



UW CSE MSR
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*Expanding
Accessibility
Research*

Technologies for improving the lives of people with ALS

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What is ALS (Lou Gehrig's Disease)

- ALS, or **amyotrophic lateral sclerosis**, is a progressive neurodegenerative disease that affects nerve cells in the brain and the spinal cord. **A-myo-trophic** comes from the Greek language. "A" means no. "Myo" refers to muscle, and "Trophic" means nourishment – "No muscle nourishment." When a muscle has no nourishment, it "atrophies" or wastes away. **Lateral** identifies the areas in a person's spinal cord where portions of the nerve cells that signal and control the muscles are located. As this area degenerates it leads to scarring or hardening ("**sclerosis**") in the region.
- Motor neurons reach from the brain to the spinal cord and from the spinal cord to the muscles throughout the body. The progressive degeneration of the motor neurons in ALS eventually leads to their demise. When the motor neurons die, the ability of the brain to initiate and control muscle movement is lost. With voluntary muscle action progressively affected, people may lose the ability to speak, eat, move and breathe. The motor nerves that are affected when you have ALS are the motor neurons that provide voluntary movements and muscle control. Examples of voluntary movements are making the effort to reach for a smart phone or step off a curb. These actions are controlled by the muscles in the arms and legs.

Source: "[What is ALS](#)", ALS Association

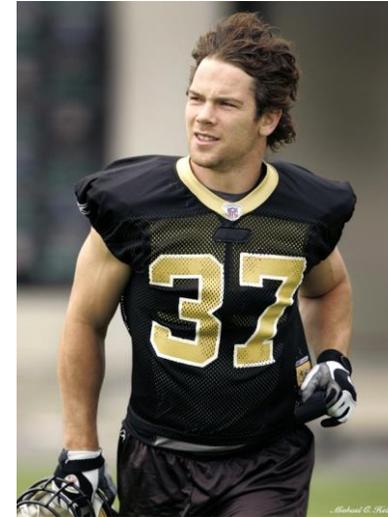
Ten Things about ALS

1. Every 90 minutes someone in the US is diagnosed with ALS.
2. The incidence rate is nearly identical for ALS and MS (2 per 100,000).
3. More than a dozen different familial genetic mutations have been linked to onset, however, the vast majority of ALS is considered sporadic with the exact cause(s) unknown.
4. ALS is also considered by most to be a heterogeneous disorder, with site of onset, progression rates and overall survival varying dramatically from patient to patient.
5. Because the process is one only of exclusion, it can take a year or more to get a confirmed diagnosis of ALS on average.
6. While the reason is unknown, military vets are twice as likely to develop ALS.
7. There are more than 150 potential treatments being looked at for ALS in the US today.
8. ALS is NOT just an old person's disease, many people in their 20s and 30s are diagnosed.
9. The ALS clinical network is incredibly supportive for trial initiation, enrollment and retention.
10. People living with ALS are super engaged and eager to help advance research and take risks.

Source: ALS Therapy Institute, [ALS Awareness Month 2012](#)

Team Gleason

- Steve Gleason played for The New Orleans Saints from 2000-2008.
- The *Gleason Initiative Foundation*: a 501c3 non-profit with the mission:
“Help provide individuals with neuromuscular diseases or injuries with leading edge technology, equipment and services”.
- Spent several \$ millions on providing equipment and services to over a hundred people with ALS.
- Got new legislation approved in Congress to expand Medicare coverage for devices.
- <http://www.teamgleason.org>



*“Until there is a cure, technology is the cure”
Steve Gleason*

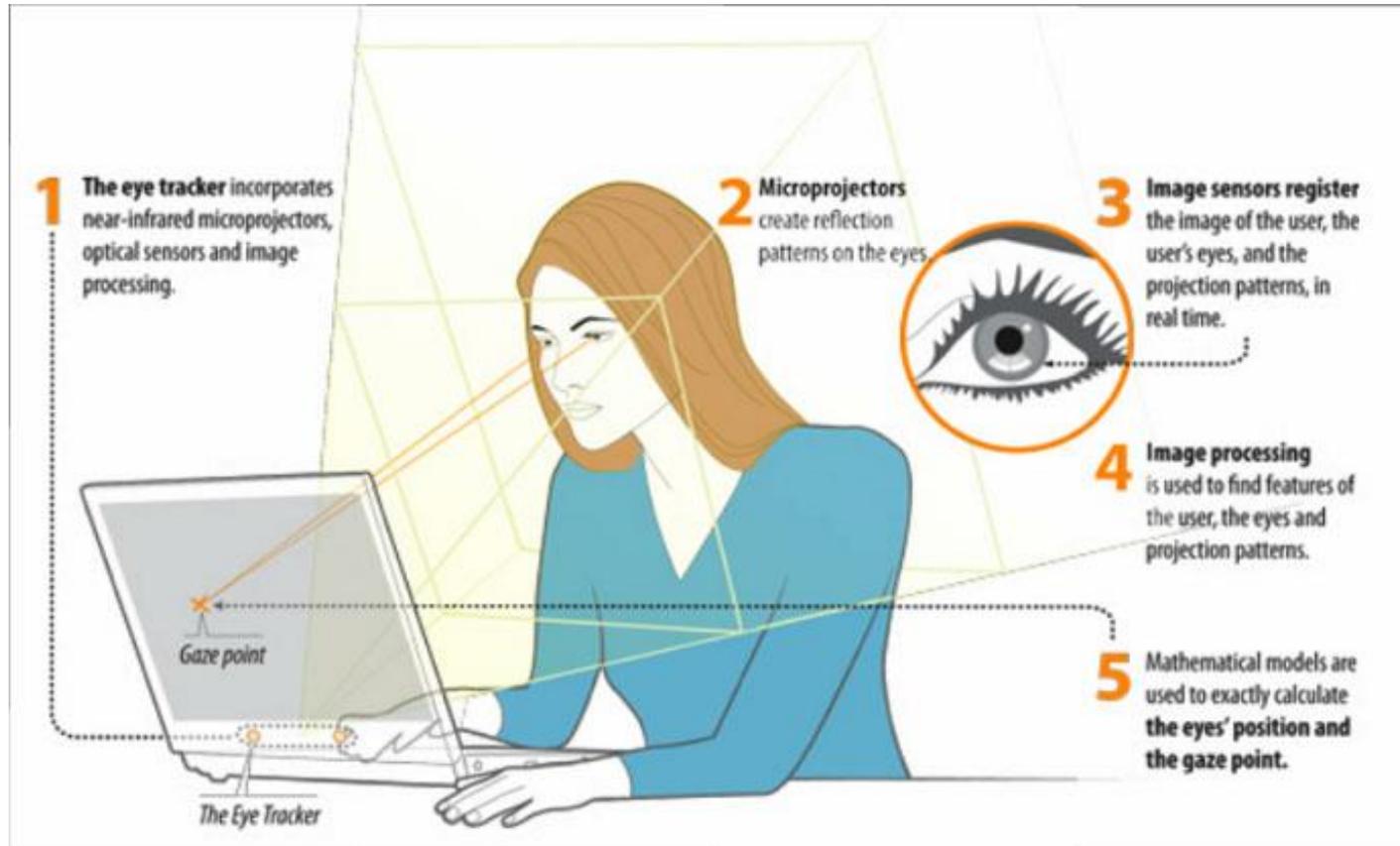


ALS Association



- Established in 1985, largest organization with the mission of leading research and assistive programs for people with ALS.
- Many programs, including the “Ice Bucket Challenge”, which raised tens of millions of dollars. Several regional chapters.
- MSR works closely with the *Evergreen Chapter* in Seattle.
- Closely connected with most ALS clinics, nationwide.
- Recently launched, in partnership with [Prize4Life](#), a \$500k Investment to launch the [Assistive Technology Challenge](#) to improve communication
- <http://www.alsa.org>

Eye-gaze tracking technology



Basic Ingredients:

- Video Camera
- IR Light Source
- Computer
- Software



UX Approaches:

- Dwell-based clicking
- Dwell-free entry

Two projects at MSR

Eye-Controlled Wheelchair



Comfortable independent mobility for people who are unable to use a joystick

Hands-Free Keyboard



Comfortable communication interface for people who are unable to use their fingers or to speak