#whatwouldyougive
What is ALS?
Amyotrophic lateral sclerosis, or ALS, is a fatal disease of the nerve cells in the brain and spinal cord. In people with ALS, motor neurons deteriorate leading to muscle weakness and paralysis. With no known treatment or cure and a prognosis of 2 to 5 years to live, it is one of the worst diseases we know of.

Who is Sarah Coglianese?
Sarah Coglianese is 38 and has been living with ALS for the past 5 years. She used to be a runner and now she’s in a wheelchair. That hasn’t stopped her though, or even slowed her down in her fight to find a treatment for ALS. Through her #whatwouldyougive campaign and her Speed 4 Sarah blog, she has built national awareness of this disease and has raised hundreds of thousands of dollars for ALS research. She lives in San Francisco with her husband Rob and feisty 7-year-old daughter Scarlett.

How much will we raise in 2017?
The goal is to raise $250K. Campaign participants can seek sponsorship through personal/professional networks and raise dollars through online personalized fundraising pages.

Why should you participate?
ALS is a death sentence. That’s just not ok. But as the world’s foremost drug discovery center focused solely on ALS, the ALS Therapy Development Institute has the greatest potential for a treatment or cure. It is working aggressively on advancing potential treatments including AT-1501, a novel antibody that acts in a highly targeted way to tamp down the immune system, and protects nerves from the progression of ALS. Significant funding is needed to take AT-1501 out of the lab freezer and into people like Sarah, who need and deserve to keep living. With 87% of every dollar donated going directly to ALS research at ALS TDI, your participation in #wwyg plays a significant role in removing the death sentence from ALS.

Contact
wwyg@als.net
617.441.7200
When does it happen?
The challenge can happen on your own watch at any time during the year, but there will also be a big national push for participation in August 2017. If you’re representing a group/organization, it might work well during larger staff meetings, team outings or during a regular work day (some challenge ideas are far less disruptive than others).

- **TAKE-AWAY:** You can organize a challenge anytime! But remember that from August 1-8, you may want to be a part of National #WWYG Week (see below).

How do you participate?
You can participate in #wwyg as an individual or as a group/organization! You can simply take a photo holding a #wwyg sign and share on social media or go further with specific challenges. #wwyg can also be an engaging team-building exercise and all for a worthy cause! It’s up to you how and when you do it! We want everyone involved!

- **TAKE-AWAY:** You can participate as an individual or you can bring the idea to your family, workplace, church group, book club...it’s up to you!

### NATIONAL #WWYG WEEK

**AUGUST 1-8, 2017**

A week of coordinated #WWYG participation across the U.S., with awareness building and fundraising, all powered by social/digital media, celebrity involvement and extensive national media outreach.

**Food for thought**
“Living” through this loss of ability has strengthened my admiration for the bravery of people with ALS and the fight they have to not let this disease dictate their lives. I’m humbled and honored to be part of the cause.

Adam Gracia, 2015 participant

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INDIVIDUAL AND GROUP CHALLENGE IDEAS

GIVE UP YOUR ARMS/HANDS
- Have someone wash your face and brush your teeth
- Have someone feed you meals
- Have someone dress you
- Have someone take notes for you in a meeting

GIVE UP YOUR LEGS
- Use a wheelchair all day
- Have someone lift you from a chair to the toilet every time you have to use it
- Have someone lift you in and out of bed
- Have someone open office doors for you

GIVE UP YOUR VOICE
- Type on your phone to communicate
- Write on paper to communicate

ALS THERAPY DEVELOPMENT INSTITUTE
Participant Guidelines

#1 **Start now:** Create your fundraising page (visit als.net/whatwouldyougive for details; if you need help, email us at wwyg@als.net) and decide on your challenge idea and timing. Reach out to your network to start raising money. If you need help setting up your fundraising page, email us at wwyg@als.net.

#2 **During your fundraising period:** Post photos/video of yourself holding your #WhatWouldYouGive sign (provided by ALS TDI) on social media, using text like “I’m giving up my right arm for the day.” “I’m giving up my legs.” “I’m giving up the ability to feed myself on [date].” #whatwouldyougive #letsmakeALShistory

#3 **Day of the Challenge:** You’re doing something powerful today so you should feel good about it! You don’t have to be sad and depressed all day! Sarah Coglianese shares that “sometimes when people help me with my basic needs, it can actually be funny!” Just keep in mind that the videos and images you post should reflect the purpose of the campaign: to share your experience and educate your social network. And let’s keep it respectful :)

#4 **After the Challenge:** Feel free to share any thoughts or experiences on social media with hashtag #whatwouldyougive. Continue encouraging your network to donate!

More information at als.net/whatwouldyougive

**Participant Support**
If you are interested in participating in the campaign, you will have access to a host of tools to help you raise funds and awareness of what you are doing to help remove the death sentence from ALS!

**Supporting Materials:**
- Social media toolkit, including assets such as video/photo/copy/Facebook frame
- Sample press release and e-mail language
- Print and digital #wwyg signs
- One-pager on ALS, the disease
- One-pager about the ALS Therapy Development Institute
- One-pager on how to involve a group/corporation
- One-pager on the impact of past #wwyg campaigns

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Opportunities for group/company involvement

#whatwouldyougive can be an engaging team-building exercise and all for a worthy cause! The challenge can happen on your own watch at any time during the year, but there will also be a big national push for participation during August 1-8, 2017. For groups/companies, it might work well during larger staff meetings, team outings or during a regular work day (some challenge ideas are far less disruptive than others). We want everyone involved! Here are a few ways to get things rolling:

- Group/company gathers members/employees in departments or small gatherings to take a photo with #wwyg signs.
- On a certain date, members/employees pick an hour (or more if desired!) and give up the use of arms/hands, voice or legs. On this date, employees post photos on social media using #whatwouldyougive, #EndALS and your own group/company-specific hashtag. Include your fundraising team’s Classy donation link (we can help you get started!)
- Invite members/employees to share their experiences if possible. If some of them spent time in a wheelchair, what was that like to navigate the office or the train on the way to the office? If others gave up the use of their voice, how did that impact their day?
- Individual/team participants compete for “most dollars raised” prize/recognition.
- Group/company is also welcome to make a donation to the campaign. We would be grateful for any amount at the group/company’s discretion. E-mail us at wwyg@als.net.

Partnership benefits

- Inclusion within #whatwouldyougive national and local media pitch efforts across print, broadcast and online outlets (complete list to be provided to partners).
- Inclusion in content appearing within author and women’s magazine contributor Sarah Coglianese’s (Brain, Child Magazine, CNN, The Mighty, The New York Times, Redbook Magazine, Scary Mommy, Sweatpants & Coffee) social channels including her popular blog “Speed for Sarah” (2,000 people read her posts on the first day they are published!)
- Brand visibility on the ALS Therapy Development Institute website, email communications (90,000 records/month) and social channels (Facebook: 15,000 followers; Twitter: 4,500 followers; Instagram: 1,700 followers), all targeting a global audience.
- The ALS Therapy Development Institute communicates with a national network of over 200 affiliates and ambassadors, who collectively have an additional reach of over 100,000 direct followers.

More information at als.net/whatwouldyougive
Since 2015

1,600 INDIVIDUALS
have raised awareness of ALS and
$400K
to help bring us closer to a treatment and cure.

The funds were immediately directed to innovative research taking place at the ALS Therapy Development Institute. With this support, ALS TDI has been able to:

• Advance AT-1501 and other promising treatments toward clinical trial
• Grow our Precision Medicine Program and bring us closer to identifying ALS subtypes
• Validate the efficacy of Copper ATSM at slowing down ALS in pre-clinical studies
• Expedite the pace of research overall by investing in cutting-edge technologies
• Continue to build greater awareness of ALS and raise additional funds for research
**A Leader**

- With 30 full-time, industry trained, drug development experts on staff, ALS TDI has screened over **300 drugs** since its inception in 1999.
- Rated a CharityNavigator.com four-star charity, ALS TDI spends **87% of each dollar** raised on research to find an effective treatment and cure for ALS.
- ALS TDI is **internationally recognized** as a leader in optimizing preclinical models of neurodegeneration for clinical translation. It partners with pharmaceutical companies and other biotechs around the world.

**AT-1501**

ALS TDI’s innovative science and cutting edge approach have resulted in the identification of AT-1501, a promising treatment for ALS. AT-1501 is an antibody therapeutic with comprehensive and promising preclinical data. It blocks specific immune cell activation and protects nerves against the progression of ALS. [als.net/AT-1501](http://als.net/AT-1501).

**Precision Medicine**

ALS TDI pioneered the ALS Precision Medicine Program, the world’s premier program and partnership with ALS patients. Only by partnering closely with people with ALS can researchers work to classify the subtypes of ALS and screen and target treatments more precisely. [als.net/precisionmedicine](http://als.net/precisionmedicine)

**Contact**

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SOMEONE IN THE U.S. IS DIAGNOSED WITH ALS

Amyotrophic Lateral Sclerosis
Lou Gehrig's disease
Motor Neuron Disease (MND)

**EVERY 90 MINS**

SOMEONE IN THE U.S. IS DIAGNOSED WITH ALS

**2-5 YEARS:**
The length of time most people live after being diagnosed with ALS.

**30,000**
The estimated number of people in the U.S. who have ALS at any given time.

**90%**
The approximate number of cases of ALS that are sporadic, occurring in families without a history of the disease. ALS shows no prejudice and affects people of all ages.

THERE IS NO CURE OR EFFECTIVE TREATMENT FOR ALS, BUT SCIENTISTS ARE WORKING HARD TO DEVELOP THERAPIES.

Active service military personnel are 2X as likely to develop ALS than the general population.
Funding the discovery of an effective treatment and cure for ALS is expensive. Drug development is expensive. At ALS TDI, we believe that dollars should never stand in the way of progress.

Since 2015, $400K has been raised by #whatwouldyougive participants. The funds were immediately directed to innovative research taking place at the ALS Therapy Development Institute. With this support, ALS TDI has been able to:

- Advance AT-1501 and other promising treatments.
- Grow our Precision Medicine Program.
- Validate the efficacy of Copper ATSM.
- Invest in cutting-edge technologies.
- Raise ALS awareness and funds for ALS research.

This year’s fundraising goal for #wwyg is $250K. Dollars raised will continue to support all of these efforts, in particular to help move AT-1501 closer to clinical trial.