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Patient Spotlight: Andrea Peet

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Andrea Lytle Peet was diagnosed with amyotrophic lateral sclerosis (ALS) in May of 2014, at the age of 33. In eight months, she went from completing a 70-mile half Ironman to walking with a cane. Instead of letting ALS define her physical capabilities, Andrea continues to race on her recumbent trike. Her goal is to become the first person with ALS to do a marathon in all 50 states. She has successfully completed marathons in ten states so far and aims to be at 21 by the time she completes Alaska in May 2020.

After encouraging her friends and family to complete a race that challenged them, Andrea founded the Team Drea Foundation in 2014, using this as an opportunity to raise money for ALS research. Team Drea has now grown to 200+ athletes and has raised over \$400,000.

"Go on, be brave" is the foundation's motto and words that Andrea strives to live by daily. Thank you, Andrea, for sharing your story as an inspiration to all of us!

If you would like to nominate someone to be highlighted in the newsletter, please email ALS@cdc.gov



The 2019 National ALS Registry Annual Surveillance Meeting was held July 23-24th in Atlanta, Georgia. There were approximately 60 attendees made up of patients, researchers, neurologists, support organizations, pharma, and other federal agencies. The conference updates stakeholders on the progress of the National ALS Registry, the Registry data and its implications, and discussed strategies to enhance the Registry for all stakeholders. Meeting minutes and an Executive Summary will be posted on the website.

Key highlights from the National ALS Registry that were presented include:

- Three abstracts were accepted for the 30th International Symposium on ALS/MND in Perth, Australia;
- The Registry assisted 45 research institutions to recruit over 1,000 patients to participate in clinical trials and epidemiological studies;
- The Registry funded 17 new studies;
- The National ALS Biorepository has collected over 50,000 biospecimens (e.g., blood, saliva, urine), from over 1,000 Registry enrollees to date that are available to researchers around the world. Learn more about the National ALS Registry [here](#).



The Biorepository has over 1,000 specimens now!

This Biorepository helps scientists better understand the cause(s) of ALS. Researchers may be able to study the genetic variation in those with ALS. Analysis of these types of specimens has already proven useful in finding important genes related to ALS and other motor neuron diseases. The National ALS Registry collects epidemiological data from people with ALS. Connecting biological samples with these data will make the National ALS Registry more complete and useful.

There are [supporting handouts](#) you can use to inform patients or researchers about the Biorepository.

NEW! The National ALS registration portal is now available in Spanish! [Visit](#) the Registry web portal to join the Registry.



Centers for Disease Control and Prevention

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