



ALS
RESEARCH
AMBASSADOR



Congratulations! Let's Do This...

Allison Bulat
Research Ambassador
Co-Chair, Patient Education and Advocacy Committee (PEACe)

A little bit about me:

- ❖ I was a competitive gymnast by the age of 8. I joined a competitive dance troupe when I was 12 years old and started teaching ballet when I was 14.
- ❖ Education is important to me. I have a BA Degree in Human Resource Management / Organizational Development, and graduate-level certifications in Project Management, Information Systems Management, Software Quality Control, and Clinical Trial Administration.
- ❖ I prefer to eat healthy, other than on the days that I prefer Mexican food or donuts.
- ❖ I love to meet new people and believe that people are inherently good.
- ❖ I have been told that I can be a little sarcastic, and maybe a little feisty sometimes. I view this as being “persistent”.
- ❖ I am a Type A (++) personality.
- ❖ Fun Fact

In Loving Memory....

Jeffrey James Pogemiller

December 02, 1961 - April 14, 2016



- And.....
 - I am a Survivor of ALS
 - I lost my husband to ALS in April of 2016 – 380 days after his diagnosis
 - I understand the effects of ALS on FAMILIES
 - And I believe there is HOPE
 - I believe NOW is the time that relevant change is happening
 - I believe we all have a moral responsibility to support that change, and
 - I believe that, in this lifetime, we CAN redefine what it means to be a “Survivor of ALS”





ABOUT US

NEALS was founded in 1995 with 9 academic clinical centers in the New England area. The NEALS membership has grown to over 140 research centers around the world committed to performing research in ALS and MND.

OUR MISSION

The mission of the Northeast Amyotrophic Lateral Sclerosis Consortium® (NEALS) is to rapidly translate scientific advances into clinical research and new treatments for people with Amyotrophic Lateral Sclerosis (ALS) and motor neuron disease.



NEALS Members

Our 141 member sites are academic research centers equipped to perform clinical trials and research in ALS and MND.



NEALS Sub-Committees

NEALS has established 16 sub-committees focused on advancing ALS research and clinical care.



NEALS Scientific Advisory Board

The SAB provides a forum for investigators and industry to vet new ideas for drugs, technologies, & trials.



NEALS Biorepository

NEALS has extensive shared clinical data and biofluid samples available to researchers to further the understanding of ALS and for developing disease biomarkers.

CRLI/Research Ambassador Fun Facts

- ✓ The first CRLI was held in 2011
- ✓ We have held **22** CRLIs to date:

Clearwater 2011-2019

Internet 2013, 2020, 2021 (2)

Philadelphia 2013, 2014, 2019, 2021

Sacramento 2017

Phoenix 2018

St. Louis 2018

Chicago 2021

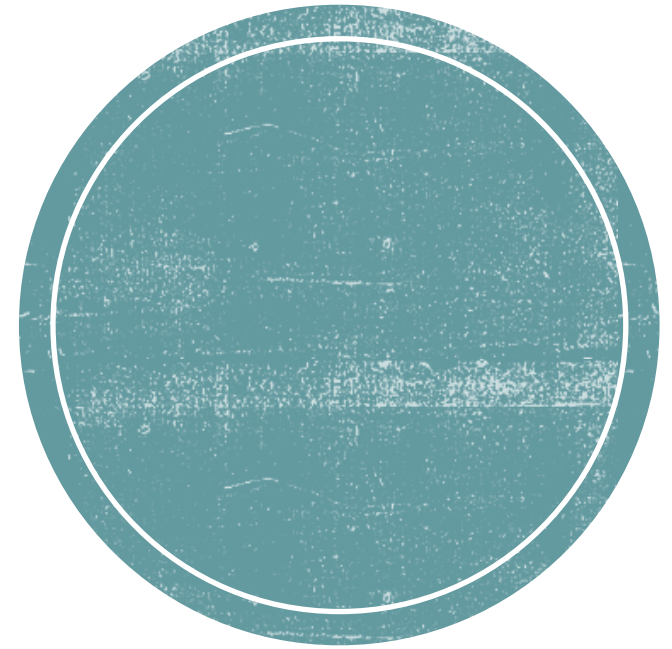
Canada (Virtual) 2021

- ✓ Over 500 Advocates Have Been Certified as Research Ambassadors
- ✓ The need for Research Ambassadors is growing exponentially, as more and more organizations are putting the patient's perspective in to all that they do.
- ✓ The Research Ambassador program continues to grow, with four classes happening in 2022.
- ✓ Two International CRLI's will be held in Fall of 2022 – Canada and Australia

| | |
|--|-------|
| ALS speaking engagement (fundraiser, support group, political event, etc.) | 2,077 |
| Organization of or participation in an ALS event | 492 |
| Interview (TV, radio, web or print) | 221 |
| Speaking or writing to a congressman | 4,430 |
| ALS video (YouTube, social media, webinar, etc.) | 174 |
| Creation of or contribution to a website, blog or social media page | 756 |
| Published article/column (web or print) | 85 |
| Serving on an ALS committee | 490 |
| Mentoring (PALS or CALS) | 332 |
| Other | 243 |

Ambassadors In Action!

**KEEP THE
(RIGHT)
CONVERSATION
GOING**





Information

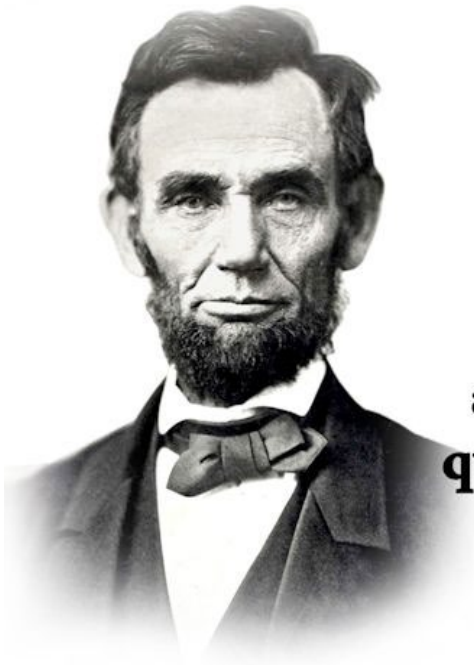
What do we talk about?

Where do we find the information?

How do we know the information is valid?



Sources



"Don't believe everything you read on the internet just because there's a picture with a quote next to it."

-Abraham Lincoln

Publications:

Is it a respected journal / publication source?

Has it been peer-reviewed?

Is the author qualified to write about this subject?

Press Releases:

Who wrote the Press Release?

What do they have to gain (if anything) from the article?

Does it align with peer-reviewed articles on the same subject?

Websites:

Read the "About Us" Section

What are the Claims

Are the Claims Backed by Scientific Publications?

Social Media:

What is the goal/purpose of the posts?

Is somebody moderating the posts?

Are the persons claims opinions or stated as facts?

If stated as facts, are those claims backed by scientific publications?

People:

What is the subject being discussed?

Do they have access to the information they are discussing?

Are they qualified to speak about the subject?

<https://www.alsuntangled.com/>

SCIENCE & ALTERNATIVE AND OFF-LABEL TREATMENTS

In 2009, a program called ALS Untangled was started to help people with ALS (PALS) make better informed decisions about Internet AOTs

There are three components to this program:

- ❖ Determining which AOTs are of interest to PALS
- ❖ Objectively reviewing each AOT using a standard protocol
- ❖ Crowd-sourcing and publication of the reviews

Ten “Red Flags”

- Large out of pocket cost
- Advertised as effective for multiple incurable conditions with different causes
- Lack of safety and scientific oversight
- Absent or limited informed consent process
- Lack of an evidenced mechanism by which the intervention might help
- Absence of regularly measured validated outcomes
- Vague or no plan to present outcomes for peer review
- The only evidence of benefit is anecdotes
- Proponents have no relevant training, presentations or publications
- Proponents portray themselves as victims, advise “divorce” from mainstream doctors



TAKE ACTION

Amplify the ALS
Message.

Your story matters,
because YOU matter.

Your Advocacy is
important for me and for
others.

Together we can make a
difference.



Build Your Advocacy Strategy

Plan Your Efforts

Identify the issue - what is your need, concern, or problem to be addressed?
What is your PASSION?

- Is it a local, state or federal issue?
- Is it a legislative issue or an administrative one?
- Who can address the issue for you in the correct venue?
- What support do you need/from whom?
- Is there a person or organization already addressing this issue?

I Am: A Research Ambassador

I AM
two of the most
powerful words.
For what you put
after them
shapes your reality.

DIETITARIAN.COM

| | |
|--------------------|--|
| My Purpose/Issue: | |
| Goal 1: | |
| Goal 2: | |
| Goal 3: | |
| My Support Person: | |

Patient Education and Advocacy Committee (PEACe)



Our Mission: To utilize education and advocacy to empower persons with ALS and their families to have a greater understanding of, and a greater role in, clinical research.

- Clinical Research Learning Institute (CRLI)
- Research Ambassador Certification Program
- Monthly Committee Meetings



Monthly PEACe Committee Meetings

NEXT MEETING: November 14th at noon ET



Live your life
from your heart.
Share from your heart.
And your story will
touch and heal
people's
soul.

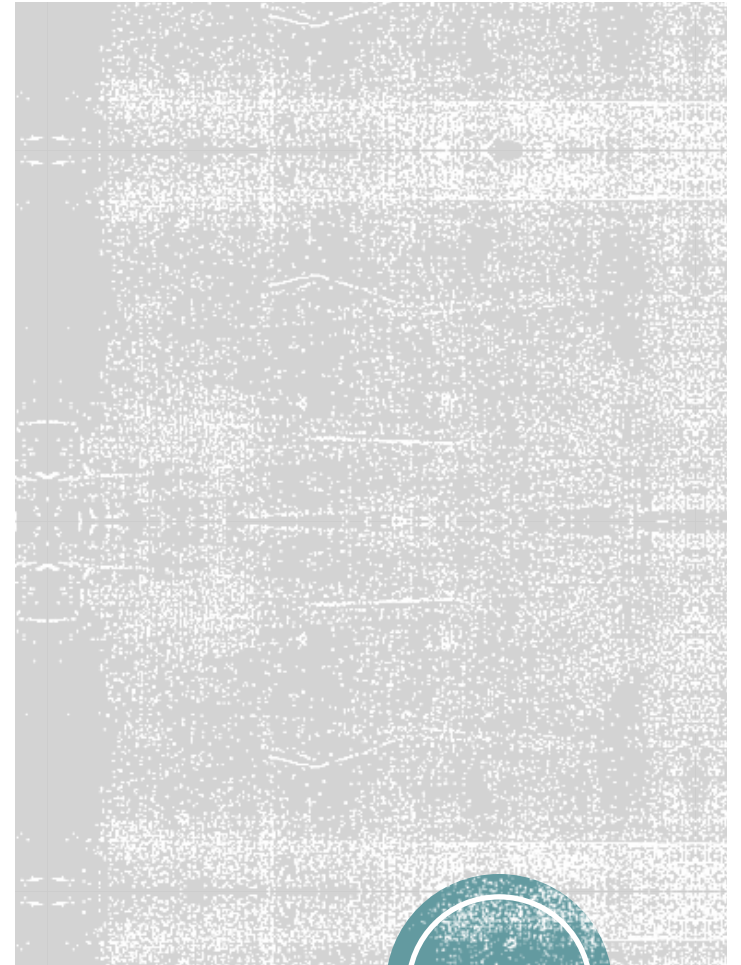
H U M A N I T Y C E N T R A L

The ~~End~~. Beginning.

Thank you

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Allison Bulat: apogemi@yahoo.com
Nadia Sethi: nadiasethi@hotmail.com

RESOURCES



<https://als.ca/> - ALS Society of Canada

The ALS Society of Canada works with the ALS community to improve the lives of people affected by ALS through support, advocacy and investment in research for a future without ALS.

[ALS Association](http://www.alsa.org)

Leading the fight to treat and cure ALS through global research and nationwide advocacy while also empowering people with Lou Gehrig's Disease and their families to live fuller lives by providing them with compassionate care and support.

www.alsa.org

Helpful links on the Association website:

About Familial ALS and Genetic Testing: www.alsa.org/als-care/resources/publications-videos/factsheets/genetic-testing-for-als.html

Living with ALS Resource Guides: www.alsa.org/als-care/resources/publications-videos/resource-guides/

[ALS Finding a Cure](#)

ALS Finding a Cure has created a series of videos to help ALS patients and their loved ones better understand the disease and the resources and support that will be needed as the disease progresses. In the following video series, you will hear from individuals living with ALS, their spouses, healthcare providers and professionals who shed light on the impact that this disease has on one's life. This series will touch on some of the most common and relevant aspects of living with this illness, whether it be you or a loved one. It is our hope that these videos will empower you to be proactive about understanding and managing ALS.

[ALS Hope Foundation](#)

The mission of the ALS Hope Foundation is to accelerate the search for a cure for ALS. The Foundation supports care and services at the MDA/ALS Center of Hope.

[ALS Untangled](#)

Scientific effort investigating alternative and off-label ALS treatments, while bringing together patients, clinicians, and scientists via Twitter.

[ALS Forums and Chat](#)

An open support community for people affected by ALS/MND.

[ALS Information at the National Institute of Health \(NIH\)](#)

Comprehensive overview of ALS provided by MedlinePlus, a service of the U.S. National Library of Medicine.

[Clinical Trials.gov](#)

Complete database of Clinical Trials



CReATe

The goal of the Clinical Research in ALS and Related Disorders for Therapeutic Development (CReATe) Consortium is to advance therapeutic development for sporadic and familial forms of amyotrophic lateral sclerosis (ALS), frontotemporal dementia (FTD), primary lateral sclerosis (PLS), multisystem proteinopathy (MSP), hereditary spastic paraplegia (HSP), and progressive muscular atrophy (PMA). The CReATe consortium aims to support this goal through study of the relationship between clinical phenotype and underlying genotype, and also through the discovery and development of biomarkers.

Everything ALS

EverythingALS is a patient-focused non-profit, part of Peter Cohen Foundation (PCF) a 501(3)c organization. Our mission is to support efforts to care for ALS patients and work to find a cure by creating a platform for direct engagement with patients, caregivers, advocates, and researchers.

Fight MND

FightMND was established with the purpose of finding effective treatments and ultimately a cure for Motor Neurone Disease.

Hope Loves Company

Hope Loves Company (HLC) is the only non-profit in the U.S. with the mission of providing educational and emotional support to children and young adults who had or have a loved one battling Amyotrophic Lateral Sclerosis (ALS) or Lou Gehrig's disease.

I Am ALS

A patient-led, patient centric community that reshapes public understanding of this disease, provides key resources to the community, and creates opportunities for patients to lead the fight against ALS and search for a cure.

International Alliance of MND/ALS Associations

The Alliance is a global network of ALS/MND associations informed by PALS/CALS, that builds capability for its members and connects to external stakeholders

MND Australia

MND Australia is the national peak body of state organisations that support those living with and impacted by Motor Neurone Disease (MND)



[Muscular Dystrophy Association \(MDA\)](#)

The MDA's website contains sections on advocacy, clinical trials, support groups, research news, and more.

[PatientsLikeMe](#)

PatientsLikeMe® creates new knowledge by charting the real-world course of disease through the shared experiences of patients. While patients interact to help improve their outcomes, the data they provide helps researchers learn how these diseases act in the real-world and accelerate the discovery of new, more effective treatments.

[Your ALS Guide](#)

Trusted tips, resources and information for your ALS journey

