

# FAQ: ALS

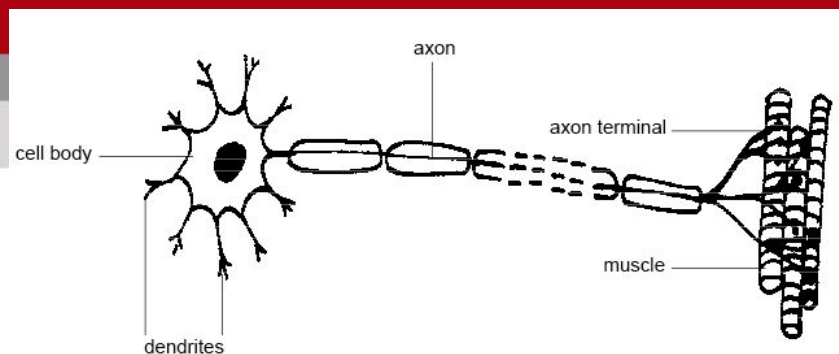
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Personal Healthcare Information



# What is the “Ice Bucket Challenge”

- Golfer Chris Kennedy is credited for directing the challenge to raise money for ALS, for his cousin
- As of Sunday, August 24, 2013 The ALS Association has received \$70.2 million in donations compared to \$2.5 million during the same time period last year
- Ice water itself has nothing to do with ALS directly

# What is ALS?



- **The name describes the symptoms:**
  - **Amyotrophic**- “muscle eating”
  - **Lateral**-”furthest from the middle of the spine or body”
  - **Sclerosis**- “hardening”
- Progressive symptoms: Muscle weakness usually starting with the limbs, loss of speech, difficulty breathing;
- Nerve cells (motor neurons) embedded in voluntary muscles are dying
- However, senses and thinking remain intact
- Physical therapy helps replace nerve cell stimulation for staving off muscle atrophy for a while
- Ultimately fatal, though technology and riluzole can prolong life

# Who gets ALS?

- The typical ALS patient would be a white male, 55 years of age
- The range for age of diagnosis is 30-70 years, but can be even younger
- Women can get ALS, but slightly more common in men (60/40)



Lou Gehrig, a famous baseball player, died at the age of 38 of ALS

# ALS in perspective: a rare disease

- ALS is relatively rare, with 2 cases per 100,000 in the US per year
- In contrast:
  - More than 1 in 3 people have prediabetes
  - The incidence of Hemophilia A ranges from 5.4 to 14.5 cases per 100,000 per year
  - Hepatitis C infection occurs in 0.5 to 20 cases per 100,000 per year

<http://www.alsa.org/als-care/resources/publications-videos/factsheets/epidemiology.html>

<http://www.cdc.gov/media/DPK/2014/dpk-diabetes-report.html>

Tirunagari S, Shaik D. Hemophilia & Acquired Hemophilia A . WebmedCentral CLINICAL TRIALS 2013;4(3):WMC004048.

<http://www.cdc.gov/hepatitis/Statistics/2009Surveillance/PDFs/2009HepSurveillanceRpt.pdf>



# The cause of ALS is of yet unknown

- Familial form of ALS, dominant inheritance (10%)
  - Mouse model
  - Superoxide dismutase mutations
  - Linkage to a type of dementia
- Sporadic form of ALS (90%)
  - Evidence of decreased Vascular Endothelial Growth Factor (VEGF)
  - Increased incidence in Gulf war veterans
  - Evidence that neurotoxins are epigenetic trigger for sporadic cases (90%)

<http://www.ncbi.nlm.nih.gov/pubmed/24987705>

<http://www.ncbi.nlm.nih.gov/pubmed/8446170?dopt=Abstract>

<http://www.ncbi.nlm.nih.gov/pubmed/18535397?dopt=Abstract>

<http://www.ncbi.nlm.nih.gov/pubmed/11465017?dopt=Abstract>



# Clinical Studies

- 730 clinical trials currently listed for ALS
  - Genetics
  - Biomarkers
  - Drugs and surgeries that impact function and progression
  - Stem cell studies
  - Medical Devices to assist movement and breathing (ie, diaphragm pacing system)

<http://www.clinicaltrials.gov>





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