

The National ALS Registry Webinar

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Agency for Toxic Substances and Disease Registry



So, I think I just want to, again, thank everybody for joining us. And this is the first time we're doing this. But in our experience from the National ALS Registry, when we talk informally to patients and to folks like yourself, we've been hearing a lot that people assume that they were registered, which makes a lot of sense — you don't have to do anything for a cancer registry, and a lot of times diseases are reported passively. So, it's really come to us to communicate the way the registry is important, to show the value to patients and to their families, and to help persons with ALS understand the best benefits of the national registry and all the research that it supports.

Why is the National ALS Registry Important?

Why Should Patients Join?

- **There are more unknowns than knowns about ALS**
- **Allows people with ALS to fight back and help defeat the disease by supporting future research**
- **Goals of the Registry:**
 - Seeks to find out what causes (etiology) ALS
 - Seeks to find out the risk factors
 - Reports on the number of ALS cases in the United States (incidence and prevalence) – attempt to identify every person with ALS in U.S.
- **What we do:**
 - ✓ Collecting and analyzing data
 - ✓ Funding external research
 - ✓ Connecting people living with ALS with clinical trials and research studies
 - ✓ Collecting biospecimens



Hi, everyone. Now this is Paul Mehta. I want to thank you for joining this afternoon.

And we know you're very busy at your chapters, in your clinics, and we certainly appreciate the time you are taking out of your busy schedule to join the webinar. It's one of those things where you are on the front lines when it comes to seeing patients and talking to caregivers — about joining research and so forth. We know it's not easy, certainly, talking to patients about ALS and all the predicaments that come with it. But I just want to give you a brief overview and a few slides about what we're doing here at the National ALS Registry and why the National ALS Registry is important and why patients should join.

We like to say there are more unknowns than knowns about ALS. No one knows what causes ALS, and so ALS is one of those diseases that — like I said, there's just more unknowns than knowns about ALS. And the registry allows people to fight back and help join the fight against ALS.

The goals of the registry are multifold. We like to look for what causes ALS, and the risk factors of ALS — We also do the epidemiology behind ALS, looking at who gets the disease, demographics, incidence and prevalence of ALS.

Our goal is to go and identify individuals in the U.S. with ALS. We also collect and analyze data. We fund external research as well. And we also work with drug companies to connect patients to clinical trials and epidemiological research as well. And we also have the National ALS Biorepository, which I'll be discussing, which collects biospecimens and is a great resource for patients, and it's completely free for them.

With a disease with so many unknowns...

- Any patient contribution counts...
- Every piece of the **puzzle** brings into focus the big picture and helps us to better understand:
 - What causes ALS?
 - Ultimately, we all want the same thing to halt, reverse, prevent, and ultimately cure ALS.
- **YOUR** influence matters—with your recommendation and explanation, patients can learn more and participate
- **YOU ARE ON THE FRONTLINES...and know your patients best.**



Inform PALS who have already Enrolled: Why take the Risk Factor Surveys (17)?

- **Helps researchers find clues about ALS:**
 - Occupations: are certain occupations at higher risk for ALS?
 - Military service: why are veterans at a greater risk of getting ALS?
 - Physical activity, smoking and drinking: are these risk factors?
 - Residential history and residential pesticide use: where did you live and did you use pesticides or insecticides?
 - Traumatic brain injuries: did you have a concussion or TBI?
 - Disease progression: how is ALS progressing (fast or slow) and what is affected
 - Open ended: tell us what you think may have caused your disease
- **Take surveys in any order (caregiver help is always appreciated)**

HELPS US SOLVE THE MYSTERIES BEHIND ALS

There's disease — ALS is one of those diseases, like I mentioned, there are many unknowns about ALS.

There are, unfortunately, many mysteries out there about ALS, certainly what causes ALS. And so the registry along with our other partners at the NIH and the DOD and so forth, as well as our partner organizations such as ALS Association, the Muscular Dystrophy Association, and the Les Turner ALS Foundation, we're all working together for a common goal of finding out what causes ALS. Ultimately, we all want the same thing: to halt, reverse, prevent, and ultimately cure ALS. That certainly is important for all of us and certainly for the patients you see every day.

And like I mentioned, you are on the front lines talking to your patients [inaudible], and your influence certainly matters, what you say is important to persons with ALS. And as in terms of, what you're — and that really matters to patients, if you say, "Listen, there's a resource which is available, which is the national ALS registry, which allows you to join the fight against ALS, be informed about clinical trials, join the National ALS Biorepository and so forth." And that certainly is very, very important. Like I said, I mean, your words, your actions are very, very important to get the word out.

So, we also have the risk factor survey. When patients come in, they can go ahead and take risk factor survey, via cdc.gov/als — they'll go ahead and join the registry. And these risk factor surveys are really important. For example, if you have patients who've already joined the registry and they haven't taken the risk factor surveys, we certainly would go and encourage them to go ahead and take them, and you can certainly let them know what they're about.

We have 17 risk factor surveys, and these are wide-ranging from occupation, which looks at certain occupations and whether they're at higher risk of ALS or not. Military service, we know veterans are at greater risk of ALS. We're not sure why they get ALS at a higher rate than non-vets.

Physical activity, smoking, drinking — these are also potential risk factors for ALS — where you lived, were you exposed to pesticide use and so forth, such as insecticides, herbicides, pesticides etc. These are also important for us to find out potential exposure routes to ALS. TBI, traumatic brain injuries, that certainly is one of those areas. For example, if a patient has had a concussion or repetitive concussions or played in a sport such as football, are they more prone to getting ALS? And so by taking all these risk factor surveys, persons with ALS are providing information which is being used to help us investigate what could be potential risk factors and the etiology, what causes ALS.

We also have a survey which is mirrored after ALS-FRS, which helps us see how the patient's progressing. It's our disease progression survey. And lastly, we also have a survey, which is an open-ended survey, which allows patients to let us know what they think may have caused their disease. And it's a free form — they can go ahead and type whatever they wish. And they can say whatever they want regarding what they feel may have caused their disease.

These risk factor surveys can be taken in any order. We certainly encourage caregivers to help ALS patients to go ahead and take these risk factor surveys. And like I mentioned, these surveys help us solve the mysteries behind ALS.

Why is the National ALS Biorepository Important?

Help researchers in the area of ALS:

- **Genetics:**
 - Identification of genes such as SOD1 and C9orf72 and others
- **Biomarker identification: indicator of a biological state or condition**
 - Help us to examine disease progression (how fast or slowly ALS progresses)
 - See if certain drugs will work or not work
 - Possibly identify if a simple blood test could catch ALS early
- **Environmental factors (analyzing patient's blood and saliva):**
 - Heavy metals (lead, arsenic, and others)
 - Persistent Organic Pollutants (e.g., pesticides, insecticides, PCBs, DDT): tough to degrade/breakdown

Details on the National ALS Biorepository

- **Biorepository is significantly different from others**
 - Linking extensive risk factor survey data with biosamples
 - Nationally representative (e.g., beyond referral centers)
 - User-friendly to PALS (e.g., use in-home phlebotomists to collect samples)
 - Collecting specimens specifically for biorepository (i.e., not use leftover study samples to constitute biorepository)
 - Pre/post mortem samples in one central biorepository
- **No charge for patients - user friendly - we come to your home**
 - Goals to collect 325 bloods, 125 salivas, and 10 post-mortem for FY19
- **Largest collection of pristine ALS samples for research, e.g., genetics, biomarkers, disease progression.**

So, we also have the National ALS Biorepository. The biorepository was an additional component that was added a few years back, and it's certainly an avenue for patients to participate in research. And the biorepository helps researchers in the areas of genetics.

We know there are many genes for ALS such as ALS — SOD1, C9ORF72, and so forth. When we collect patient samples we'll identify what genes are present by genotyping the samples.

We also are looking at biomarker identification. So, for example, we all know there's no blood test currently available for ALS. But we're looking to see, are there certain markers which potentially could be used for biomarkers in the future?

We're also looking at the environmental factors. So, for example, we'll go ahead and test their blood for heavy metals, lead, arsenic, etc., as well as something called persistent organic pollutants, which are pesticides, insecticides, and so forth. And so, all these contaminants are potentially toxic in the patient's body. These data are being analyzed and we'll go ahead and publish the findings as well.

Just kind of more information on the biorepository. So, all the risk factor surveys I mentioned previously — those are connected to the patient samples themselves. So, we have a rich database of exactly where the patient worked, what was their occupation, like I mentioned, were they in the military, where do they live, and all that information is connected to the risk factor surveys and to these actual patient samples themselves. That's why they're so valuable.

And we also make sure that these samples are collected in — not just from one single place but across the country. So, the data is from a nationally representative sample.

And more importantly this is user friendly. This is their biorepository for the patients. We like to say this is the patient's registry. And so, it's user friendly to patients. We come to their homes to collect blood, urine, saliva, and we want to make sure they can do it in their home. And like I said, there is no charge whatsoever to them at all.

For FY19, which is this fiscal year, we're looking to collect 320 blood, 325 saliva's and 10 postmortem patients as well. We're actually up, doing very well and achieving the goal for fiscal year '19. Also, the National ALS Biorepository in three to five years most likely will be the largest collection of pristine ALS samples for research including genetics, biomarkers, disease progression, and so forth.

Research “Success”—did you know the Registry contributed to these studies.... <https://www.cdc.gov/als/ALSExternalResearchfundedbyRegistry.html>

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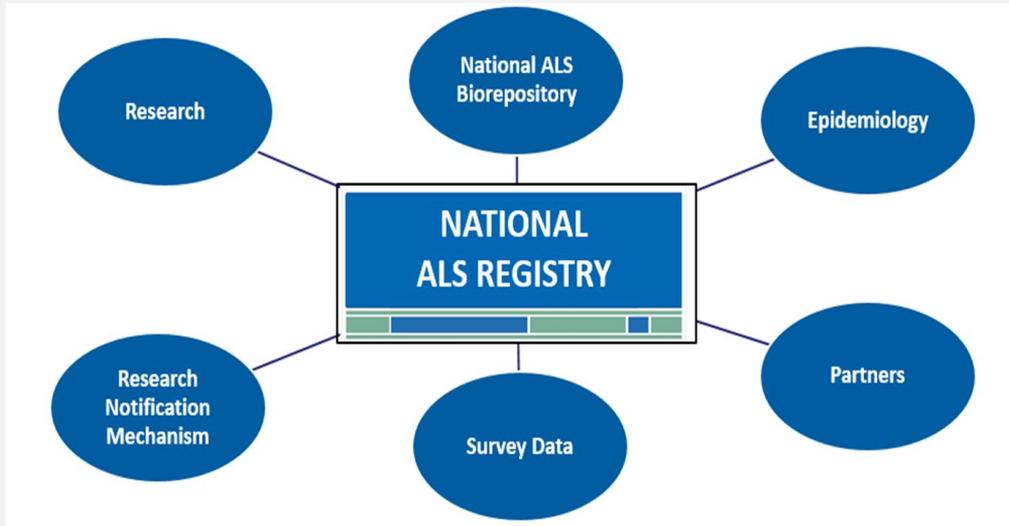
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We also have, this slide just kind of highlights all the research that we are doing with our partner organizations. So, you may not know, but we also fund grants and these grants are given directly to these institutions such as: University of Michigan, Columbia, and so forth. And all these institutions are examining risk factors for ALS and stuff that we can't do internally, but they are doing on themselves.

So, for example, Dartmouth is looking at something called cyanobacteria harmful algal blooms as a potential risk factor for ALS. Michigan is looking at organophosphates. Columbia is also looking at organophosphates and so forth. University of Miami's looking at the genetics of ALS. And our Trinity College in Dublin is comparing the European population to the Latin American population and trying to find out why the Latin American individuals get ALS at a lower rate than the Europeans. Is there a certain commonality? Are there certain risk factors that persons with ALS were exposed to in Europe which they were not exposed to in Latin America? And so forth. The genetics behind that is also very important too.

National ALS Registry is Unique and One of a Kind...



Registry Does More than Just Count ALS Cases

So, in closing we like to say we do a lot more than just count ALS cases. There's a lot of facets of the registry. There are registries out there, which Janine mentioned earlier, like the cancer registry, which are just collecting who gets cancer and so forth. Because ALS is so unique, as well as the pathology of ALS, and the severity of ALS, we want to go above and beyond to make sure we are doing what we can to find out what causes ALS.

So, like I mentioned, the National ALS Biorepository, which we do epidemiology of ALS. We work very closely with partner organizations — some of you who joined us on the phone, obviously are with the ALS Association, MDA, and the Les Turner ALS Foundation. We travel around the country giving patient talks as well as talks at patient and researcher symposiums. So, if you would be interested in having us come out and possibly give a talk to certainly go ahead and send us an email. And we can see if we're available to give a talk at your symposium or other event.

In summary, there are many ways persons with ALS can further ALS research through the National ALS Registry:

Contributing to the risk factor survey data, which is a rich source of information, available to researchers and which allows us to solve the mysteries behind ALS.

Participating in the notification system, which allows patients to connect with clinical trials, and epi studies. You may be aware of some of the clinical trials helped recruit for including BrainStorm, Emulex Pharmaceuticals, and Massachusetts General Hospital, just to name a few. MGH is conducting a number of clinical trials. And so, we're working with these organizations to make sure we can help them recruit for their clinical trials.

And the Registry is also funding research.

In closing we do a lot more than just count ALS cases. And so, we certainly appreciate your help and your partnership by talking to ALS patients about the registry so these patients can join the fight against ALS.

That is correct. You can — first join the registry, and then you can opt in to receive information about the biorepository. And our team will go ahead and mail information to the patients within 2 weeks about the biorepository. And they'll go ahead and contact them up to 3 times maximum, once the letter has been delivered, about the biorepository and how they can participate

Under-Enrolled States Outreach Project

▪ **Background**

- This current project is based on the Georgia pilot project, which found a successful increase in enrollment following targeted outreach to areas of under-enrollment.

▪ **Goals and Objectives**

- Focus on under-enrolled states and identify health districts within those states which could benefit from increased Registry outreach.
- States included: Hawaii, Mississippi, New York, West Virginia, Utah, and Wyoming
- Joint collaboration project with the ALS Association and the Muscular Dystrophy Association (MDA)

Good afternoon, everyone. I wanted to start off by discussing the Under Enrolled States Outreach Project. Now, this is transitioning a little from what Paul was discussing about the overall registry to a pilot project that we have seen positive impacts from.

So, a little bit of background about this project. The current project was based on a Georgia pilot project, which we did a couple of years ago. And it found some positive and successful increases in enrollment based on targeted outreach to areas of under-enrollment. So, for this project, what our goals were to focus on under-enrolled states and identify the health districts within those states which could benefit from increased enrollment.

So, for this project, the states we included based on their under-enrollment were Hawaii, Mississippi, New York, West Virginia, Utah, and Wyoming. And these states were selected based on our assessment of enrollment across the United States. Again, this project was a collaboration between the ALS Association and MDA.

So, I want to talk about three main tools that we used for this project. And some background on this project. The project was held from December of 2018 to May of 2019. And the three tools we had — the first was a nationally approved telephone script

Tools Used for the Outreach Project

- **Nationally approved telephone script**

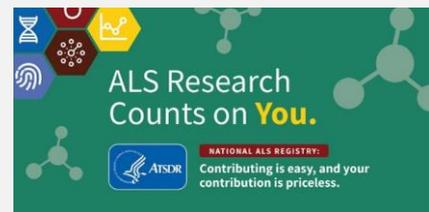
- Phone script template created by the ALS Registry to be used by the Partners during periodic outreach calls to ALS patients served by their local chapters and clinics

- **Social media messaging and outreach**

- Registry Master Table includes pre-approved messages for Facebook and Twitter
- Approved graphics for promoting the Registry

- **Partner-specific events**

- Targeted outreach during local events



So, this phone script is a template that the ALS registry created to be used by the partners during their outreach calls to ALS patients served by the local chapters and clinics. I have a copy of this script on the next slide. So, you will be able to see the exact content that we included in this script. And now, this script is available not only for this staff within the 6 states for the Under Enrolled States Project but for the entire U.S. and for our partners across the United States. So that was one of the first tools we had.

The second was increased social media messaging and outreach. So, the ALS registry has a master table, which includes preapproved messages for Facebook and Twitter. Basically, we want to have all the resources available for you all to promote the registry to increase awareness and to make those resources available for you, for us to meet that common goal. We also have approved graphics for promoting the registry. And these resources are on our website. And so, we want to make it easy for you all to access it at the local level as well.

The third tool we had for this outreach project were partner-specific events. And now what we found was that when our partners had specific events — for example, patient symposiums or walks — and they had increased outreach regarding the registry, we found that increase in enrollment. So just having that one-on-one conversation with the patients or the families really helped spread the message about the registry throughout the local areas.

Phone Script- available for partners

Hi! This is _____ calling from (partner organization). I'm just calling to check in and see how you're doing. [Wait for answer and respond accordingly, including offering any resources that may prove helpful for their given situation]

We have an upcoming event for (partner organization) families that I wanted to make sure you're aware of. [Depending upon when call is made, mention (partner organization) holiday party, support group meeting, educational event, etc.]

(Insert partner organization) is also working with the National ALS Registry. It is a program of the federal Agency for Toxic Substances and Disease Registry (ATSDR), which is a sister agency to the CDC, and we're helping spread the word about it. Have you heard of the National ALS Registry?

The National ALS Registry collects and analyzes data about people living with ALS. No one knows what causes most cases of ALS. The information shared with the National ALS Registry may help scientists discover factors that cause ALS and could contribute to a better understanding of the disease. Signing up with (insert partner organization) to receive information or services does not enroll you in the National ALS Registry. You have to register separately to join the National ALS Registry.

Here's where we need your help! Because no one knows what causes most cases of ALS, this type of data may help scientists contribute to a better understanding of ALS. Thousands of people with ALS have already shared their information with the National ALS Registry, and the more information provided by those with ALS, the more information researchers will have to work with.

The benefits of the Registry don't stop there! The Registry can connect you with ALS researchers. If you take part in the National ALS Registry, you can sign up to learn about opportunities to participate in clinical trials and studies. You also can use the Registry website to find ALS-specific health services and support groups.

If you have already registered, you have started to share your information with the National ALS Registry. Please consider taking the risk factor surveys to share even more information. The more information provided by those living with ALS, the more information researchers will have as they work to learn more about this disease.

Would you like me to provide the Registry website address to you, or send you more information? [If "yes" to more information, ask if the person would prefer mail or email.]

Thank you for your time.

So here is the example of the phone script. Now, I know the font for this is a little bit small. But I want to reassure everyone that this script is available online for you all to use. And at your own time, when you read through this script, what you'll see is that we've kind of provided a template for the messaging to reach our patients and families. So basically, in our conversation with local staff, we realized that it is a little bit of a challenge for everyone to disseminate a uniform message of what the registry is and what resources we provide, how we collect data, and all of that.

So, this script is an IRB-approved script that you all can use whether you are calling a family or a patient or even when you are having a one-on-one conversation. So, if you see this script, we have blank spots for you all to insert your partner organization. So, if you're from the ALS Association or if you're from MDA or from the Les Turner Foundation, any of the organizations can use this script based on what area you're in.

Best Practices for Registry Enrollment

- The Registry is **voluntary**. You can tell people about the Registry but cannot coerce them to take part.
- Do not **over promise**. The Registry is a form of public health surveillance and cannot find a cure or treatment of ALS.
 - Use IRB approved materials to describe the benefits of taking part in the Registry.
 - The Registry can assist Researchers by helping them recruit participants for ALS studies and providing samples from the Biorepository.
- Participation is **confidential** so do not ask people if they are in the Registry. It is ok if they tell you.
- When assisting people registering, the participant should read or be read all the materials on the screen exactly as written. You are just there to physically assist them. The participant has to answer all the questions and agree (or not) to all requests. The "I Agree" box should not be checked unless the participant has agreed.

Now, one of the last things I want to discuss — going away from the Under Enrolled States Project — is some best practices for registry enrollment. One of our take-homes from this webinar is to provide you all with some resources on how you can engage in conversation with ALS patients and families and kind of the dos and don'ts and best practices.

So, the first point I want to highlight is the registry is voluntary. So, when you're talking to patients or caregivers, you want to emphasize the registry, but you also don't want to twist their arms into taking part. That is the first point that I want to highlight.

The next point is we don't want to overpromise. So, the registry is a form of public health surveillance. So, we're not promising to find a cure or treatment. But we just want to educate families and caregivers and patients on what the registry is. And we do this by using IRB-approved materials to describe the benefit of taking a part in the registry.

Another point that you all can share with families and caregivers is that the registry can assist researchers by helping them recruit participants, for ALS studies and providing samples from the biorepository. So once a patient and the families are enrolled in the registry, they have access to participating with other ALS studies because researchers come to us to recruit for different trials.

Another point we want to emphasize is that participation is confidential. So, when you're working with a patient or family or caregiver, you don't want to directly ask someone, "Are you in the registry?" If they tell you that information, it is okay. But you just want to more educate them on the registry and not just ask or, "Have you already enrolled in the registry?"

And the last point I want to emphasize is that when you're assisting people and patients and families register through the portal, you want to read all the materials on the screen exactly as written. So, we know that a lot of our partner organizations have staff that kind of focus on educating patients and caregivers on what the registry is. And so, we want to make sure that you're delivering that exact message. So, you're just there to physically assist them. You want to read everything on this screen as it is. And you want to make sure that the participant answers all the questions and agree to or not agree to all the requests. Only then is when you want to check the "I agree" box. You want to make sure that even though you are assisting the patient, you're making sure that you are delivering all the information from our end to their end

National ALS Registry Outreach



Here's an overview slide of some pictures of the registry and some of our outreach. Like Paul mentioned in his section, we do go to numerous events, we attend conferences, we attend educational symposiums. So, you see some pictures on the slide of registry staff at various walks, conferences, and things like that. So, if you ever want to have the registry participate in your event, send us an email and we can try to accommodate as we can based on our schedule.

Communicating with Patients

- Potential obstacles
- Sharing the benefits
- Understanding timing



Thank you so much. And I know that sounds very complicated about enrolling, but that is one of the reasons we're talking with each other today.

Because communicating with patients — it doesn't have to be as restrictive as possible. And we have an actual real-life expert with us. Jennifer Hjelle will be speaking with us in just a second. And she has some really good ideas. We reached out to her because we know that she can talk very practically and frankly about what are obstacles to communicate effectively with people with ALS with their families, and how do you really talk about the registry? How do you show value and as Reshma pointed out, without feeling coercive, you want to educate. But the importance of that is really understanding critical things about timing — when do you approach patients? And how do you talk about it?

So, I'm going to be thankful that Jennifer has agreed to talk with us today. And she is calling in and going to talk a little bit about some of her practical experience and maybe some actual tips that might be helpful for the rest of us. And Jennifer, take it away

Jennifer Hjelle, Executive Director ALS Association MN/ND/SD Chapter

1. Staff Training

- In order for us to convey the importance of the ALS registry, our Care Services staff needs to understand it and why it is critical for people to enroll.
- Annual training with all staff as part of monthly staff meeting.

2. Consistency:

- The number one reason we have so much success is that we talk about it **ALL.THE.TIME.**
 - First encounter
 - Two Week Follow up call
 - All following meetings/calls with family



I do want to say although I appreciate the words of support, they all really should go to our care services staff. Because it all starts with those in our offices that are either meeting with people with ALS or talking to them on the phone. And that's why the number 1 thing is to make sure that our care services staff really understand the registry and understand how critical it is for people to enroll.

In addition to our care services staff, at least once a year we'll have a topic at our all-staff meeting. So, everybody in the office is aware of it. Because everybody in the office interacts with families in other ways. And so, I think it's important for everybody on the team to understand what the registry is and why it's important.

So, I think the absolute number 1 reason that we have always had high enrollment in the three states that we serve is because we literally talk about it all the time. I mean, it's kind of ridiculous — we're pretty, pretty maniacal about it.

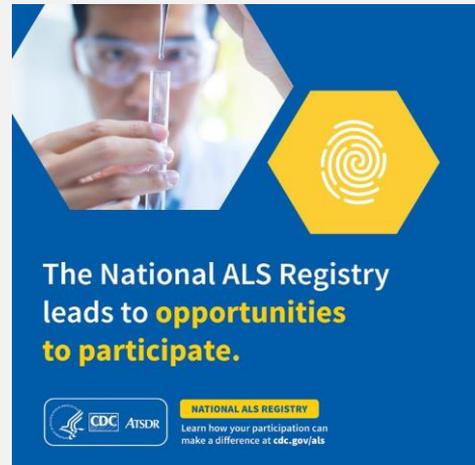
Oftentimes, we will potentially bring up the registry at our very first encounter with a family, if nothing more than just to plant the seed. We likely aren't going to go into it very in much detail because it's overwhelming that first encounter. So, if they seem very overwhelmed at that first meeting, we'll just wait and typically do it later.

So, after somebody is enrolled at our chapter, we'll call 2 weeks later just to check in — see if they have any questions — and we'll bring it up on that 2-week follow-up call. But then after that, we just bring it up at every meeting. So, and it's usually just to see if they have any questions. Did they have any issues with the registry? Are they aware of the surveys? And if they let us know that they have registered, great, we'll make that checkbox in their account just to make sure that we don't keep bringing it up to them on a regular basis.

And that picture there is of our lovely team here in the office.

Why should people enroll?

- This is the largest ALS research study to date and they can participate in it from the comfort of their own home.
- Everyone qualifies to be part of this study.
- Sharing of their own cause ideas



So, the number 1 — just to kind of go through some of the talking points our team uses when they're talking with families. Often it naturally comes up when families ask about research. So, we let them know that this is the biggest ALS research study that they can participate in. And even if they're not able to or don't qualify to be in a clinical trial, everyone qualifies to be part of the registry. And they can do it from the comfort of their own home. They don't need to have any type of stress around getting somewhere or doing anything. It's super easy to be part of it.

And oftentimes, one of the lead-ins is people will share with us that they have an idea that they think it's this or that, that might have caused them to have ALS. And we automatically bring up the registry letting them know that one of the surveys gives them an opportunity to share that idea and how beneficial that could be.

Overcoming barriers



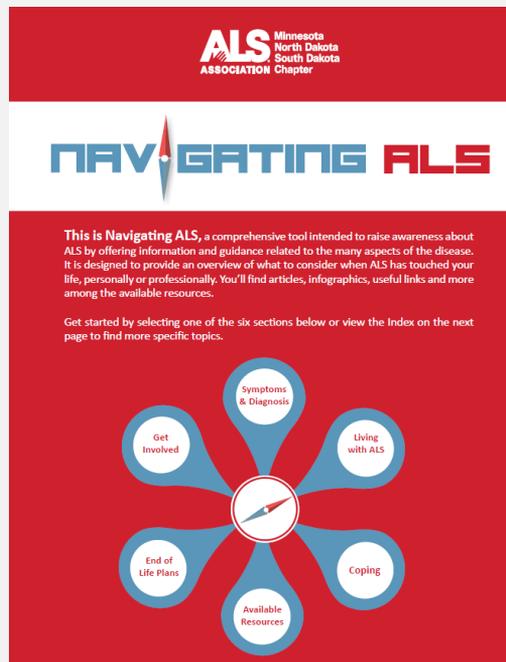
So, barriers, and I'm sure many of you on the phone have had barriers. And there are some folks that just are adamantly against not wanting to share their information. And we respect that, and we move on — you're just always going to have that.

Some of the barriers that we get often here, we might have someone who is older, doesn't like technology, seems reluctant about that piece of it. We'll often suggest that either an adult grandchild or adult child might like to work on this project with that loved one. We've had a lot of families tell us that they learned a lot about a grandma or dad while helping them through that process. And we'll also share with them that this, although this might not help them, it might help their grandchildren and children. And sometimes family members will have a greater buy-in to this than the person with ALS themselves.

And then if there's no family to do it and the person really wants to enroll but has some fear around that, if they don't mind us knowing their answers, one of our care services coordinators will help them enroll and complete the survey. And the person with ALS is either on their phone and at home and we'll be in our office, going through it with them.

- Allies:
 - Clinic partners
 - Clinics Meeting

- Additional promotion
 - Web Site/Navigation Tool
 - Special Events



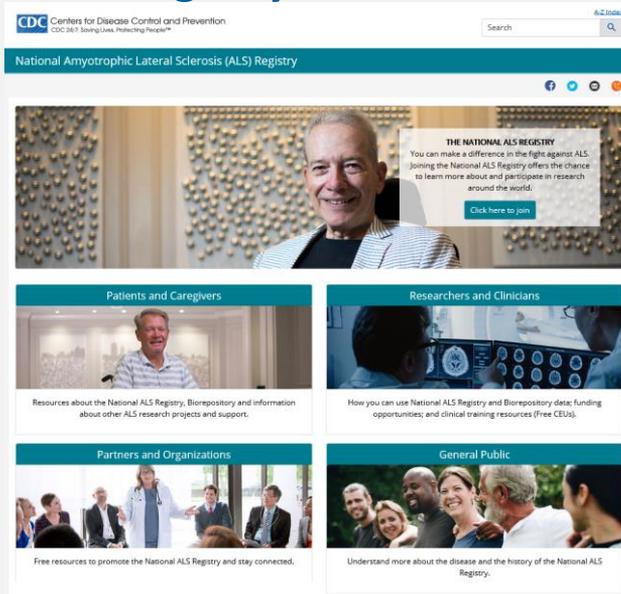
Allies. So, I think the other reason that we have had such success is that in addition to our chapter staff, our clinic partners are very well versed in the registry. So, somebody is at clinic, they're not only hearing about it from us, they're hearing about it from their neurologist and likely other people on the clinic team. So that it's rare that a family in our area has not heard of the registry because everybody's bringing it up.

And the other thing, we do a meeting three times a year with all our clinics in the same room together, and we'll often have a topic specifically about the registry and how each clinic is promoting it and talking about it. We'll share stats that we've received from the registry to make sure that everybody's just kind of up to date on what it's producing and what's happening.

We also we have it on our website in our navigation tool, which you can see a picture of here. So, it's all over everywhere somebody goes with ALS in our service area, they can't help but see it. We'll have information about it at our special events, at our walks and other events so that there's always an opportunity for people to ask questions and for us to educate.

So that is our kind of down-and-dirty on how we do that. And I think just to sum up before I move this on we don't like to overcomplicate things here. If as much as there's all sorts of ways we can promote this, it all comes down to just consistently bringing it up and understanding what an important role this registry can have in getting us towards treatments and a cure.

The National ALS Registry Website



Jennifer, thank you so much. This is Janine again, and I really love the intergenerational aspect, the quality time. And the idea that people do want to share their ideas. And I love the idea that maybe a younger person or a child or grandchild could not only learn the stories and their history but kind of assist with some of the more computer-savvy aspects. I think that's a great idea as well as multiple sources of information.

And we know from proven Health Belief Model and other theories that people, all of us need to hear multiple messages from multiple sources. And then we bring that information together. And that helps us make health decisions. So, I think you brought up a great point.

And I want to remind people that we will put up a lot of these resources and share these slides. So, you can just listen comfortably and not have to write everything down.

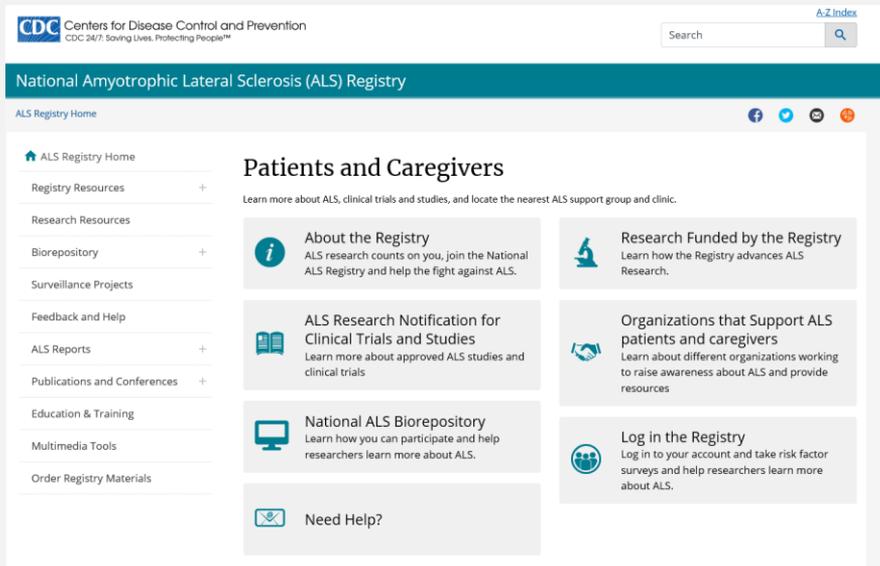
And speaking of the website, I'm so happy to introduce Ati Paziraei, who I want to thank, because she was instrumental in putting together this webinar. And she's going to walk you through some very good news for us about the website, which don't even look now — it's not live yet. It's still our regular one. But she's going to walk you through sort of the how and why of how we got to this place. Thank you so much for organizing this, Ati, and take it away.

And as Janine mentioned, I'm currently working with the ALS team on streamlining this new ALS homepage.

But before we start this discussion, I'd like to kind of address the development of the redesign first, kind of how we got here. So basically, last year after receiving feedback about the homepage and hearing what patients and partners did or didn't like, we devoted our time to sort out the content on our website by who might use them and how they might use them. So, we really focused on our target audience — we examined who uses the website the most and how to make it easier for these visitors to find what they're looking for, which is why you'll see 4 new main sections on the website.

We organize content and resources into 4 main buckets: patients and caregivers, partners and organizations, researchers and clinicians, and the general public.

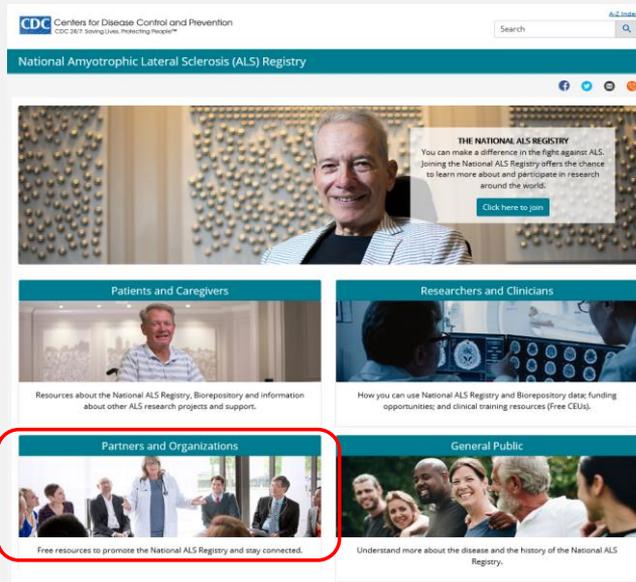
The National ALS Registry Website



And since our primary goal is to help register people who are living with ALS, the "click here to join" button that you see in the upper right corner will continue to remain on the banner of the homepage. And in the next slide, we will have the first look into the patients and caregivers' bucket.

So, we really wanted to make it easier for visitors to find exactly what they're looking for. So, we created segments that highlight a variety of topics that would benefit a person living with ALS and their caregivers, hence the title. So, we designed this new layout by organizing key information that would be most useful to this specific target audience. For example, we added information about the registry, the different organizations that support ALS, how to log in to the registry, and more.

The National ALS Registry Website



So, although we're still in the development stages for partners and organizations bucket, we wanted you all to know that we had our partners in mind and made this portal just for you. The goal is to create a space that will allow our partners to easily access our resources, like the look and feel of the patient and caregiver layout that we just saw. We're in the process of creating a page that will hopefully be your new favorite space on the website. And on this page, you'll be able to find different types of resources including video to show, to show patients; posters and infographics for your clinic; social media graphics; and, of course, the option to order materials.

The National ALS Registry Newsletter



Welcome to our second edition of the new National ALS Registry newsletter. Our goal for the newsletter is to better inform patients, caregivers, researchers, and our partners about the National ALS Registry.



Patient Spotlight: Darrin Altman

Darrin Altman was diagnosed with an ALS variant in 2009. Before his diagnosis, Darrin worked as a Spanish Court Interpreter and received a Master's Degree in Spanish Linguistics.

More Than Counting Cases

What do Brainstorm Cell Therapeutics, Cytokinines, Orphazyme, Amylyx Pharmaceuticals, and Massachusetts General Hospital have in common? They have all used the National ALS Registry's notification tool to help recruit for their respective clinical trials. These trials are looking to halt, reverse, and possibly cure ALS.

The National ALS Registry has helped recruit over 1,000 patients for over 40 clinical trials and epidemiological studies.

Click [here](#) to learn more about research studies contributing to the National ALS Registry and other clinical trials.



The National ALS Registry Webinar- Coming soon

(For Partner Organizations)

The National ALS Registry program is hosting an informative LIVE WEBINAR to improve your important contribution to the National ALS Registry. Topics include a better understanding of the Registry, its research contributions, and the upcoming redesigned ALS website.

Please join us on **June 19th at 12pm** Save the dates will be sent soon electronically.

May is ALS Awareness Month
Check out our social media resources

[Appointment Card Reminder](#)
[Clinic Poster and Handout](#)
[The National ALS Registry Web Buttons](#)



We want to hear from you

Have any questions or feedback on our newsletter?



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And you'll also be able to sign up for our newsletter within this new layout, which hopefully this isn't anyone's first time hearing about the National ALS Registry newsletter. We're on our third edition, and we'll be planning on sending these out quarterly. This newsletter is honestly — it's a great opportunity to learn about the work that the registry does. We designed the newsletter into 3 different sections: one for patients; news for researchers; and, of course, news for our partners. We even have a patient spotlight segment. So, the next time you're chatting with a person who has ALS and they have a cool story that they would like to share, please make sure to reach out to us.

We rely on YOU to help spread the word!

- www.cdc.gov/als has FREE materials available for you
- Print
 - Posters, brochures, ready-to-print newspaper articles, appointment card reminders
- Digital assets
 - Social media, web-ready graphics, blogs



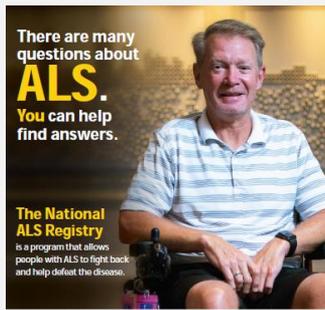
And in closing, we are working hard on this new website. And we'll let you know as soon as it is live. But in the meantime, as Janine mentioned, our current website is still live; you can still access all the different tools that are waiting for you. And so, we really wanted to share this specific process with you all today so that we can hear your feedback. And I really encourage you all to share any comments and your feedback on the upcoming Q&A slide. Off to you, Janine.

As Ati mentioned, we do have a lot of resources, and we realized they were a little bit spread out across the website. But I just wanted to remind you, these are all there now and they are all ready for you to use — you can take anything that you find. And we've really tried to work to develop these things with you in mind.

And we are happy to help and support, and if you have events or other things, and you don't have the expertise or you need stuff, please let us know. We're happy to help, and I realize stuff is spread out now — the video is in a different place than something that you, the infographics, but we're working to get all that organized so that you can use it more easily.

Your turn! Ask questions

- Jennifer is the expert in real-life patient recruitment!



There are many questions about **ALS**. You can help find answers.

The National ALS Registry is a program that allows people with ALS to fight back and help defeat the disease.

We are working towards a better future for people living with ALS by:

- Collecting and analyzing data
- Striving to better understand the disease
- Helping researchers find possible risk factors

Your participation can make a difference.

Ask us about the Registry today. For more information, call (800) 232-4626 or visit clic.gov/als.



Support ALS Research by Telling Your Story

Tell Your Story with Risk Factor Surveys

The National ALS Registry gives people living with ALS the opportunity to share their story and help further research by completing risk factor surveys. There are 17 different surveys, and each asks about different topics, such as:

- Environmental exposures—where you worked or lived
- Job history
- Military History
- Physical Activity
- Pesticide Use
- Head and Neck Injuries

The Importance of Completing the Risk Factor Surveys

- Your story provides crucial information for the Registry. As more people with ALS complete these surveys, the Registry has more data. Every piece of data helps researchers better understand the disease and its possible causes.
- Researchers across the world can use these data for studies.

Common Questions

How long will it take to complete?
Most surveys take about 5 minutes to finish. Some surveys take longer. You do not need to complete all the surveys at one time. You can stop and return to it later.

Do I need to take the surveys in order?
You don't have to, but it's best to start with Survey 1.

Can I change my answers?
You cannot change your answers after you have completed and submitted the survey.

How many times do I have to complete each risk factor survey?
Each survey can be taken only one time, except the Disease Progression survey. You can take this survey three times during the first year, and then twice a year after that.

What if I need more help?
If you have any questions or need assistance, you can ask a family member, caregiver, friend, or your local ALS chapter office, or clinic.

ALS Research Counts on You. You can learn more at clic.gov/als.



Wonderful. Jennifer, one of the questions that we received — you touched on the timing of patients being or people with recently diagnosed, they and their family might be a little overwhelmed. Could you expand a little bit on maybe how you approach it for the very first time? When is a good time to do that?

Yeah, so a lot of times we must play it by ear if they're overwhelmed to a point where that first interaction might not make sense. We might either mention it briefly or we'll just wait until our 2-week follow-up call. And typically, what can happen on either that first interaction or that follow-up call, families will ask: "Why does this happen? Why do you think I, why do I have this — what, how on earth? What did I do wrong?" And often we'll work in 1) we don't know. And one of the ways we're trying to figure it out is through the registry. So, we'll bridge it that way.

And just softly give them some information on we're working hard on that. And here's a way that you can help figure that out. So that often is, it's a softer transition to it, and it puts the family in a position to be proactive about being part of it. So that's one way, and I think that the biggest thing is to be using your gut instinct on how the family might receive that information and continuing to just softly bring it up after those first couple of engagements. Eventually it will just land easier for them.

Thank you. I think that sensitivity is good to keep in mind. I'm not sure that anyone else is unmuted, but we did get another question for Dr. Mehta. People were wondering about getting the clinical trial notifications — how people with ALS or their families can learn more about that.

Sure. So, when a patient signs up for the registry, they'll go ahead and opt in for clinical trials and notifications. And from there, we'll go ahead, send the email out once we have a notification. So, let's say a drug company comes to us for an upcoming clinical trial and is going to work with us. And once the trial is approved, we'll go ahead and send an email notification to the patient themselves. And then the patient will go ahead and contact the drug company directly. We don't give any sort of information, no patient names, where they live, etc. So, we're very, very keen, and very, very strict on privacy, obviously. So, the patient will go ahead and contact the drug company about information about the clinical trial and so forth.

Thank you. I know that what we have heard just from working with folks with ALS and their families, it was important for them to feel like they were contributing to research.

National ALS Registry

Visit cdc.gov/als for more information



U.S. Department of
Health and Human Services
Centers for Disease
Control and Prevention
Agency for Toxic Substances
and Disease Registry