


Attachment 5

ALS Case Registration Form (screenshots)

**Agency for Toxic Substances & Disease Registry**

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National Amyotrophic Lateral Sclerosis (ALS) Registry

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If you need assistance registering, please contact the National ALS Registry System Administrator by calling 1-877-442-9719 or email the ALSSystemAdmin@cdc.gov.

Form Approved
OMB No. 0923-0041
Exp. Date xxx/xx/201x

*** Required Fields**

Create Persons with ALS (PALS) Account

Contact Us:

 Agency for Toxic Substances and Disease Registry
4770 Buford Hwy NE
Atlanta, GA 30341

800-232-4636
TTY: (888) 232-6348
Monday-Friday:
8am-8pm
Closed Holidays
[Contact CDC-INFO](#)

Title:

First Name:

MI:

Last Name:

Suffix:

Gender: Male Female

Date of Birth: / /

Social Security Number: -- (Last 5 digits)

Confirm Social Security Number: -- (Last 5 digits)

Country:

State/Province:

Outside US & Canada State/Province:

City:

Email:

National ALS Registry Email Consent
I give consent to ATSDR to send me email updates regarding my Account and the National ALS Registry. (As described in the ALS Consent Form your information will not be shared).
 I Agree

Create Username:
Your username must be between 6 and 12 characters. It can contain letters, numbers, punctuation or special characters.
Example: JohnDoe123

Username:

Create Password:
Your password should be between 9 and 15 characters. It may not contain your username or any part of your full name.
Your Password should be created using 3 of the following 4 character types:
Uppercase Numbers
Lowercase Punctuation or Special Characters (Ex: @, %, &, \$, %)

Example: Jump12345

Password: Confirm Password:

Security Questions (Please answer at least 3 questions.) *

What is your city of birth?

What is your high school name?

What is the name of your favorite childhood friend?

What is your favorite pet's name?

In what town was your first job?

Who was your childhood hero?


CDC estimates the average public reporting burden for this collection of information as 10 minutes per response, including the time for reviewing instructions, searching existing data/information sources, gathering and maintaining the data/information needed, and completing and reviewing the collection of information. An agency may not conduct or sponsor, and a person is not required to respond to a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to CDC/ATSDR Information Collection Review Office, 1600 Clifton Road NE, MS D-74, Atlanta, Georgia 30333; ATTN: PRA (0923-0041).

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Agency for Toxic Substances and Disease Registry, 4770 Buford Hwy NE, Atlanta, GA 30341, USA
Contact CDC: 800-232-4636 / TTY: 888-232-6348



National Amyotrophic Lateral Sclerosis (ALS) Registry

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National ALS Research Notification Consent

Research is an important part of the National ALS Registry. Not all research is done by ATSDR. Sometimes other ALS researchers would like to contact people in the National ALS Registry to ask them to take part in clinical research. If you want to receive emails from ATSDR about clinical research, please check the "I Agree" box below.

We will not give the researchers your name or contact information. If you want to be part of a project, you will have to contact the researcher listed in the email.

I Agree

National ALS Biorepository Participant Interest

Research is an important part of the National ALS Registry. Specimens are needed for much of this research. The National ALS Biorepository is a new part of the National ALS Registry. If you are interested in learning more about the Biorepository, please check the "Yes" box. A sample of interested PALS will get information packets.

I Agree

- I would like to learn more about donating biospecimens to the National ALS Biorepository
- I would like to learn more about donating postmortem tissues to the National ALS Biorepository
- I would like to learn more about donating both biospecimens and postmortem tissues to the National ALS Biorepository

Please provide your mailing address and phone number. This information will be used to make sure we ask PALS from all over the US to take part. We will also use this information to contact you if you are selected.

Address: <input style="width: 90%;" type="text"/>	City: <input style="width: 90%;" type="text"/>
State: <input style="width: 90%;" type="text"/>	Zip: <input style="width: 90%;" type="text"/>
Phone: <input style="width: 90%;" type="text"/>	

National ALS Research Notification Global Unique Identifier(GUID)

Many groups are doing ALS research. It is important for researchers to be able to combine data across studies. It is also important to make sure that when combining data that each person is only included one time. A Global Unique Identifier (GUID) is a code assigned to each patient's data. This code does not include personal information. The GUID enables tracking and following of patients over time and across diseases, registries, studies and countries. Several groups such as the National Institute of Health (NIH) and NeuroBANK™ create GUIDs that can be used to link data across studies.

We are asking if you would like us to create GUID(s) for the data you gave the National ALS Registry. If you agree to have us create GUID(s), please check I agree below and answer a few questions needed to create the GUID(s).

I Agree

First Name at Birth: <input style="width: 90%;" type="text"/>	Date of Birth: Month: <input style="width: 20%;" type="text"/> Day: <input style="width: 20%;" type="text"/> Year: <input style="width: 20%;" type="text"/>
Middle Name at Birth: <input style="width: 90%;" type="text"/>	City or Municipality of Birth: <input style="width: 90%;" type="text"/>
Last Name at Birth: <input style="width: 90%;" type="text"/>	Country of Birth: <input style="width: 90%;" type="text"/>
Sex at Birth: <input style="width: 90%;" type="text"/>	

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