "Many Shades of ALS" to explain what the issues that non whites have issues with registering. Maybe then the Registry could pivot to find ways to break down those barriers. Thank you.	Jenny Gore Dwyer	live answered	Andrea Pauls Backman (Moderator)

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2:42	I would say the real value of the Registry is to keep people who share the reasons why a person has ALS from also getting ALS	Neil Thakur	live answered	Andrea Pauls Backman (Moderator)
2:49	sure	Neil Thakur		
2:51	Last year's stakeholder group stressed the need to examine the performance of the algorithm across different demographic groups. What have you found?	Stephen Finger	live answered	Andrea Pauls Backman (Moderator)
2:53	Why not?	Stephen Finger	We did not see a significant difference in the 2018 overall prevalence by demographics. Nothing caught our eye regarding a change in age at diagnosis, race, sex, etc.	Jaime S. Raymond (ATSDR)
2:56	I think that Stephen's point about the whole algorithm and demographic groups would be valuable to pursue in the coming year.	M. C. Collet	Thank you, Cathy.	Andrea Pauls Backman (Moderator)
2:56	Can Dr. Mehta speak about the review committee for this RFA? Do they look at what's already gotten funded (looking at the portfolio across registry and NIH funded) to make recommendations for funding?	Kuldip Dave	live answered	Andrea Pauls Backman (Moderator)

2:56	What are the barriers to reporting ethnicity like the MENA and differentiating Asian communities where we know there are different genotypes prevalent among those ethnicities?	Michelle Lorenz	Small numbers in the Registry makes it difficult to look at particular races and ethnicities. We are looking at a comparison in age at diagnosis, site of onset, etc. for white vs. black vs. other races. We have discussed internally at specific races that might be affected differently.	Jaime S. Raymond (ATSDR)
2:59	I have a hard stop at 3. Nice job hosting Andrea!	Neil Thakur	Thanks, Neil - great to have you join!	Andrea Pauls Backman (Moderator)