

| Time (EST) | Question Asked | Asked By | Answer | Answered By |
|------------|---|------------------------|--|----------------------------------|
| 8:53 | will this recorded? thanks | t s | Hello t s, Thank you for your question. Due to limitations regarding consent, the meeting will not be recorded for publication but a transcript will be available on the CDC website, cdc.gov/als . Thank you for joining us today! | Tori Bahe (Ross Strategic) |
| 9:06 | Transmission still garbled ? pods | Benjamin Rix Brooks MD | Thank you Benjamin. We will have Paul remove his headphones to help with the audio. | Tori Bahe (Ross Strategic) |
| 9:10 | 5 year old numbers? Is this the best we can do? | Gudjon Sigurdsson | Thank you, Gudjon. Paul is answering this question now. | Andrea Pauls Backman (Moderator) |
| 9:11 | The overall prevalence and incidence of ALS cases is more in whites compared to blacks. Any thoughts? | Nitesh Sanghai | live answered | Andrea Pauls Backman (Moderator) |
| 9:12 | How is it that each demographic group is estimated to be missing over 30% of cases but the overall rate is 27%? How much confidence do you have in the 27% figure? | Stephen Finger | live answered | Andrea Pauls Backman (Moderator) |
| 9:12 | How is it that each demographic group is estimated to be missing over 30% of cases but the overall rate is 27%? How much confidence do you have in the 27% figure? | Stephen Finger | Yes, we do feel confident regarding the 27% figure. The race data has 17.2% missing race which makes the % missing slightly more unstable and gives a higher percentage. The overall missing of 27% is a more accurate number because it includes all of the ALS cases the Registry has. | Jaime S. Raymond (ATSDR) |
| 9:13 | Re clinical trial notification -- The registry's list of interventional trials continues to be < 10% of recruiting interventional trials for ALS. I don't think people depending on notification realize that. How about just pulling all ALS recruiting trials from clinical trials dot gov and featuring one each week? Just cycle through them. It's public info on clinical trials dot gov. Or just send a link for a list of recruiting interventional trials on clinicaltrials.gov and a link for observational trials there to people every quarter? | M. C. Collet | live answered | Andrea Pauls Backman (Moderator) |
| 9:13 | Re clinical trial notification -- The registry's list of interventional trials continues to be < 10% of recruiting interventional trials for ALS. I don't think people depending on notification realize that. How about just pulling all ALS recruiting trials from clinical trials dot gov and featuring one each week? Just cycle through them. It's public info on clinical trials dot gov. Or just send a link for a list of recruiting interventional trials on clinicaltrials.gov and a link for observational trials there to people every quarter? | M. C. Collet | The clinical trial research notification tool is currently used to help researchers recruit Registry-enrolled PALS into active trials and studies. We don't control what types of studies that researchers want us to recruit for (e.g., interventional trials). | Kevin Horton (ATSDR) |

| | | | | |
|-------------|---|------------------|--|----------------------------------|
| 9:14 | How often are you now running the death data against the database? Thanks. | M. C. Collet | live answered | Andrea Pauls Backman (Moderator) |
| 9:14 | How often are you now running the death data against the database? Thanks. | M. C. Collet | We send data to NDI twice a year and then update our web portal once it is finalized annually. | Jaime S. Raymond (ATSDR) |
| 9:16 | Hello from the Karolinska Institute in Sweden: in the US, is the registry used by research teams to pre-screen for ALS trials? | Juliette Foucher | The Registry data is not used as a pre-screening tool for ALS clinical trials since the Registry does not collect current clinical data. There is a research notification tool letting people with ALS know that a sponsor or researcher has an open trial or study. | Andrea Pauls Backman (Moderator) |
| 9:17 | We know that respiratory failure is linked with ALS pathology, how could you crosslink the cardiovascular comorbidity with ALS. Is it a new signal, which we shouldn't miss | Nitesh Sanghai | live answered | Andrea Pauls Backman (Moderator) |
| 9:29 | On missing cases and demographics , it is not just race. It is age and gender. | Stephen Finger | Yes, that is correct. | Jaime S. Raymond (ATSDR) |
| 9:29 | How many HCPs completed the continuing ed? Do you have info on their specialties? What is the cost to provide CE? Thanks. | M. C. Collet | The CE just launched so we don't have any of this information regarding completions. The CE was done in house so there was no additional cost. | Jaime S. Raymond (ATSDR) |
| 9:29 | How many HCPs completed the continuing ed? Do you have info on their specialties? What is the cost to provide CE? Thanks. | M. C. Collet | We have just relaunched as Jaime stated. For this relaunch, our CE module and post-tests are linked to internal service which can provide us with the statistics on how many people have visited and taken the CE. Any result from this is pending as this has just started. | Moon Han (ATSDR) |
| 9:29 | Hello from Switzerland, how do you avoid double data using different data bases? Thanks | Peter Ambühl | live answered | Andrea Pauls Backman (Moderator) |
| 9:29 | Hello from Switzerland, how do you avoid double data using different data bases? Thanks | Peter Ambühl | We have an extensive deduplication process that is done within each dataset as well as between the datasets. This is done each time the data is updated to ensure we are not counting ALS cases more than once. | Jaime S. Raymond (ATSDR) |
| 9:34 | Why were the stakeholder sessions concluded? | Stephen Finger | Paul is answering this now. Looks like stakeholder groups are continuing. | Andrea Pauls Backman (Moderator) |
| 9:36 | On the registry home page, there are references to two different kinds of "Dashboard"s. Confusing. | M. C. Collet | We will look into that. Thank you. | Jaime S. Raymond (ATSDR) |
| 9:36 | On the registry home page, there are references to two different kinds of "Dashboard"s. Confusing. | M. C. Collet | One is the dashboard of ALS estimates and pertaining information. The other is the Enrollee/Registrant dashboard which displays surveys and such. We can definitely look into making it a better distinction. | Moon Han (ATSDR) |

| | | | | |
|-------------|--|---------------------|--|----------------------------------|
| 9:39 | I don't think the slides are progressing through Dr. Mehta's narrative. It seems as if the presentation is stuck on one slide. | Juliet Pierce | Transition does seem low, but the past few slides have been tables of similar format recapping on the topics discussed/addressed from the Stakeholder meeting and such. | Moon Han (ATSDR) |
| 9:40 | We saw last year that people with ALS we surveyed would be motivated far more by understanding the use and importance of the data and by seeing reported results of their participation than by any tangible gift. I hope this will probed more. | M. C. Collet | live answered | Jaime S. Raymond (ATSDR) |
| 9:40 | We saw last year that people with ALS we surveyed would be motivated far more by understanding the use and importance of the data and by seeing reported results of their participation than by any tangible gift. I hope this will probed more. | M. C. Collet | Yes, we are in the process of creating bite size pieces of information regarding epidemiologic studies that have been published. We hope this way of presenting the information will be well received. | Jaime S. Raymond (ATSDR) |
| 9:42 | Could substances from the Anniston site in AL be contaminating the aquifer? | Antoinette Harrison | live answered | Andrea Pauls Backman (Moderator) |
| 9:42 | Could substances from the Anniston site in AL be contaminating the aquifer? | Antoinette Harrison | Hi Toni! Checking now. Bart Guetti (not Meifang Li (Dartmouth College)) | Meifang Li (Dartmouth College) |
| 9:42 | Could substances from the Anniston site in AL be contaminating the aquifer? | Antoinette Harrison | Just sent you a map of Anniston,tomt-pharma, but it bounced. please send me your address if you would like to see the map. there are a lot of superfund sites in the City | Meifang Li (Dartmouth College) |
| 9:44 | Why completely new people on stakeholder groups every year? Most businesses find continuity important. I can see cycling new people on, but completely new groups? | M. C. Collet | A wide group of stakeholders is always important to get a diverse group of opinions. Of course, there are people who continue to give input to the Registry year over year, which is very helpful. | Andrea Pauls Backman (Moderator) |
| 9:44 | Why completely new people on stakeholder groups every year? Most businesses find continuity important. I can see cycling new people on, but completely new groups? | M. C. Collet | We want to make sure that we're hearing from different subgroups. We will be meeting with ALS healthcare providers soon to hear how we can better promote the registry through them. | Kevin Horton (ATSDR) |
| 9:45 | We don't have to pick between the two. We can motivate using data and incentives. This is not an either-or situation. | Sarah Parvanta | Good point, thank you, Sarah. | Andrea Pauls Backman (Moderator) |
| 9:46 | Being a participant in a study in the Netherland at the UMC, Sponsor is a US company, as well as in others in Sweden, Switzerland I guess, that checking can't be done unless I have a single ID for all studies worldwide. | Peter Ambühl | | |
| 9:47 | Is there a way to save the Q&A? Thanks. | M. C. Collet | Thank you for your question. The questions and answers will be included in the meeting summary. | Tori Bahe (Ross Strategic) |

| | | | | |
|--------------|---|--------------------|---|----------------------------------|
| 9:47 | Can you say more about why post-mortem donations are no longer accepted? | Anne Supplee | The National ALS Biorepository coordinates and plans both inhouse (premortem) and postmortem donations. We can reach out and get more information. | Moon Han (ATSDR) |
| 9:47 | Can you say more about why post-mortem donations are no longer accepted? | Anne Supplee | A percentage of the Biorepository funding was shifted to the Johns Hopkins/Temple ALS for their post-mortem collections. So at this point, any new postmortem tissue samples will be directed to them | Kevin Horton (ATSDR) |
| 9:50 | Have you seen any helpful, interesting trends, changes in data over the years the Registry has existed? | Diane Hoey | live answered | Andrea Pauls Backman (Moderator) |
| 9:52 | Do you have any thoughts on the use of ICD-10 code G12.21 to identify ALS patients in various claims databases? Will the use of the code leave out a lot of patients? | Maithili Deshpande | live answered | Andrea Pauls Backman (Moderator) |
| 9:53 | Thank you Andrea and Dr. Paul for answering the questions. | Nitesh Sanghai | | |
| 9:53 | If you missed over half of blacks in Massachusetts do you think you are underestimating missing cases in the prevalence estimates? | Stephen Finger | live answered | Andrea Pauls Backman (Moderator) |
| 9:53 | why is the data on webpages so old? "Page last reviewed: April 28, 2017" | Lynn Brielmaier | The contents on the webpages do get updated regularly. We will also make sure to update the dates that we "reviewed" as well. | Moon Han (ATSDR) |
| 9:55 | Considering the multifactorial nature of ALS, do you think there is the need of cocktail treatment. Further, do we need a new drug discovery area incorporating multiple molecules in single capsule in the future. Any thoughts? | Nitesh Sanghai | live answered | Andrea Pauls Backman (Moderator) |
| 9:55 | Considering the multifactorial nature of ALS, do you think there is the need of cocktail treatment. Further, do we need a new drug discovery area incorporating multiple molecules in single capsule in the future. Any thoughts? | Nitesh Sanghai | Yes. A cocktail treatment regimen should also be investigated. This has proven successful in HIV care. As for drug discovery, these need to be further investigated for safety and efficacy. | Paul Mehta (ATSDR) |
| 9:55 | https://www.atsdr.cdc.gov/about/mission_vision_goals.htm# | Lynn Brielmaier | Lynn, I believe the webpages are updated regularly. The date in the webpage footers may not have been updated, however. | Andrea Pauls Backman (Moderator) |
| 9:58 | But they missed over 50% | Stephen Finger | Thanks for the follow up, Stephen. Sorry we ran out of time. I think this is a question for follow up between you and Dr. Mehta. | Andrea Pauls Backman (Moderator) |
| 10:01 | Dr. Paul, I have a question, which I want to understand with regulatory perspective. What is more important ALSFRS positive outcomes or the positive survival outcomes with QoL | Nitesh Sanghai | live answered | Andrea Pauls Backman (Moderator) |

| | | | | |
|--------------|---|------------------------|--|----------------------------------|
| 10:01 | Dr. Paul, I have a question, which I want to understand with regulatory perspective. What is more important ALSFRS positive outcomes or the positive survival outcomes with QoL | Nitesh Sanghai | ALSFRS and QOL are measuring two different areas. ALSFRS is the disease progression itself while QOL looks at how the person with ALS is dealing on a daily basis. Both are important, but it is hard to say if one is more important than the other. | Paul Mehta (ATSDR) |
| 10:09 | Can you speak to how COVID has changed tissue acquisitions? | Lynn Brielmaier | COVID/Pandemic had definitely affected the logistics of visiting in-home for blood donation by the National ALS Biorepository. It has limited the visits, thus the number of biospecimen acquisition. Processing these biospecimen in the lab has also been affected, as labs were shut down as well. We are hoping to rebound and resume to normal activity level processing what is in the inventory and also encouraging the registrants to consent to receive Biorepository information. | Moon Han (ATSDR) |
| 10:19 | In the past over 97% of biorepository patients were white. What is the current rate? What is the rate in the tissue bank ? | Stephen Finger | live answered | Andrea Pauls Backman (Moderator) |
| 10:19 | In the past over 97% of biorepository patients were white. What is the current rate? What is the rate in the tissue bank ? | Stephen Finger | The portal is currently 94.5% White. It has become slightly more diverse. As for the Temple tissue bank, I will defer to Dr. Ostrow. | Paul Mehta (ATSDR) |
| 10:22 | Thank you Dr. Paul. EMA looks for survival whereas, FDA looks for ALSFRS, which seems to be subjective | Nitesh Sanghai | Correct. Both of them have differing ways to approve drugs. | Paul Mehta (ATSDR) |
| 10:23 | Are these samples from original NIH ALS station (Chen) or from Canadian studies (Strong) and subsequent Mayo studies (Kurland)? | Benjamin Rix Brooks MD | live answered | Andrea Pauls Backman (Moderator) |
| 10:24 | I would recommend blurring patient's names on pictures. | Juliette Foucher | live answered | Andrea Pauls Backman (Moderator) |
| 10:27 | Introduce too cells or tissues to correct mutation at he site, like sequencing information a 2 component system. could ALS not use a DNA tool to fix individual DNA cut, paste, edit text? like repairing double strand ? | Lakeia Nard | | |
| 10:29 | Thank you Dr. Paul. | Nitesh Sanghai | | |
| 10:32 | Great work out there. | Nitesh Sanghai | | |
| 10:35 | programmable protein that in nature is programmed by two separate molecules of RNA. A single protein and a single RNA provide scientist with ability to program this enzyme as molecular scalpel to cut double stranded DNA at sites directed by piece of RNA, can this method be beneficial? | | | |

| | | | | |
|--------------|---|-------------------|---|----------------------------------|
| 10:36 | Further, I feel like most of our scientific community is working towards G93 mice models. It is highly aggressive mice model, compared to other ALS mice models. Sometimes, I believe the drug discovery in these models could give misleading information, also, the new molecules effects could be converted in this highly expressed mice models | Nitesh Sanghai | Thank you for this information. | Paul Mehta (ATSDR) |
| 10:37 | Expanding the ALS registry under 18 can be beneficial to finding cures/treatment. | | Agree. This is something we can look at, but we would need approval/consent from those below the age of 18. | Paul Mehta (ATSDR) |
| 10:38 | Very good point for linking the samples with the studies | Nitesh Sanghai | | |
| 10:40 | pedi-ALS expand the registry to under 18 and the melanated communities please | | | |
| 10:40 | How about the biorepository? | Stephen Finger | live answered | Andrea Pauls Backman (Moderator) |
| 10:41 | Are there any demographic data on the HCPs who take the continuing ed? Thanks. | M. C. Collet | This information is currently not available. Whether this data is collected by the organization who would provide us with the statistics is unknown. We can inquire. | Moon Han (ATSDR) |
| 10:41 | why is the registry not expanded to under 18???? | | This was mentioned by Dr. Mehta during presentation. It is not approved by IRB for us to collect information on those under 18 years of age. | Moon Han (ATSDR) |
| 10:42 | Stephen Finger (You): How about the biorepository? | Stephen Finger | The biorepository patients are only tracked by state representation not race, but it is about the same as the web portal. | Jaime S. Raymond (ATSDR) |
| 10:43 | my son was 7 when he passed. i donated his samples to the NIH, why is the ALS not expanded to 18 ?? | | | |
| 10:43 | Most of the Guam samples are not from white people and that will increase the diversity of our biorepository. | Kathleen Wilsbach | It is definitely a great addition. | Moon Han (ATSDR) |
| 10:43 | Most of the Guam samples are not from white people and that will increase the diversity of our biorepository. | Kathleen Wilsbach | Good point. | Paul Mehta (ATSDR) |
| 10:43 | 18 and under? | | This would require approvals on our and is something we have discussed internally and will revisit. Our condolences on the passing of your son. We will review again including those below 18. Thank you. | Paul Mehta (ATSDR) |
| 10:44 | This question was answered for the portal but not for the biorepository | Stephen Finger | The team is working on this answer. | Andrea Pauls Backman (Moderator) |
| 10:44 | This question was answered for the portal but not for the biorepository | Stephen Finger | Jaime answered the question above. | Andrea Pauls Backman (Moderator) |
| 10:48 | I am with Melanin Children Matter Inc, | | | |

| | | | | |
|--------------|---|------------------------|--|----------------------------------|
| 10:48 | Melanin Children Matter Inc | | | |
| 10:49 | Do you think that the lack of ethnic representation in the prevalence reports impacts the lack of diverse participation in the registry? Not just the %, but the way it is presented as White, Black and “other” — I’m curious to understand why more ethnicities are not pulled out. | Aditi Narayan Minkoff | This is a great insight. There is always a possibility of degree of visibility affecting willingness. As for the data, due to multiple databases are being used to get our estimate, harmonizing the race category can be challenging. Some databases may lack a more detailed racial subgroup. Due to inconsistencies, stratification with sufficient sample count for proper estimation may be challenging. | Moon Han (ATSDR) |
| 10:50 | As a pharmacists would you support having a designation of ALS drugs for the US Formulary? | Benjamin Rix Brooks MD | live answered | Andrea Pauls Backman (Moderator) |
| 10:50 | I was denied when I tried registering my son who passed away at 7. between misdiagnosis and racial disparities i am fighting for child ALS and other rare diseases. | | Yes, we have submitted a brief report regarding JALS cases in our data (18-24 years due to our current constraints of not collecting data for persons less than 18). Adding younger patients is on our radar and we are exploring what we would need to do in order to start collecting this data. Thank you for your support in this effort. | Jaime S. Raymond (ATSDR) |
| 10:52 | Thanks. I was curious as to whether the CE was reaching physicians in minority groups. We'll never fix DEI in patient data until we address DEI in the ranks of physicians represented. Thank you. | M. C. Collet | You are welcome. | Moon Han (ATSDR) |
| 10:52 | Thanks. I was curious as to whether the CE was reaching physicians in minority groups. We'll never fix DEI in patient data until we address DEI in the ranks of physicians represented. Thank you. | M. C. Collet | Agree, DEI needs to addressed/improved in healthcare. | Paul Mehta (ATSDR) |
| 10:56 | These questions were not answered in the first session. 2018 Prevalence. Why did you choose to use the model that excluded demographic variables from the analysis for your main results? What were the range of estimates for the other specifications that were not selected? Why do you think each of the three models that allowed for variation by the demographic characteristics produced significantly higher estimates of missing cases? | Stephen Finger | While an estimate of the overall 2018 prevalence was our main target, we also sought estimates within strata of key demographic variables (sex, age, and race). It is to be expected that the total adjusted case count obtained using a covariate-free log-linear capture-recapture modeling strategy would differ from the summed estimates across strata based on applying such a strategy accounting for covariates. Generally speaking, however, the total case count and prevalence estimates were found to be quite consistent either way. This is the reason that the results from the model excluding demographic variables were highlighted in the text of the report, while the more granular stratum-specific estimates are also reported in Table 1. The estimated total case count is in the neighborhood of 30,000 (ranging from about 26,000 to 31,000), | Paul Mehta (ATSDR) |

regardless of whether covariates were ignored or of which stratified analysis is considered.

| | | | | |
|--------------|--|-----------------|--|----------------------------------|
| 10:56 | <p>These questions were not answered in the first session. 2018 Prevalence. Why did you choose to use the model that excluded demographic variables from the analysis for your main results? What were the range of estimates for the other specifications that were not selected? Why do you think each of the three models that allowed for variation by the demographic characteristics produced significantly higher estimates of missing cases?</p> | Stephen Finger | Regarding estimates from other specifications, no we do have those estimates for those not selected. | Jaime S. Raymond (ATSDR) |
| 10:57 | <p>Updated algorithm. The updated algorithm identified approximately 1,600 additional patients for 2017. What are the demographics for that group? Has the new algorithm improved case ascertainment of minority patients?</p> | Stephen Finger | We have not analyzed those specific 1600 likely ALS cases by demographic factors. It is possible they are younger and possibly more diverse. | Jaime S. Raymond (ATSDR) |
| 11:02 | <p>Payers are using Inclusion & Exclusion data from the clinical trials. This leaves PLWALS >24 months post Dx out in the cold.</p> | Lynn Brielmaier | live answered | Andrea Pauls Backman (Moderator) |
| 11:03 | <p>I extend my sincere gratitude for your condolences. Over a year ago, I initiated contact with the ALS Registry, demonstrating my commitment to the cause. I kindly request that you keep me informed about any developments concerning the decision to expand the ALS Registry to include individuals under the age of 18.</p> <p>In my capacity as a representative of Melanin Children Matter Inc., I remain steadfast in my ad</p> | | Lakeia, I send my condolences. As a mother, this is heartbreaking. We thank you for your support and please do reach out to us if there is anything we can do together to include this vulnerable population and advance the research that can benefit the children. | Moon Han (ATSDR) |

| | | | | |
|---------------------|--|------------------------|--|---|
| <p>11:04</p> | <p>remain steadfast in my advocacy efforts to broaden the ALS Registry's scope. Furthermore, I emphasize the critical importance of facilitating early access to whole genome sequencing within this context.</p> <p>Your cooperation and support in this matter are greatly appreciated. I eagerly await updates and look forward to continued collaboration in advancing these crucial initiatives.</p> | | <p>Thank you for your support. We will keep you updated.</p> | <p>Jaime S. Raymond (ATSDR)</p> |
| <p>11:05</p> | <p>formulary data is usually out of date.</p> | <p>Lynn Brielmaier</p> | | |
| <p>11:06</p> | <p>I am participating in both the CDC and TDI ARC repository studies. Are they sharing data? Also I asked my doctor at major ALs university Als clinic if they were interested in this and the answer was no</p> | | <p>We are not sharing data at this time, but this may change in the future.</p> | <p>Paul Mehta (ATSDR)</p> |
| <p>11:08</p> | <p>Can we be confident in this range if the two estimates using complete demographic data fall outside of the range? What were the estimates from the other specifications that were not selected ?</p> | <p>Stephen Finger</p> | | |
| <p>11:11</p> | <p>I need to be in another meeting this afternoon and will miss Dr Weisskopf. I have two questions related to his expertise.</p> <ol style="list-style-type: none"> 1. What have been the results of the studies of military outside the US? Has there been any consensus on ALS in other countries' military members? 2. Has anyone used the Million Veterans project to look at ALS? <p>Thank you.</p> | <p>M. C. Collet</p> | <p>These are excellent questions. It would be great if someone can ask Dr. Weisskopf during the session this afternoon.</p> | <p>Lyle Ostrow (Temple University)</p> |
| <p>11:11</p> | <p>I need to be in another meeting this afternoon and will miss Dr Weisskopf. I have two questions related to his expertise.</p> <ol style="list-style-type: none"> 1. What have been the results of the studies of military outside the US? Has there been any consensus on ALS in other countries' military members? 2. Has anyone used the Million Veterans project to look at ALS? <p>Thank you.</p> | <p>M. C. Collet</p> | <p>I will pose these to Dr. Weisskopf this afternoon. Also, all Q&A will be transcribed and added to the home page of the website at the end of each day's session.</p> | <p>Andrea Pauls Backman (Moderator)</p> |
| <p>11:12</p> | <p>When I have to break away for another meeting, I lose the Q and A.</p> <p>Is there a way for you to save the whole Q and A for us so that we can see questions answered while we were off of this zoom temporarily? Thank you.</p> | <p>M. C. Collet</p> | <p>We are looking to include the full list of answered questions in the Executive Summary that will be posted on the CDC website, cdc.gov/als</p> | <p>Tori Bahe (Ross Strategic)</p> |

| | | | | |
|--------------|--|-----------------|---|----------------------------------|
| 11:12 | When I have to break away for another meeting, I lose the Q and A. Is there a way for you to save the whole Q and A for us so that we can see questions answered while we were off of this zoom temporarily? Thank you. | M. C. Collet | They will included in the Executive Summary as well. | Paul Mehta (ATSDR) |
| 11:13 | I didn't explain my second question well about my doctors seeming disinterest in digging deeper into these databases and me as their patient. With your talking about the lack of databases sharing/working together, I am disheartened. This is my life and impending death, and it sounds like politics, egos and profits are standing in the way of true - and faster help. | | The Registry collaborates with a number of groups and we are always looking to expand our partnerships. Throughout the years we have partnered and continue to partner with the NIH, Neurobank, Johns Hopkins, Temple. We are always open to productive and constructive partnerships than can benefit persons with ALS. | Paul Mehta (ATSDR) |
| 11:13 | I didn't explain my second question well about my doctors seeming disinterest in digging deeper into these databases and me as their patient. With your talking about the lack of databases sharing/working together, I am disheartened. This is my life and impending death, and it sounds like politics, egos and profits are standing in the way of true - and faster help. | | I'm sorry to hear of your experience, Myra. One of the goals of the ALS Strategic Plan that was approved earlier this year is to encourage more collaboration and partnerships. The follow up steps are taking place as we speak. | Andrea Pauls Backman (Moderator) |
| 12:40 | What do we know of why the Vagus nerve is not effected like UMN's & LMN's? | Lynn Brielmaier | live answered | Andrea Pauls Backman (Moderator) |
| 12:40 | What do we know of why the Vagus nerve is not effected like UMN's & LMN's? | Lynn Brielmaier | The Vagus nerve does appear to be impacted in bulbar onset of ALS, see link: https://pubmed.ncbi.nlm.nih.gov/33167079/#:~:text=In%20controls%20and%20ALS%20patients,in%20bulbar%20affected%20ALS%20patients.In%20general,vagus%20nerve%20is%20linked%20to%20gastrointestinal%20conditions,such%20as%20GERD%20and%20others. | Paul Mehta (ATSDR) |
| 12:44 | How do we start getting Natural History Studies to include and analyze fecal samples? | Lynn Brielmaier | live answered | Andrea Pauls Backman (Moderator) |
| 12:50 | are the controls in the human study household controls? | Sarah Parvanta | live answered | Andrea Pauls Backman (Moderator) |
| 12:50 | Awesome talk Dr. Benjamin. Could you please let me know are these pathologies, i.e. decrease in microbiome is a result of Aggressive SOD1 mutation. As your studies are in G93A mice models. OR can we think in opposite manner, whether microbiome decrease leads to SOD1 aggregation. How confident are you in the risk factors involved | Nitesh Sanghai | live answered | Andrea Pauls Backman (Moderator) |

| | | | | |
|--------------|---|------------------------|--|----------------------------------|
| 12:53 | Could you please let me know the microbiome you looked into ALS mice models. I was wondering whether, the same microbiome is found in the humans. Are we comparing apples to apples | Nitesh Sanghai | live answered | Andrea Pauls Backman (Moderator) |
| 12:53 | Are gut microbiome results related to amount of stool produced | Benjamin Rix Brooks MD | live answered | Andrea Pauls Backman (Moderator) |
| 12:56 | given the importance of the comparator groups, have you compared to other disease groups, and how were the controls matched. Similarly have you performed any longitudinal analyses to identify changes with meds or diet or disease progression? | Emily vonScheven | live answered | Andrea Pauls Backman (Moderator) |
| 12:59 | Could you please explain how the pathologies in your ALS models affects mostly the brain axis rather than spinal cord axis. Or are they both correlated--Just for curiosity | Nitesh Sanghai | live answered | Andrea Pauls Backman (Moderator) |
| 13:01 | When you look at family members are you looking at people with similar history or pre-symptomatic patients ? | Stephen Finger | live answered | Andrea Pauls Backman (Moderator) |
| 13:04 | For PWALS would you suggest that they use probiotics to promote lipids ? | Jonathan Guest | live answered | Andrea Pauls Backman (Moderator) |
| 13:09 | the main advantage of family members is similarities of diet? | Lynn Brielmaier | | |
| 13:10 | I was asking this question because in the mouse models the pathologies are restricted to the spinal cord axis. | Nitesh Sanghai | | |
| 13:10 | Since there seems to be fewer anti-inflammatory bacteria in ALS patients, do you think focusing on consuming foods that decrease inflammation in the gut would be beneficial? | Morgan Quinn | live answered | Andrea Pauls Backman (Moderator) |
| 13:17 | Dr. Benzamin was awesome. Thank you Dr. Benzamin for your efforts in ALS research. | Nitesh Sanghai | | |
| 13:23 | Has algal blooms been considered as a pollution source? | Brian Kaplan | live answered | Andrea Pauls Backman (Moderator) |
| 13:24 | how is diesel exhaust similar and different? (many engines are exempted from emissions controls) | Lynn Brielmaier | live answered | Andrea Pauls Backman (Moderator) |
| 13:26 | Do the models consider indoor air? | Brian Kaplan | live answered | Andrea Pauls Backman (Moderator) |
| 13:30 | How do we add our own data for this study? | | Thanks, Myra. If you have submitted your environmental surveys in the Registry, you are part of this database. | Andrea Pauls Backman (Moderator) |

| | | | | |
|--------------|--|------------------|---------------|----------------------------------|
| 13:35 | how do you control for other geographically associated predictors of health and medical care, including access to care, income, other resources and other SoDH? | Emily vonScheven | live answered | Andrea Pauls Backman (Moderator) |
| 13:39 | Dr. Goutman, can you talk more about your team's role in environmental health policy? How do you share your impressive work to create change? | Lauren Webb | live answered | Andrea Pauls Backman (Moderator) |
| 13:40 | Can you speak a little more about the potential impact of agriculture and related exposures on ALS? | Sheri Strahl | live answered | Andrea Pauls Backman (Moderator) |
| 14:03 | Can you share more about Camp Lejeune toxic water victims and connections to ALS? | Tyler Gaetano | live answered | Andrea Pauls Backman (Moderator) |
| 14:06 | Marc, I am assuming this database contains the participants from the Million Veteran Study; individuals in this study have consented to genetic studies. Do you have access to these data--this would allow you to investigate a genetic link to exposure risk. Thanks, Eva Feldman | Eva Feldman | live answered | Andrea Pauls Backman (Moderator) |
| 14:08 | The Sagiaju paper found vast demographic differences between cases identified as "definite" and those classified as "possible " indicating that disadvantaged patients were missed when you require multiple visits to qualify as "ALS". You may need to be careful with these definitions. | Stephen Finger | live answered | Andrea Pauls Backman (Moderator) |
| 14:12 | Your comments on Statins are very interesting. Are you looking at Creatine Kinase as a factor? I have been told that a high CK level is a reason not to use Statins. | Jonathan Guest | live answered | Andrea Pauls Backman (Moderator) |
| 14:48 | From the latest prevalence report. I am concerned that the estimate of only missing 27% of cases overestimates our ability to identify cases and is in conflict with other findings. 38% of cases were missed in Massachusetts. Roughly 40% of patients use private insurance and would not be picked up by the new algorithm. | Stephen Finger | live answered | Andrea Pauls Backman (Moderator) |
| 14:50 | Can we be confident in the range from the latest paper if the two other estimates using complete demographic data fall outside of the range ? What were the estimates from the other specifications in that paper that were not selected? | Stephen Finger | live answered | Andrea Pauls Backman (Moderator) |
| 14:53 | How much funding \$ would be needed to set up a national registry? | Peter Ambühl | live answered | Andrea Pauls Backman (Moderator) |

| | | | | |
|--------------|---|------------------------|------------------------------|----------------------------------|
| 14:56 | Francois Gand from NURO. I have two questions for Dr. Metha. 1. Have you looked at how ALS FRS-R score is being affected by QOL? 2. Would you be interested in learning how Brain-based Communication (from non-communicative ALS patients) can affect the ALS FRS-R score? | Francois Gand | live answered | Andrea Pauls Backman (Moderator) |
| 15:01 | I am back n | Stephen Finger | | |
| 15:06 | >> We could help you at that level. (www.nuro.world) | Francois Gand | Thank you, you can email me. | Paul Mehta (ATSDR) |
| 15:09 | MUNIX adds objective muscle electrophysiology to ALSFRS-R | Lynn Brielmaier | live answered | Andrea Pauls Backman (Moderator) |
| 15:09 | Thank you Dr. Metha. Will do shortly. | Francois Gand | | |
| 15:10 | I don't remember whether Relyvrio or Radicava claims that life may be extended by a couple of months. Does this mean quality of life will be improved or just we may live longer | | live answered | Andrea Pauls Backman (Moderator) |
| 15:15 | Are there any CDC studies looking at USA distribution of ALS and Enterovirus D68 | Benjamin Rix Brooks MD | live answered | Andrea Pauls Backman (Moderator) |