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**Person Living with PLS Spotlight: Dr Rick Nelms:
Biologist, Educator, Artist**

For this issue of the Registry Newsletter, the National ALS Registry recognizes Dr. Rick Nelms, a truly inspirational person. After Dr. Nelms received a diagnosis of Primary Lateral Sclerosis (PLS), which can progress to ALS, he became focused on an artistic outlet and now hopes to inspire other people living with amyotrophic lateral sclerosis or motor neuron disease (ALS/MND) to explore their own creative abilities.

Early Life and Career



Light Has Dawned

Dr. Nelms has had a robust career in spite of the challenge of living on the autism spectrum that caused him to be bullied as a child at school in the United Kingdom in the 60s. Dr. Nelms became a research biologist specializing in numerical ecology. Later, he switched careers to become an educator for UK's sixth-form colleges, the equivalent to the American junior college for students aged 16-19. Dr. Nelms' own childhood experiences and love of education prepared him to develop programs to support students with learning disabilities, such as dyslexia and autism, as well as pioneer computer graphics for students to use as learning tools.

Dr. Nelms was always interested in assessing what students had actually learned during their studies and worked as an examiner for UK and international students. He also trained other examiners to revise and prepare examination papers. Following his 20 year teaching career, Dr. Nelms began his work managing the assessment of International GCE Biology, for 'The University of Cambridge International Examinations.'

Life-changing Diagnosis

In his free time, Dr. Nelms had always enjoyed cycling. However, he suddenly and unexpectedly had three severe crashes. Shortly after the last crash, he began experiencing unexpected falls while working. With his background as a biologist, Dr. Nelms knew his prognosis wasn't good when he began experiencing fasciculations—spontaneous involuntary muscle contractions—in his legs. Dr. Nelms eventually had to retire early from the job he loved because of his symptoms.

Doctors initially had difficulty diagnosing Dr. Nelms' worsening symptoms. Medical notes from his earlier diagnosis for complex post-traumatic stress disorder (PTSD) from his childhood misled neurologists. It wasn't until he was in an emergency room that a doctor examined him without seeing the prior notes. This doctor referred him to the Head of Neurology who narrowed down his diagnosis.



Dawn over the Alps

Ten years after his first symptoms and after multiple genetic tests, scans, and electromyography (EMG) nerve conduction studies, Dr. Nelms was diagnosed with PLS. The muscle stiffness, spasms, pain, and fatigue changed Dr. Nelms' life, as he had loved cycling, walking, do-it-yourself car maintenance, and occasionally painting. PLS had restricted his mobility, and he now used a powerchair to get around. However, a previous diagnosis for severe memory problems turned out to be inaccurate and was instead the result of prolonged prescription to painkillers.

Foray into Art



AI Cat

For fun, Dr. Nelms had begun trying to use his computer to paint like the pointillists who painted using dots. As soon as Rick was diagnosed with PLS, he recorded his voice and used it to digitally paint with the help of iPad apps. Dr. Nelms' digital artwork coincided with the start of the COVID-19 pandemic, and connected him with Under the Thinking Tree, an organization that helped him reduce stress. He made two paintings while attending their online wellbeing classes. The organization's leadership noticed his work, and within a week, they invited Dr. Nelms to become their Artist in Residence. This kickstarted his career in art.

It's a long process to virtually paint using only his voice. However, each day provides Dr. Nelms with new excitement and experiences as he navigates different approaches to his art and ways to use technology to paint. Dr. Nelms' experiences expressing himself by painting called him to encourage other people living with motor neuron diseases (MND) to discover art

for themselves.

Current Art Projects

Dr. Nelms would like to highlight two projects very dear to him. The first one reveals Dr. Nelms' work with a local hospice near Cambridge, Arthur Rank Hospice. The hospice engages people who have illnesses with a way to do art. Dr. Nelms helped the hospice learn to use donated iPads by choosing an app called Portrait Painter by Jixipix Software. He then trained staff, volunteers, and patients to paint with the app, and how to train others. He hopes that this project will allow patients a way to make beautiful art to share with family and friends and to add value during difficult times.

Dr. Nelms' second project came about through a partnership with the Sheffield Institute of Translational Neuroscience (SITraN) based at the University of Sheffield in the UK. The partnership began after Dr. Nelms painted a portrait of Dame Professor Pamela Shaw, head of SITraN. Professor Shaw then introduced him to Dr. Scott Allen, the head of



Octagon, Ely Cathedral

SITraN's Readable Research project. A team of scientists, clinicians, patients, and caregivers use Readable Research to produce summaries of relevant scientific papers across the whole range of neurodegenerative diseases, including ALS/MND. Dr. Nelms and Dr. Allen hatched a plan to enhance the Readable Research summaries by providing artwork that increases people's understanding of MND and the research on those diseases. Dr. Nelms shines a light on the importance of providing various ways for people to learn about research who are unfamiliar with scientific papers, and specifically people who learn better visually than in writing.

Additional Work in the MND Community

In addition to his artwork, Dr. Nelms is an active member for many projects for the MND community. He also is involved in projects with SITraN, Sheffield Motor Neuron Disorders Research Advisory Group (SMND RAG), and as part of the new MND Translational Accelerator (MNDAcc) based at Oxford University. Dr. Nelms and his wife Sue work for the Motor Neuron Disease Association (MNDA), reviewing materials for the Education and Information Department. Dr. Nelms also works for a National Institute of Health and Care Research (NIHR) funded Policy Research Unit based in Exeter for developing policy in dementia and

neurodegeneration.

We conclude this spotlight with a heartfelt message from Rick Nelms:

“So, there you have a fairly unconventional vignette of the life of a fairly unconventional man, but one who has tried to make the best of the situations he has found himself in throughout his life. To finish this spotlight, I can do no better than to put the words which I use as the short form of the signature I put on the end of my emails. Rather naively, I sign most of my emails ‘Love from Rick,’ followed by this: (Dr Rick Nelms, biologist, educator, innovator, advocate, writer, and artist living with MND, painting without brushes, painting hope.)

‘Painting Without Brushes’ because I can’t control a brush now. I use an adapted PC to paint at home and a smartphone and tablet on our travels.

‘Painting Hope’ because I am incurably positive, and because ongoing research is getting ever closer to effective treatments for neurodegenerative diseases. ‘Painting Hope’ also refers to my Christian faith.

Thank you for your attention, Love from Rick.”



Good Days and Bad Days

To explore Rick's artwork and contributions further, visit the links provided below.

<https://underthethinkingtree.com/ricks-paintings>

<https://drrickblog.wordpress.com>

<https://www.readableresearch.com/artwork>

<https://www.flickr.com/photos/drickzt/>

The artwork accompanying this spotlight was created by Rick Nelms and used with his permission

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

Meet the National ALS Registry Team

Jaime Raymond, MPH



Jaime Raymond has been at the Centers for Disease Control and Prevention since 2001. In the last 7 years, she has worked directly with the Agency for Toxic Substances and Disease Registry's (ATSDR) National ALS Registry. Jaime collaborates with the Center for Medicaid/Medicare Services (CMS), the Veteran's Affairs (VA), and the ALS web portal data to create a national estimate of prevalence and incidence for ALS annually. She also studies the National ALS web portal survey data, analyzing the surveys to learn more about the risk factors that may lead to an ALS diagnosis.

To date, she has co-authored over 16 ALS publications, including manuscripts relating to clinical onset, menopause, and juvenile ALS. Jaime is currently analyzing head trauma and ALS, as well as how the COVID-19 pandemic impacted ALS deaths in the United States. Before coming to the National ALS Registry, Jaime worked 15 years in the

Lead Poisoning Prevention Branch at CDC. Jaime earned a master's in public health at Emory University with a concentration in Epidemiology and a Bachelor of Science degree in Mathematics from Indiana University. When Jaime is not working on ALS, she enjoys running and watching her children compete in various sports with her husband.

To view some of Jaime's publications, visit the links below:

- [A brief report on juvenile amyotrophic lateral sclerosis cases in the United States National ALS Registry: 2010–2018](#)
- [Comparing Amyotrophic lateral sclerosis \(ALS\) patient characteristics from the National ALS Registry and the Massachusetts ALS Registry, data through 2015](#)
- [History of vigorous leisure-time physical activity and early onset amyotrophic lateral sclerosis \(ALS\), data from the national ALS registry: 2010–2018](#)
- [Reproductive History and Age of Onset for Women Diagnosed with Amyotrophic Lateral Sclerosis: Data from the National ALS Registry: 2010-2018](#)

Meet our Grantees
Fang Fang, PhD
Karolinska Institute, Sweden

Dr. Fang is a Professor in Epidemiology and Head of the Unit of Integrative Epidemiology, Institute of Environmental Medicine, Karolinska Institute, Sweden. During the past 20 years, she has focused on the etiology and prognostic indicators of amyotrophic lateral sclerosis (ALS). Her team is specifically interested in environmental risk factors for ALS and the involvement of the whole-body physiology in ALS etiopathogenesis. In collaboration with the Neurology Clinic at the Karolinska University Hospital, since 2016, Dr. Fang has established an ongoing population-based case-control study called “ALSrisc” in Stockholm, enrolling all newly diagnosed ALS patients in the greater Stockholm area, as well as the siblings and spouses of the ALS patients as relative controls. All ALS patients enrolled in the study are also being longitudinally followed. Dr. Fang has also contributed to the buildup of a national quality register for ALS, the Swedish Motor Neuron Disease (MND) Registry, which was started in 2016 and that currently has more than 90% of all ALS patients in Sweden.



Summary of National ALS Registry-funded projects:

Military service, traumatic brain injuries (TBI), chronic neuroinflammation, and infections have all been suggested as potential risk factors for amyotrophic lateral sclerosis (ALS). The current, existing knowledge is, however, limited by systematic and random errors. Moreover, the underlying mechanisms linking together those risk factors and the initiation and progression of ALS are still largely unknown.

Dr. Fang’s research project that was funded by the National ALS Registry in 2021 is entitled “Identify and Evaluate Potential Risk Factors for Amyotrophic Lateral Sclerosis - A Unique Contribution from Sweden”. It uses the extensive data and biospecimens collected in a unique, Swedish national ALS registry to identify and evaluate military service, TBI, mental disorders, and infections as potential risk and prognostic factors for ALS. The project focuses on understanding their interactions with individual genetic susceptibility to ALS, chemical

exposures, and gut microbiome.

Dr. Fang will replicate some of these findings in the U.S. National ALS Registry together with Dr. Manish Aurora at Icahn School of Medicine at Mount Sinai, who is a sub-award PI of this project. Findings from this project are expected to advance our understanding of ALS as a disease, and provide new knowledge for disease prevention and treatment, fully supporting the ATSDR National ALS Registry's mission.

External Links

[Dr. Fang's Profile at Karolinska Institute](#)

[National ALS Registry Funded Research Projects](#)

2024 National ALS Registry Annual Meeting Update



The National ALS Registry has held an annual meeting since 2011. This meeting has been an important way for neurologists, researchers, advocacy groups, and especially patients and caregivers, to provide guidance and direction for the Registry's initiatives.

This year's meeting will be held virtually on September 4th-5th. Further details regarding the meeting agenda and invitations will be sent out later this year when meeting plans are finalized.

The meeting agenda, transcript of the Q&A questions, and summary report will eventually be found at the Registry's website at: [Meetings Page](#)

2024 ALS Registry Research Update

Research is critical to helping scientists and persons living with ALS better understand the disease. The overarching goal of the research is to examine potential risk factors for developing ALS. One of the fundamental functions of the National ALS Registry is to provide researchers with data to aid in pushing ALS research further along and to help fund this research.

- Since the Winter 2023 Newsletter, the Registry has been involved in three new publications of ALS research: studying how hobbies and exercise affect ALS in Michigan, the effect of persistent organic pollutants on ALS, and a National Academies workshop on accelerating ALS treatments.



- The Registry's Clinical Trial Notification system is helping two new clinical trials in 2024 recruit study participants.

The National ALS Registry is steadfast in its commitment to push ALS Research along and continues to count on researchers and Registry members to participate.

You can learn more about the new research in 2023 involving the Registry at the following links:

- [Published research papers](#)
- [External Research funded by the National ALS Registry](#)
- [Active ALS Research Notification for Clinical Trials and Studies](#)

Have any questions or feedback on our newsletter?
We invite you to reach out to us.
als@cdc.gov



Centers for Disease Control and Prevention

1600 Clifton Rd Atlanta, GA 30329 1-800-CDC-INFO (800-232-4636) TTY: 888-232-6348

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