



CEO CHALLENGE



What is the CEO Challenge?

The CEO Challenge, formerly known as the CEO Soak, has made a splash within the ALS community every summer throughout RI! Inspired by the viral 2014 Ice Bucket Challenge, the CEO Challenge motivates community leaders to *take the challenge* to help us support patients and families in RI living with this debilitating disease.

ALS United Rhode Island, formerly ALS Association Rhode Island Chapter, rebranded in January 2024 to better serve our community. We have a new name, but our mission and commitment to the local ALS community has never been stronger.



We are looking for companies of any size, from all different sectors, to join us for this unique event. Some event jargon to know while reading this packet:

The Soakee – Is the designated company executive who gets soaked

The Challenger – Employees who donate and raise money to see their soakee get soaked

Frequently asked questions

Do I have to be a CEO to participate? No! Anyone can get soaked!

What do I wear? Business professional attire is encouraged.

Is there a fundraising minimum? No. Set a high yet attainable goal! We encourage participants to try to raise at least \$2,500

I have a small team. Should we participate? Yes! You can make a difference in the fight against ALS. Plus, it's just a really fun event - and a great teambuilding experience!

How do I sign up?

REGISTER: Contact events@alsunitedri.org to get started!

FUNDRAISE: Read CEO Challenge Welcome packet for fundraising ideas, sample emails, and ALS facts. Start by making a self-donation. Then send emails to your network and/or staff asking them to help you hit your goal. Use provided sample email templates or pull from the ALS statistics provided to explain the impact your fundraising has on the ALS community. Make sure to share your progress on social media along the way!

GET SOAKED! Film a video of your "Challenge" with your team and submit it to the website by the designated deadline (August 22, 2024). You can choose to take the challenge at home, work, a local fire station, or anywhere you want! Your video will be featured on our social media platforms.

Facts About ALS



5,000+
people are diagnosed
per year



2-5 years
is the average life
expectancy



90%
of cases occur without
family history



10%
of cases are inherited
through a mutated
gene



\$2 billion
estimated cost to develop
a drug to slow or stop the
progression of ALS



\$250,000
estimated, annual out-of-
pocket cost for caring for a
person with ALS



Every **90 minutes**
someone is diagnosed, or
someone passes
away from ALS

There is NO CURE for ALS

Diagnosis

Difficult to diagnose
Often diagnosed by
ruling out other disease,
which may take months
or years



Military

**Veterans are more
likely to get ALS**

ALS impacts veterans regardless
of the branch they served in and
affects those who served in
both peacetime and war



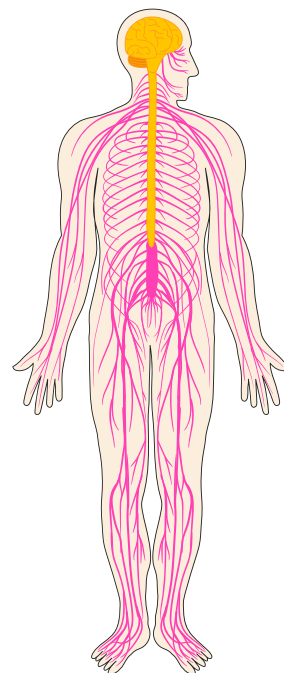
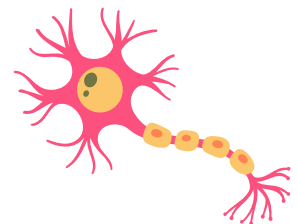
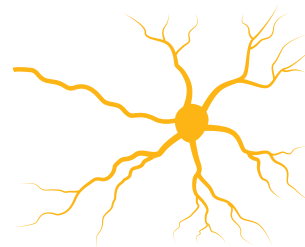
What is ALS?

Amyotrophic Lateral Sclerosis (ALS) was identified in 1869 by Jean-Martin Charcot, a French neurologist. However, it was not until the 1930s and '40s, with the diagnosis and death of Lou Gehrig, that public attention first focused on the disease. This progressive, fatal neurodegenerative disease is characterized by deterioration of a select group of nerve cells and pathways in the brain and spinal cord; which leads to progressive paralysis of the muscles. The muscles that are affected are those considered under your voluntary control, including the diaphragm, which can lead to difficulty breathing. ALS does not attack the senses of sight, touch, hearing, taste, and smell.

SYMPTOMS

Early symptoms vary with individuals and not everyone with ALS develops all of them, but symptoms usually include:

- Abnormal fatigue and weakness of the arms and/or legs
- Tripping or dropping things
- Slurred and nasal speech
- Difficulty chewing, swallowing, or breathing
- Difficulty with simple tasks requiring manual dexterity
- Increasing problems moving
- Muscle cramps and twitches





Formerly the ALS Association of RI Chapter, ALS United RI is the only non-profit in Rhode Island dedicated to serving patients and families impacted by this devastating disease.

ALS United RI provides comprehensive care and clinical services to improve the quality of life for people with ALS and their families, while advocating for increased support and advancing innovative therapies to end ALS.

How we help

Once ALS is diagnosed, patients and families face a multitude of physical, emotional and financial needs. To provide assistance throughout their ALS journey, ALS United RI provides the following, free, personalized services and support, regardless of insurance or immigration status.

- Louise Wilcox Multidisciplinary ALS Clinic; Patients can see six specialists in just one clinic visit, all organized by our staff nurse
- Medical Equipment Loan Program
- Home Modifications
- Respite Care Assistance
- Support Groups
- Handicapped transportation
- Consultations and home visits
- Education programs
- Patient Advocacy

How you can help!

BECOME A SOAKEE

Register today as a Soakee and set your fundraising goal!

CORPORATE GIVING

Ask your company to support you with a gifted donation and/or fundraising for your team.

COMPANY MATCH

Are you or other employees donating to your team? Ask your company to match these donations.

CHALLENGES & COMPETITIONS

Set up challenges between departments, floors, or partners to increase fundraising dollars.

Sponsorship Opportunities

Base Sponsorship Benefits

- Logo Placement
- CEO Challenge website
- Welcome packet (printed materials and resources of Soakee)
- Social media post
- Post-event photos/videos (as applicable)
- Option for customized employee kickoff/educational event hosted by ALS United Rhode Island
- Executive invited to participate in the event

	\$1K	\$2.5K	\$5K
	Silver	Gold	Platinum
Base sponsorship benefits	✓	✓	✓
Company logo displayed on event signage		✓	✓
Designated Soakee featured in post-event photos & videos (as applicable)		✓	✓
Opportunity to speak at Walk ALS opening ceremony, August 25th			✓
10X10 tent and table promotional opportunity at Walk ALS			✓
Recognition in print and social media			✓

CEO Challenge Agreement Form

Please complete the information below. The company name listed will be used on promotional material as written; **please list it as you would like it to appear**, including capitalization, hyphens, and registered marks, if necessary. Distribution of sponsorship benefits begin once the form is received.

Soakee Name: _____ **Soakee Title:** _____

Company Name: _____

Contact Name: _____

Email: _____

Address: _____

City: _____ **State:** _____ **Zip:** _____

Phone: _____ **Fax:** _____

Company's Web Address: _____

Signature: _____

If you or your company is sponsoring, the sponsorship agreement form is due promptly to ALS United Rhode Island to ensure company name and/or logo placement on agreed upon marketing materials. Logos in EPS and JPG format must be submitted with agreement. Sponsor, cash or in-kind, must have written consent from ALS United Rhode Island to use the ALS United Rhode Island name or logo in any marketing collateral, media release, etc. regarding their attendance and/or partnership.

- I am proud to be a **Soakee** at the **CEO Challenge**. Please send me more information on how to register
- I (or my company) is proud to be a sponsor at the _____ level
- Enclosed is check # _____ for \$ _____
- Please invoice me at the address above



For more information, contact:

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