QUADRANT
STRATEGIES

I AM ALS Messaging Research

October, 2018

Research Methodology

Our research for I AM ALS was conducted in four phases. We used two sets of in-depth interviews and a targeted digital listening report to craft campaign messages and a detailed description of ALS, which we then tested and refined based on the results of a nationally-representative online survey.

Phase	Process	Objectives
ALS Expert Interviews	In-depth interviews with 7 ALS doctors, researchers, and advocates.	• Uncover best practices for describing and introducing ALS. • Assess the current state of ALS research. • Determine current opportunities and challenges for ALS organizations. • Discover examples of successful ALS fundraisers and messages. • Collect feedback on initial 11 campaign messages options.
Digital Listening	Analysis of ALS and Ice Bucket Challenge social conversations and news coverage.	• Examine the lasting impact of the Ice Bucket Challenge. • Analyze recent news coverage and social conversations about ALS to reveal what Americans are seeing and saying online about the disease. • Map the ALS influencer and fundraiser landscapes.
DC Insider Interviews	In-depth interviews with 10 messaging and policy experts in Washington, DC.	• Reveal motivations behind donating to and supporting relevant causes. • Evaluate responses to various short facts and statistics about ALS. • Collect feedback on 4 ALS descriptions drafted based on expert suggestions. • Collect feedback on 8 refined campaign messages messages.
Online Survey	A nationally-representative survey with 500 members of the US General Population.	• Test a single refined ALS description. • Compare 8 refined campaign messages. • Measure attitudes towards the Ice Bucket Challenge and interest in future fundraisers. • Provide final recommendations for campaign messaging and ALS description.

EXECUTIVE SUMMARY

ALS Description

The Takeaway: Relatively few Americans are aware of ALS and fewer have a personal connection. However, by simply describing the disease with compelling language, **I AM ALS can increase both interest in learning about ALS and willingness to donate.**

Key Elements: After speaking with ALS experts, we developed four descriptions that emphasized the **progressive and sporadic** nature of the disease while also **conveying hope** about the future. Refining these definitions with DC Insiders, we learned that the definition should be **non-technical and focus on fatality and paralysis**. Finally, survey participants indicated that the definition should also **address causes, treatments, and affected populations**.

Recommended Description of ALS

ALS is a disease that attacks cells in the body that control movement. It makes the brain stop talking to the muscles, causing increased paralysis over time. Ultimately, patients become prisoners within their own bodies, unable to eat, breathe, or move on their own. Their mind remains sharp so they are fully aware of what's happening to them. ALS is not inherited and can affect anyone. It is always fatal and patients typically live for 3 to 5 years after diagnosis. Scientists have yet to identify causes or cures for ALS, but they believe significant treatment breakthroughs are possible within the next 5 years.

ALS Messaging

Process: We tested 11 messages in interviews with ALS experts. Based on their feedback, we refined the list down to 8 messages that we tested with DC Insiders. Incorporating their responses, we improved the 8 messages and tested them in our nationally-representative survey of 500 Americans.

The good news: The messages generated a significant interest in learning more about ALS and made Americans and DC Insiders much more likely to donate and volunteer. This was true for those with no prior knowledge of ALS, those with personal connections to the disease, and those who frequently donate to other causes.

Key components of messaging: I AM ALS messaging should:

- **Provide Hope:** Position scientific breakthroughs, revolutionary treatments, and a cure as realistic achievements.
- **Be Direct:** Outline specific needs and areas that supporter donations will address.
- **Show Impact of ALS:** Reemphasize elements of the ALS description that show its effect on patients.
- **Make it Relevant:** Describe why everyone should care about ALS: it is sporadic and unpredictable.
- **Show Impact of Donating:** Show the value of supporting ALS research to additional communities and causes.
- **Have a Call to Action:** Build a movement and specifically ask audiences to participate.

Recommended Message House

Of the 8 messages tested in our survey, we found that Science Triumph, Anyone Anywhere, and Force Multiplier were seen as the most hopeful, credible, and capable of generating interest in donating. Based on these messages – as well as the principles and learnings from all phases of our research – we recommend using the following message house:

Doctors, researchers, and scientists are closer to finding a cure for ALS than ever before, using better science than we would have thought possible just ten years ago. These experts believe a breakthrough is on the horizon, but they can't get there without the necessary funding.

Join us. Join the movement to stop ALS and bring new set of treatments within reach.

ALS Traps Patients Within Their Own Bodies

ALS robs patients of their abilities, leaving them unable to eat, breathe, or move on their own. We need to cure ALS, because no one should become a prisoner within their own body.

ALS Can Affect Anyone

ALS can strike anyone at any time. Over 90% of ALS patients have no family history with the disease. Your support is needed to stop this disease that affects men and women of every age, race, and ethnicity.

Investing in ALS Research Saves Millions of Lives

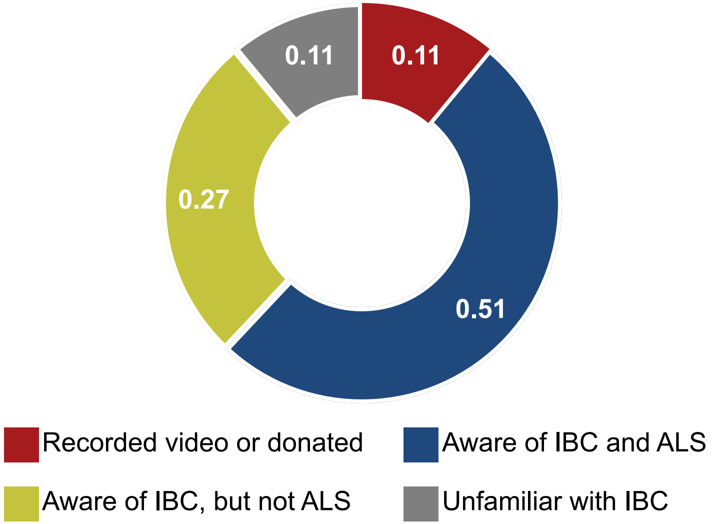
An estimated 1 in 15 adults alive today – 135 million people – will be diagnosed with a neurological disease. By producing a cure for ALS, we'll help eliminate dozens of other diseases such as Parkinson's, Alzheimer's, and Huntington's.

ICE BUCKET CHALLENGE

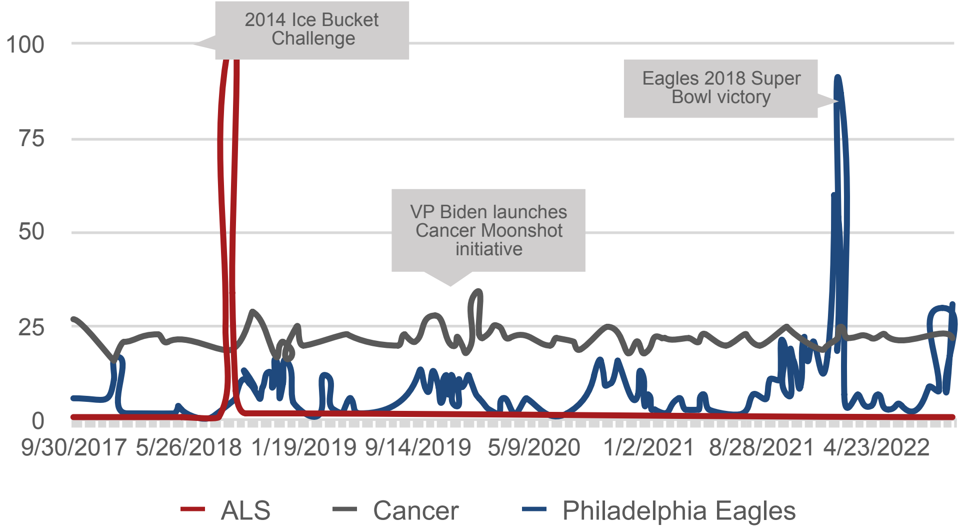
The general public is highly aware of the Ice Bucket Challenge and its connection to ALS

In our survey, 89% of Americans were familiar with the Ice Bucket Challenge and 62% knew about its connection to ALS. Using Google search activity as a measure of interest, the Ice Bucket Challenge ranks higher than major national events such as the Super Bowl and presidential primary results. The Ice Bucket Challenge generated more interest in ALS than any other event did for cancer or a neurological disease such as MS or Alzheimer's.

Which of the following best describes your level of involvement in the 2014 Ice Bucket Challenge? *Showing %*



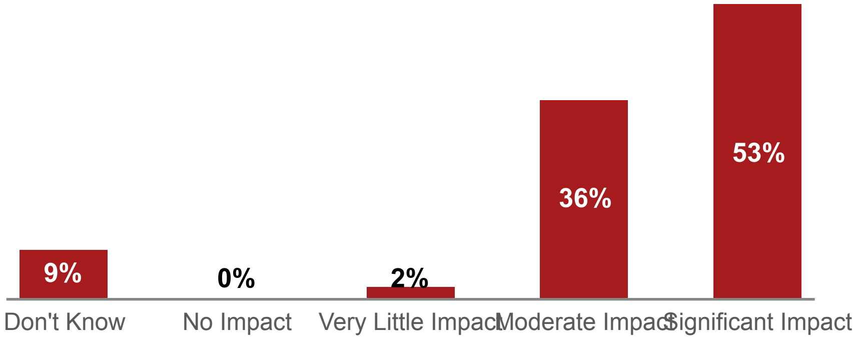
Relative Number of Google Searches by Week, 2014 – Present



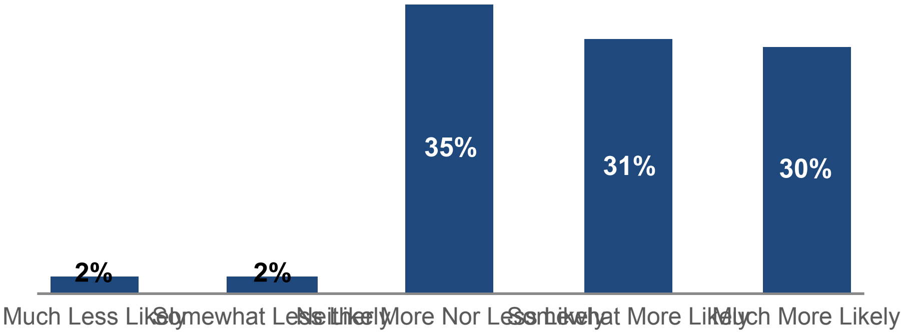
And learning about the Ice Bucket Challenge increased willingness to donate to ALS

Americans believe the money raised by the Ice Bucket Challenge positively impacted the state of ALS research and more than half of Americans who participated in the Challenge think it had a significant impact. As a result, Americans indicate that they are willing to donate to an ALS non-profit in the future, even those who previously donated. Americans also indicate that the success of the Ice Bucket Challenge makes them more willing to donate, even when hearing that $220 million has already been raised.

To the best of your knowledge, what level of impact did the Ice Bucket Challenge have in advancing the state of ALS research and treatments?
Showing % among people who did IBC



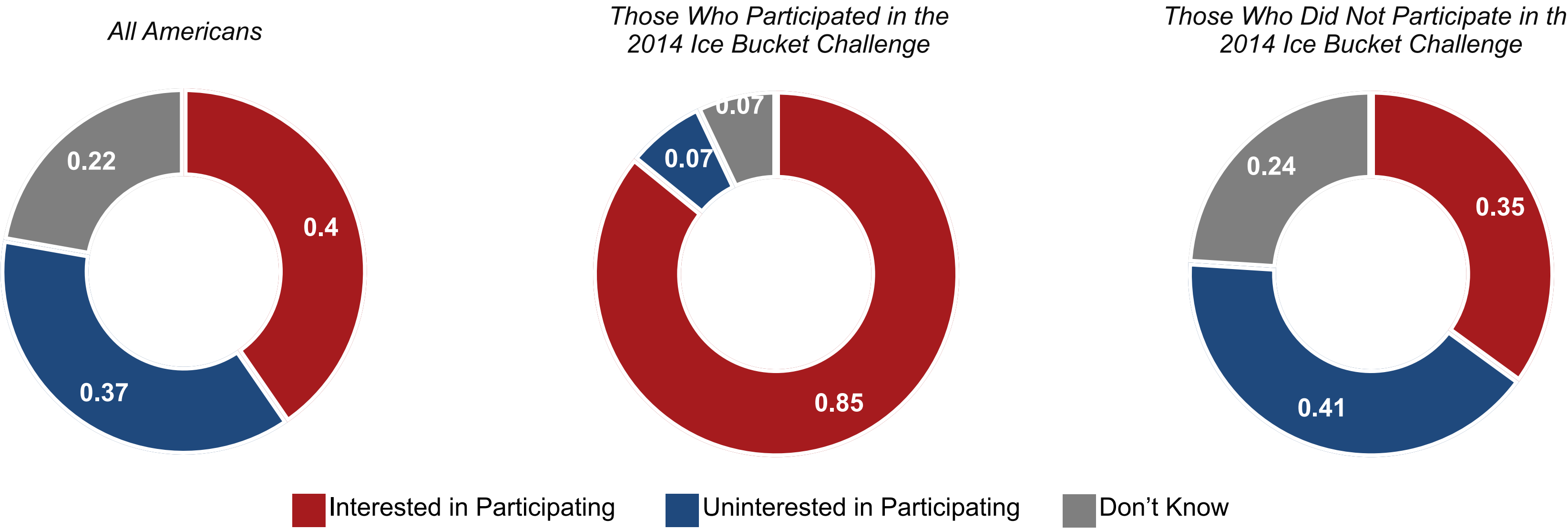
Does hearing about the success of the Ice Bucket Challenge make you more or less likely to donate to support ALS research in the future?
Showing % among donors



However, Americans are mixed about the participating in the Challenge again

Despite the strong interest in donating to an ALS charity, Americans are split overall in their desire to participate in a 2019 Ice Bucket Challenge to commemorate the five-year anniversary of the fundraiser. While those who donated or recorded a video as part of the original event were highly supportive of the idea, a plurality of those who did not participate indicated they were uninterested.

2019 is the 5 year anniversary of the Ice Bucket Challenge. Which of the following most accurately describes your willingness to participate in a 5-year anniversary Ice Bucket Challenge? *Showing %*


All Americans

Those Who Participated in the 2014 Ice Bucket Challenge

Those Who Did Not Participate in the 2014 Ice Bucket Challenge

Additionally, recent campaigns have struggled to reach large audiences and focus on ALS

Viral fundraisers such as the Ice Bucket Challenge are primarily remembered for funny or “fail” videos rather than their impacts on the diseases they target. Additionally, recent campaigns such as the ALS Pepper Challenge have primarily earned new coverage for celebrity involvement rather than general public participation.

Sample Popular ALS Pepper Challenge and Ice Bucket Challenge Social Posts and YouTube Videos

Entertainment Tonight

Kelly Clarkson hilariously begs Jesus to "take the wheel" during the #ALSPepperChallenge! et.tv/2nt8i5U

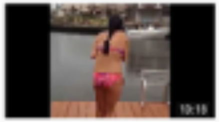
8:46 PM - 1 Feb 2018

Jaime King

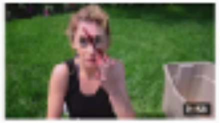
#Throwback to the #IceBucketChallenge for ALS! @taylorswift13 and I were absolutely freezing!!!

11:21 AM - 16 Aug 2018

#TBT ALS Ice Bucket Challenge Fail Compilation
Funny Vines – 373,000 Views



Funniest ALS Ice Bucket Challenges + Fails Compilation
Max Funke – 12 Million Views



Ultimate Ice Bucket Challenge Fail Compilation
Tube Dude – 12 Million Views

Best ALS Ice Bucket Challenge Fail Compilation
Fail Army – 6 Million Views

At the same time, experts urge caution when discussing the Ice Bucket Challenge

While researchers and representatives of prominent ALS organizations recognize the historic amount of money raised by the Ice Bucket Challenge, they suggested that they rarely mention the fundraiser due to concerns about its impact. Primarily, these experts agreed that the **donations have not directly resulted in notable scientific breakthroughs** and that it is **difficult to describe how the funds have been distributed**. Additionally, many cautioned against replicating the Ice Bucket Challenge or simi**lar fundraisers because they have not lead to repeat donations or increased public knowledge** about ALS.

Key Quotes from In-Depth Interviews with ALS Experts

"CRISPR wasn't discovered because of the Ice Bucket Challenge. The drug that was approved by FDA had nothing to do with the Ice Bucket Challenge." – ALS Expert

"You open yourself up to questions like "how, show me the evidence" and we're careful not to provide something that we can't back up. $140 million of that $220 million is sitting in a bank and hasn't been spent." – ALS Expert

"The Ice Bucket Challenge was a blip… 98% of those people never gave again. Awareness is not engagement." – ALS Expert

Ice Bucket Challenge Recommendations

The Ice Bucket Challenge can be useful to initially connect with audiences but should not be the central focus of a campaign. Messaging about the Challenge should:

1. Use the Ice Bucket Challenge to introduce ALS to new audiences or remind them where they may have heard about the disease.
2. Leverage the upcoming 5-year anniversary to generate media attention and donor interest in new ALS fundraisers, organizations, and awareness campaigns.
3. Tread carefully when discussing the direct impact of Ice Bucket Challenge funds or comparing the amount of money raised to the amount needed for future research and patient treatment.

Key Quotes from In-Depth Interviews

"I do think that it's one of those things that cannot be repeated. Yes these viral things are well organized campaigns but it had a dose of randomness. I think it can be used in some messaging campaigns to remind people." – ALS Expert

"I say, 'You remember the Ice Bucket Challenge don't you?' And they say, 'Oh yeah, I remember that.' And I say, 'that was done to support research and treatment for ALS.' And I'll leave it at that." – ALS Expert

ALS DESCRIPTION

We tested five descriptions, each based on ALS expert recommendations, in two phases

Phase	Name	Description
DC Insider Interviews	Scientific	ALS is a progressive neurodegenerative disease that causes patients to lose muscle mass, making it increasingly difficult to initiate and control muscle movement. ALS is not contagious, and more than 90 percent of ALS cases are not inherited, meaning it can affect anyone. ALS is typically diagnosed as early as age 40 and at current rates, more than 500,000 Americans living today will die from the disease.
	Patient Impact	ALS attacks cells that control movement throughout the body. It makes the brain stop talking to the muscles, meaning patients become increasingly paralyzed and ultimately losing the ability to eat, breathe, and move on their own. ALS can affect anyone and scientists have identified few causes or meaningful treatments for the disease. The disease is always fatal and patients typically live for 3 to 5 years after diagnosis.
	Loss of Ability	ALS is a disease of loss that robs your body of its ability to function because the brain stops talking to the muscles. Over time, even the simplest tasks become difficult, such as buttoning a shirt or writing. The disease progresses until not a single muscle in your body works and you can't walk, eat, or breathe on your own. It is always fatal.
	Emotional	ALS is a really terrible disease that kills someone within just a few years of their being diagnosed. It robs them of the physical ability to things on their own without impacting their mental ability. They have to rely on other people to feed and clothe them. Eventually, patients become completely paralyzed and the disease ultimately kills them.
National Survey	--	ALS is a disease that attacks cells in the body that control movement. It makes the brain stop talking to the muscles, causing increased paralysis over time. Ultimately, patients become prisoners within their own bodies, unable to eat, breathe, or move on their own. Their mind remains sharp so they are fully aware of what's happening to them. ALS can affect anyone. It is always fatal and patients typically live for 3 to 5 years after diagnosis. There is currently no cure for ALS, but scientists believe significant breakthroughs in treating ALS can happen within the next 5 years.

We found the description should be non-technical and emphasize that ALS is progressive and fatal

- **Non-technical descriptions:** Phrases such as “the brain stops talking to your muscles” or “ALS attacks the brain cells that control your muscles” are effective non-technical descriptions of ALS.
  - *“I say people lose their strength while maintaining their consciousness.”* – ALS Expert
  - *“Your body loses its ability to function because the brain stops talking to your muscles.”* – ALS Expert

- **Progressive nature:** It is effective to describe the impact of ALS as bringing about a “loss of ability” and that it is “progressive.”
  - *“It robs a person of their ability to do anything on their own and they become dependent on other people to feed them, go to the bathroom, etc.…that elicits a response from people of ‘shit, I like to do things on my own.”* – ALS Expert
  - *“I like this one better [Impact on Patients]. Paralyzed makes it feel even more serious even though it starts out with small inconveniences.”* – DC Insider

- **Fatal:** When introducing ALS to new audiences, experts emphasize that the disease is currently fatal and irreversible.
  - *“I’ll say that ALS is a really terrible disease that kills someone within just a few years of them being diagnosed.”* – ALS Expert
  - *“That is very straightforward and direct. I would say that for me, that’s a good concise way of people like woah, my initial understanding was right, but I wonder if leading with what you end with – ALS is deadly – would not sugar coat it up front. That would raise the importance of raising as much awareness as possible. Open with that it is a fatal diagnosis.”* – DC Insider

It should convey hope, urgency, and describe the unpredictable nature of ALS

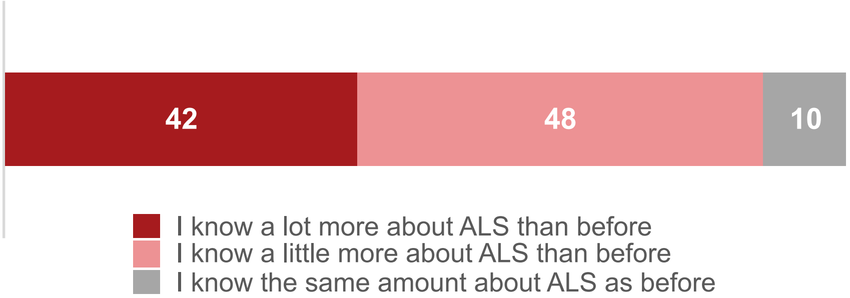
- **Unpredictable and sporadic:** Describing the unpredictable nature of ALS--not infectious and except in a small number of cases, not hereditary--is seen as one of the main reasons for the general public to care.
  - *“You have to make it very real and personal and I think another component of successful campaigns, that the message that ALS is not as rare as people think it is.”* – ALS Expert
  - *“It's clear but scary. You use phrases like, it can attack anybody. Some of the statistics you were using make me wonder if I would get it today.”* – DC Insider
  - *“I think that’s very effective because percentage wise most people don’t know someone with ALS and I think it goes a long way to really personalizing this. The one thing I would add is that it’s possible to find a cure. [Anyone Anywhere]”* – DC Insider

- **Hopeful and urgent:** The description should be relatable, hopeful, and urgent.
  - *“We need to convey correctly that what’s been happening in the last five years is extraordinary and much better than the last 50 without overclaiming… I’m optimistic that I’ll see a treatment before I retire.”* – ALS expert
  - *“To enact change, you have to be passionate and powerful. The status quo hasn’t worked. The definition of insanity is doing the same thing and expecting a different result.”* – ALS expert
  - *“You have to start with some sense of hope.”* – DC Insider

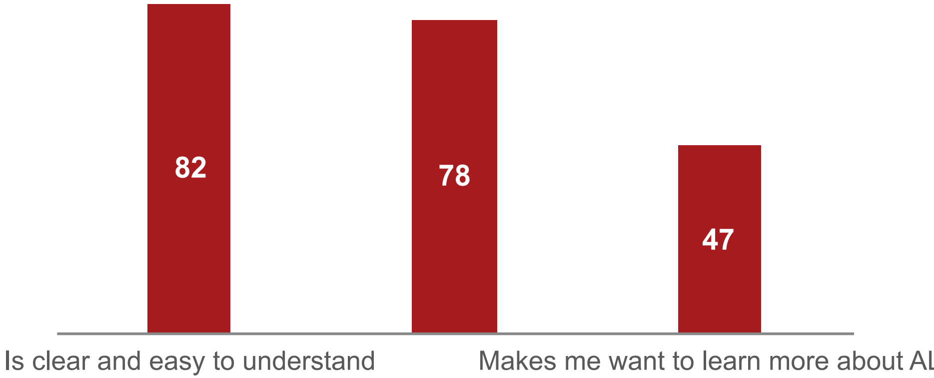
Americans say the new description of ALS is clear and informative

<u>Survey Description:</u> ALS is a disease that attacks cells in the body that control movement. It makes the brain stop talking to the muscles, causing increased paralysis over time. Ultimately, patients become prisoners within their own bodies, unable to eat, breathe, or move on their own. Their mind remains sharp so they are fully aware of what's happening to them. ALS can affect anyone. It is always fatal and patients typically live for 3 to 5 years after diagnosis. There is currently no cure for ALS, but scientists believe significant breakthroughs in treating ALS can happen within the next 5 years.

After reading this description, which of the following statements best describes your understanding of ALS? *Showing %*



Which of the following characteristics apply to this description of ALS? *Showing % applies a great deal*



However, people still have important questions

- **Causes:** People are confused about whether ALS is an inherited disease and want to know more about any environmental contributors or risk factors.
    - *“Is it genetic? Are there environmental contributors?”*
    - *“How does someone get this disease? Are there risk factors, early warning signs, symptoms, etc.?”*

- **Affected Populations:** Some are curious to know what groups ALS affects most. They want to know more about the profile of the kind of person that develops ALS.
    - *“Who does it affect? What ages?”*
    - **“***Does it only occur in adults?”*
    - *“Maybe the age ranges that generally have the disease and maybe if a particular sex has the disease more often.”*

- **Treatments:** People want to know if there are any treatments available for those with ALS that can improve quality of life.
    - *“What treatments are available? What increases the risk of ALS?”*
    - *“Are there any treatments that can improve the quality of life or prolong life?”*
    - *“Are there medications to slow down the process?”*

Recommended ALS Description

After incorporating feedback* from survey participants, we recommend that I AM ALS use the following description of ALS:

ALS is a disease that attacks cells in the body that control movement. It makes the brain stop talking to the muscles, causing increased paralysis over time. Ultimately, patients become prisoners within their own bodies, unable to eat, breathe, or move on their own. Their mind remains sharp so they are fully aware of what's happening to them. ALS is not inherited and can affect anyone. It is always fatal and patients typically live for 3 to 5 years after diagnosis. Scientists have yet to identify causes or cures for ALS, but they believe significant treatment breakthroughs are possible within the next 5 years.

**Highlighting indicates additions to the description based on survey participant feedback*

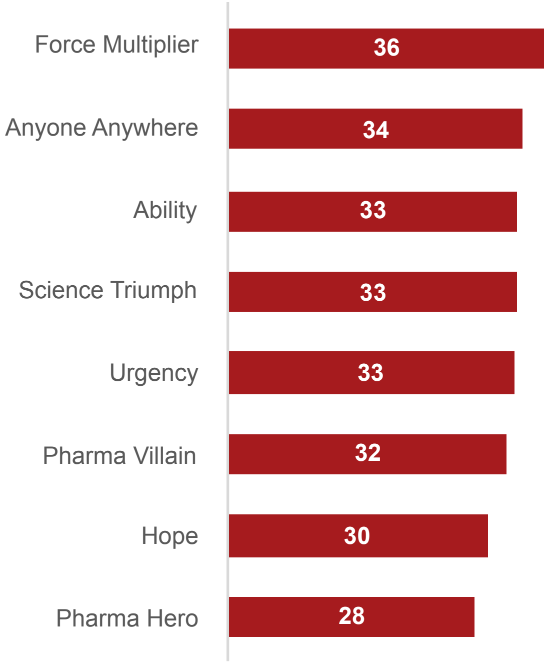
I AM ALS MESSAGING

We tested eight messages in the survey

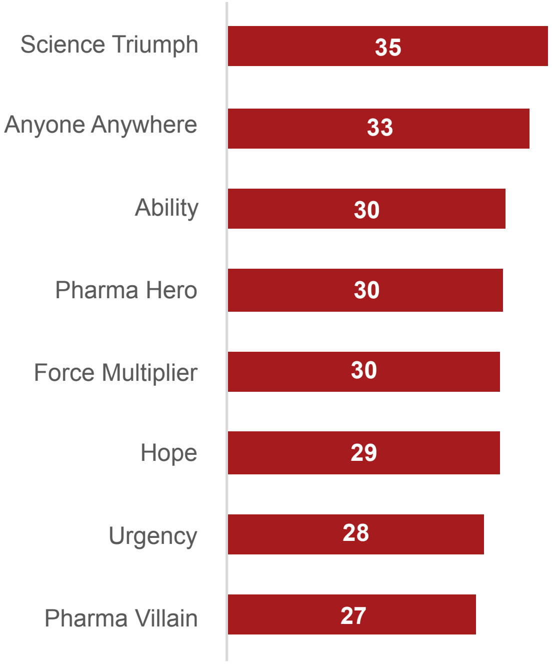
Message	Text
Anyone Anywhere	ALS can strike anyone at any time. Over 90% of ALS patients have no family history with the disease and it affects men and women of every race, ethnicity, and age. The good news is that a new set of treatments is within reach. Join the movement to stop ALS, because no one should become a prisoner within their own body.
Force Multiplier	An estimated 1 in 15 adults alive today will be diagnosed with a neurological disease. That’s an estimated 135 million people. By supporting ALS research, you are helping to build a movement that will produce a cure for ALS as well as well as dozens of other diseases such as Parkinson's, Alzheimer's, and Huntington's — saving millions of lives.
Science Triumph	Right now, doctors, researchers, and scientists are closer to finding a cure for ALS than ever before, using better science than we would have thought possible just ten years ago. These experts believe a breakthrough is on the horizon, but they can’t get there without the necessary funding. We’ve rallied our friends and families before – around polio, breast cancer, and HIV – and we can do it again. We need your help to bring an end to ALS.
Ability	ALS is a disease that silences patients, making them increasingly paralyzed and eventually unable to walk, talk, or breathe on their own. And because their mental capabilities remain intact, they are fully aware of what’s happening to them. But now, the ALS community is coming together in support of a new campaign that will give a voice to patients to tell their stories and support to researchers looking for a cure. Join the movement, help us defeat ALS.
Urgency	Now is the time to cure ALS. Every 75 minutes someone is diagnosed with this terrible disease that leaves them paralyzed, unable to eat, breathe, or move on their own. The average lifespan for someone living with ALS is just 3 to 5 years. Patients and their families urgently need your help to fund the research that will find a cure for ALS.
Pharma Villain	While the Ice Bucket Challenge raised $220 million to combat ALS, big pharma still sits on the sidelines. ALS receives less private research funding and 2 to 3 times less total funding than similar diseases. Pharmaceutical companies helped produce effective treatments for HIV, MS, polio, smallpox and more, but they have not stepped up for ALS. We’re on the brink of breakthroughs, but big pharma needs to put people over profits and invest in finding a cure.
Hope	ALS patients, their families, caregivers, and doctors have a new reason to hope. They are joining together in a new movement to support the awareness, research, and advocacy priorities that will lead to breakthroughs in our understanding of ALS and effective treatments for the disease. To transform this hope into reality we need your help.
Pharma Steps Up	Pharmaceutical companies are making a big push to develop new treatments for ALS. They know finding a cure won’t happen unless they commit resources that move critical new drugs through the development pipeline. Big pharma’s investment will not only accelerate finding a cure for ALS, it will lead to big breakthroughs in treating related diseases like Alzheimer’s and Parkinson’s. It’s a win-win, because patients get effective treatments, and big pharma brings commercially viable drugs to market.

And measured their impact on interest in donating, hope for a cure, and believability

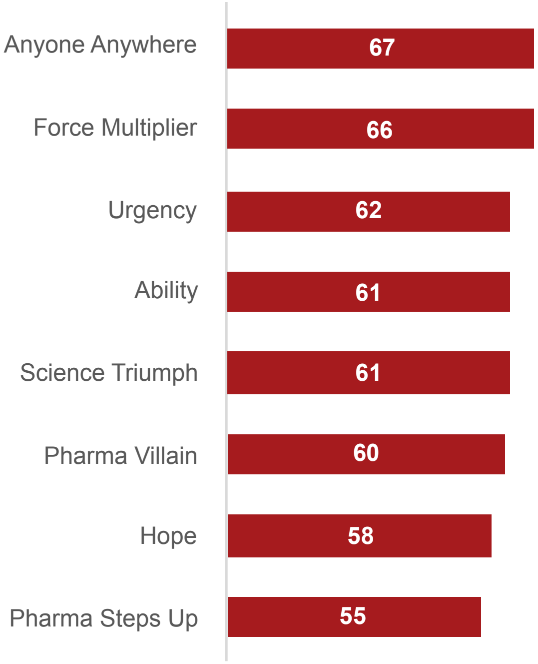
How much more or less likely are you to **donate** to an ALS non-profit or charity?
Showing % much more likely



How much more or less **hope** do you have… [about] a cure for ALS?
Showing % much more hopeful



How much do you **believe** this message? How realistic are its promises?
Showing net believability %



Index Score Methodology

We create Index Scores in order to compare the efficacy of each message using a single metric. Our score takes into account how believable each message is overall as well as the number of participants it made much more hopeful about finding a cure and much more likely to donate to an ALS non-profit. The overall scores – as well as breakdowns by key audiences – are displayed on the next slide.

Index Score

=

Net believability
(Very + somewhat believable) – (Not very + not at all believable)

+

2x Much more likely to donate
to an ALS non-profit

+

2x Much more hopeful
about finding a cure for ALS within a few years

MESSAGE RANKING – BY COLOR	
Higher scoring message	🟩

Index Score by Message and Audience

Message	All Americans	Moderate to High Knowledge of ALS	Little to No Knowledge of ALS	Donors to Other Causes
Anyone Anywhere	200	222	182	238
Force Multiplier	198	225	177	247
Science Triumph	198	219	181	244
Ability	188	219	164	240
Urgency	183	208	164	230
Pharma Villain	178	210	153	218
Hope	176	209	151	217
Pharma Steps Up	171	188	158	214

Science Triumph, Anyone Anywhere, and Force Multiplier are the most effective messages

Select the words or phrases that you found most compelling in this statement. *Showing all*

Science Triumph

Right now, doctors, researchers, and scientists are closer to finding a cure for ALS than ever before, using better science than we would have thought possible just ten years ago. These experts believe a breakthrough is on the horizon, but they can't get there without the necessary funding. We've rallied our friends and families before – around polio, breast cancer, and HIV – and we can do it again. We need your help to bring an end to ALS.

Anyone Anywhere

ALS can strike anyone at any time. Over 90% of ALS patients have no family history with the disease and it affects men and women of every race, ethnicity, and age. The good news is that a new set of treatments is within reach. Join the movement to stop ALS, because no one should become a prisoner within their own body.

Force Multiplier

An estimated 1 in 15 adults alive today will be diagnosed with a neurological disease. That's an estimated 135 million people. By supporting ALS research, you are helping to build a movement that will produce a cure for ALS as well as well as dozens of other diseases such as Parkinson's, Alzheimer's, and Huntington's — saving millions of lives.

Science Triumph creates hope by showing how donations will lead to scientific breakthroughs

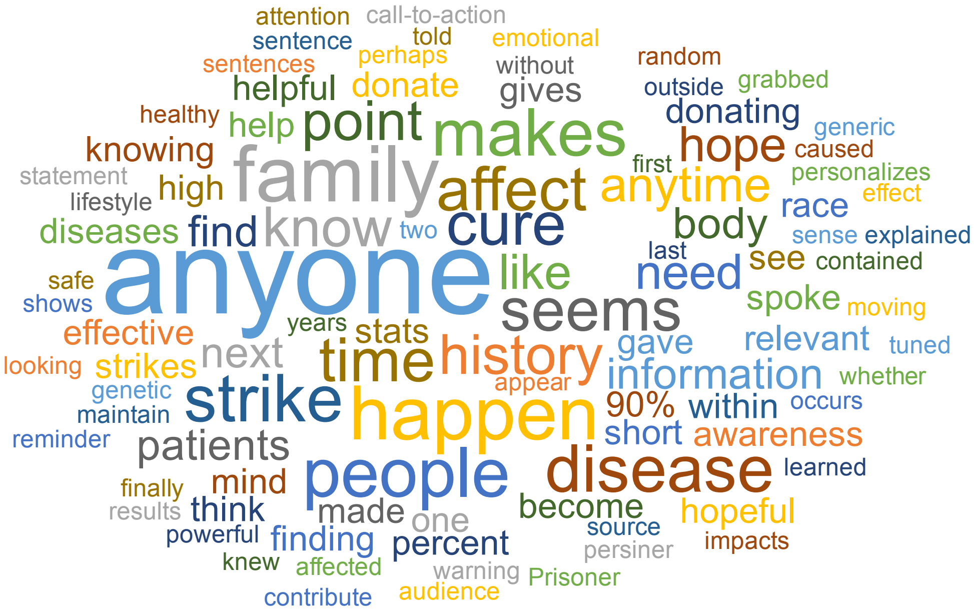
Select the words or phrases that you found most compelling in this statement.
Showing all

Science Triumph resonated with Americans because it is…

- **Hopeful:** It suggests that a cure or significant breakthrough is on the horizon.
- **Expert-driven:** It uses scientists and doctors as messengers to build credibility.
- **Specific:** It directly outlines the need for research funding and asks for help.
- **Positive:** It celebrates past progress without losing a sense of urgency.

Anyone Anywhere creates urgency by making ALS a personal and relatable disease

Select the words or phrases that you found most compelling in this statement.
Showing all



Anyone Anywhere resonated with Americans because it is…

- **Pressing:** It describes how ALS is sporadic and unpredictable to make audiences care.
- **Relevant:** It makes ALS personal by showing how it could affect your loved ones.
- **Serious:** It uses words such as “strike” and “prisoner” to define the impact of the disease and motivate audiences.

Force Multiplier creates purpose by describing the universal impact of donor support

Select the words or phrases that you found most compelling in this statement.
Showing all

Force Multiplier resonated with Americans because it is…

- **Impactful:** It explains the value of donating to ALS without pitting causes against each other.
- **Bold:** It calls for building a movement to save millions of lives.
- **Direct:** It outlines what the outcome of audience donations will be.
- **Credible:** It uses multiple supporting statistics to make its point.

Recommended Message House

Doctors, researchers, and scientists are closer to finding a cure for ALS than ever before, using better science than we would have thought possible just ten years ago. These experts believe a breakthrough is on the horizon, but they can't get there without the necessary funding.

Join us. Join the movement to stop ALS and bring new set of treatments within reach.

ALS Traps Patients Within Their Own Bodies

ALS robs patients of their abilities, leaving them unable to eat, breathe, or move on their own. We need to cure ALS, because no one should become a prisoner within their own body.

ALS Can Affect Anyone

ALS can strike anyone at any time. Over 90% of ALS patients have no family history with the disease. Your support is needed to stop this disease that affects men and women of every age, race, and ethnicity.

Investing in ALS Research Saves Millions of Lives

An estimated 1 in 15 adults alive today – 135 million people – will be diagnosed with a neurological disease. By producing a cure for ALS, we'll help eliminate dozens of other diseases such as Parkinson's, Alzheimer's, and Huntington's.

MESSAGING DO’S AND DON’TS

Messaging "Do's"

- **Make ALS Relatable: It needs to become known as a more personal disease.** Audiences need to better related to ALS by understanding the physical toll of the disease (such as the loss of ability) and understand it could impact their own friends and family.
  - *"You have to make it very real and personal and I think another component of successful campaigns, that the message that ALS is not as rare as people think it is."* – ALS Expert

- **Be Hopeful: Messaging should be positive and uplifting to challenge the status quo.** Experts believe existing campaigns are too focused on fear and short-term patient care. They want messages to inspire patients and reflect current optimism about the future of ALS research.
  - *"We need to convey correctly that what's been happening in the last five years is extraordinary and much better than the last 50 without overclaiming… I'm optimistic that I'll see a treatment before I retire."* – ALS Expert

- **Emphasize Urgency: Messaging needs to be pressing, combative, and empowering for patients.** Experts agree that the patient voice is missing from many organizations and believe the ALS space could benefit from adopting aggressive tactics and messages to spark immediate change and help rally people to the cause.
  - *"The 'Right to Try' movement came out of the ALS space. The patients did it themselves. It really pushed the issue and it shows the power of a group of passionate individuals."* – ALS Expert

Messaging “Do’s”

- **Promote the search for a cure.** Survey participants found messaging that mentioned a cure to be both hopeful and realistic. Additionally, DC Insiders indicated that they understood “cure” to ultimately mean a set of effective treatments.

- **Include compelling phrases and statistics in campaign messages.** DC Insiders indicated that campaign messaging could benefit from the use of language from the ALS description.
  - *Examples: 3-5 year lifespan, 90% of cases are not inherited, increasingly paralyzed, brain stops talking to the muscles, etc.*

- **Outline specific needs that audience involvement or donations will solve.** These messages generate urgency as well as a sense of involvement for audiences. Messages that are too conceptual or high level are not relatable for audiences and do not accurately convey a need for their participation.

- **Show, Don’t Tell to Create Hope.** Don't say we have new reason to hope. Say we are closer to finding a cure for ALS than ever before, and include proof points such as the current state of research.

- **Say That Funding Supports Patient Care, Drug Development and Research.** Americans are more likely to donate to a non-profit or charity when they know specifics of where the money is going. Survey participants supported patient care, patient technology, drug development, and genetic research in equal proportions.

- **Tell audiences to get involved rather than asking help.** Americans are more interested in supporting ALS organizations when they feel they are part of a movement and not just sources of funding. Phrases such as “join us” or “join the fight” are more effective than “we need your help.”

Messaging "Don'ts"

- **Don't Focus on Public Education or Government Advocacy:** Americans are much more interested in donating to causes that advance the state of ALS research or improve patient care than efforts directed to raise awareness or influence policymakers.
    - *22% of Americans indicated that they would be less likely to donate to an ALS non-profit if they knew the money was being used for "public education and awareness campaigns" while 35% said they would be less likely to donate to "advocacy directed at elected or government officials."*

- **Don't Frame Your Objectives as Fundraising or Awareness Campaigns:** Messaging experts suggested that I AM ALS should position itself as part of a movement and encourage audiences to join in, giving them a sense of purpose and involvement. Messages that outlined fundraising or awareness goals made participants feel unimportant.

- **Don't Use Stigma, Fatality, or Lack of Awareness to Create a Sense of Urgency:** The ALS description alone effectively conveys the severity of the disease and need for support to Americans. Messages that focused on negatives or past mistakes made audiences feel guilty and less hopeful about the future.

- **Don't Make Pharmaceutical Companies Central to Messaging:** Americans have strong negative opinions of pharmaceutical companies that cut both ways. Messages that overly criticize pharma make Americans less hopeful about the prospect of finding a cure and messages that celebrate pharma investments make Americans feel as though their donations aren't needed.

- **Don't Overstate the Importance of Radicava:** ALS Experts cautioned that Radicava is not a true breakthrough while DC Insiders and Americans surveyed indicated it made them less likely to donate to support new research. Instead, I AM ALS should focus on the need to develop new drugs and more effective treatments.

Additional Messaging Recommendations

Key Overall Messaging Themes:

- **Provide Hope:** Position scientific breakthroughs, revolutionary treatments, and a cure as realistic achievements.
- **Be Credible:** Leverage compelling statistics and reference medical consensus to support your case.
- **Show Impact of ALS:** Reemphasize elements of the ALS description that show its effect on patients.
- **Make it Relevant:** Describe why everyone should care about ALS: it is sporadic and unpredictable.
- **Be Direct:** Outline specific needs and areas that supporter donations will address.
- **Show Impact of Donating:** Show the value of supporting ALS research to additional communities and causes.
- **Have a Call to Action:** Build a movement and specifically ask audiences to participate.

Audience-Specific Themes:

- **Donors:** Use themes from Force Multiplier that show the value of donations and unite multiple causes.
- **New Audiences:** Emphasize phrases from the Ability message and ALS description that educate about the disease.
- **ALS Community:** Explicitly use the Urgency message or themes from Science Triumph that outline an immediate need.
- **Medical Experts:** Employ Force Multiplier, Science Triumph, and Pharma Steps Up messages that celebrate past successes and future possibilities.

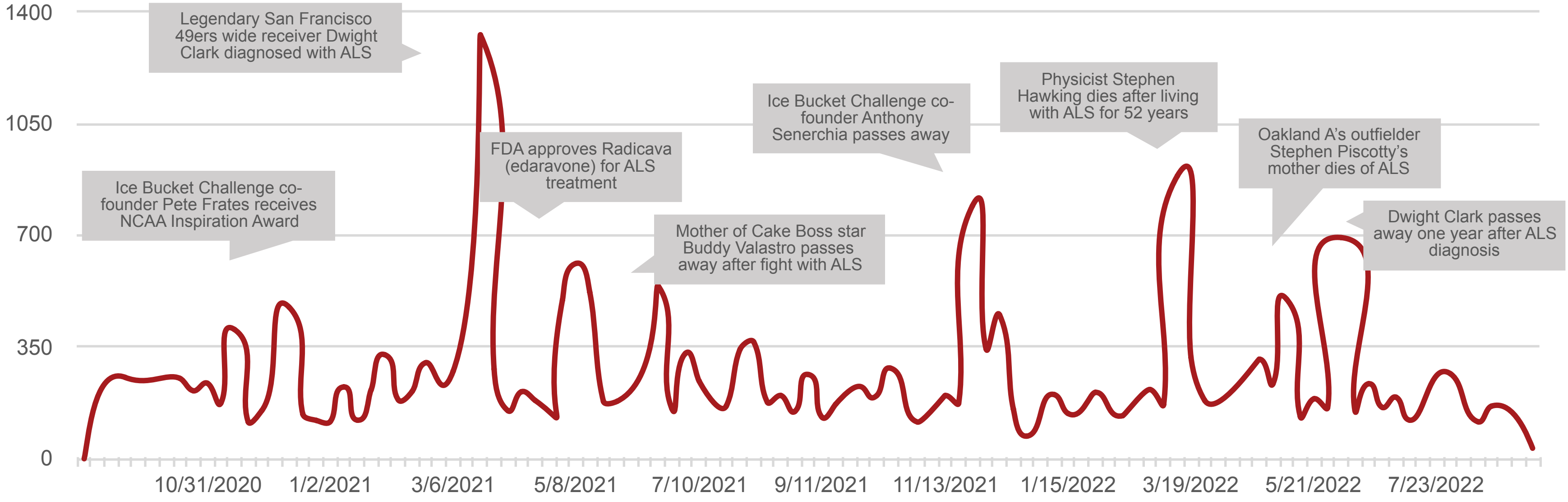
APPENDIX

Media Landscape

Most people hear about ALS due to news coverage of celebrity diagnoses and deaths

News stories about ALS and Google searches for the disease are primarily driven by events such as athlete and entertainer diagnoses and deaths. Day-to-day coverage of ALS is limited to local outlet stories about individual fundraisers and medical industry outlet stories about recent studies and drug trials.

Number of News and Blog Headlines About ALS by Week, Last Two Years



Popular stories about ALS fall into three categories: individuals, groups, and technologies

Beyond stories about celebrity diagnoses, large national news outlet coverage of ALS typically focuses on:

1. **New technology** such as stem cells, artificial intelligence, or speech and eye tracking devices
2. **Research on affected groups** such as NFL players, truck drivers, and veterans
3. **Personal profiles** of scientists or advocates connected to the disease

Popular National News Stories About ALS Shared on Social Media, Last Year

Startling Jump In NFL Player Claims For Parkinson's And ALS Pushes Payout Projections Past 65-Year Total In 18 Months
Los Angeles Times

Military Veterans Are Twice As Likely To Develop ALS—Inside The Search For Answers
People

Diesel Exhaust Might Raise Truckers' Odds For ALS
WebMD

Biotech Entrepreneur, 29, Raises $32 Million To Use AI To Develop Drugs For Parkinson's, ALS
Forbes

Scientist Is Ravaged By ALS, The Disease He Was Working To Spare Others From
Washington Post

ALS Patient Hopes Stem Cell Treatment Will Be "A Powerful Weapon"
CBS News

Pete Frates and Steve Gleason are the advocates who earn the most media coverage

Pete Frates and Steve Gleason earned the most news coverage and social engagements of all ALS advocates due to their range of partnerships with sports teams, politicians, musicians, technology companies and more. Other notable campaigns – from Ady Barkan, Frank Mongeillo, and Matthew Bellina – focused on policy issues such as insurance coverage and experimental drugs trials.

Top ALS Advocates Mentioned News Stories and Blogs, Last Two Years

Name	Description	News Mentions
Pete Frates	Co-Founder of the Ice Bucket Challenge	1,576
Steve Gleason	Former NFL Player; Founder of Team Gleason	1,208
Stephen Piscotty	Oakland A's Outfielder; Son of ALS Victim	591
Eric Bastings	FDA Office of Drug Evaluation Division of Neurology Products	429
OJ Brigance	Former NFL Player; Founder of Brigance Brigade	428
Ady Barkan	Director of Local Progress, Center for Popular Democracy	417
Brian Frederick	EVP of Communications, ALS Association	400
Pat Quinn	Co-Founder of the Ice Bucket Challenge	233
Stephen Hillenburg	Creator of Spongebob Squarepants	215
Frank Mongeillo and Matthew Bellina	Right to Try Activists	195

Recent fundraisers have not created large or sustained campaigns about ALS

Social conversations about ALS fundraisers are also closely linked to specific diagnoses and deaths, as advocates often request donations in honor loved ones or celebrities. Other mentions of donations to ALS are driven by one-time events such as charity auctions or GoFundMe campaigns for individuals. Discussions about these campaigns rarely last for more than a few days and typically do not attract significant news coverage. While the ALS Pepper Challenge raised $590,000 for ALS TDI, the campaign was primarily driven by celebrities rather than the general public.

Social Posts About ALS Donations and Fundraising Campaigns per Day, Last Year

Calls for ALSA donations after Anthony Senerchia passes away

"ALSA has > $100 million in its bank account… where's the urgency?" – Democratic Activist Ady Barkan

#ALSPepperChallenge videos from Tom Haberstroh, Steve Gleason, Jimmy Kimmel, Kelly Clarkson, and more

Calls for ALSA and ALS TDI donations after Stephen Hawking dies

Chicago Cubs and New York Yankees donate to ALS TDI in honor of Oakland A's player Stephen Piscotty's mother

Global ALS Awareness Day

Ice Bucket Challenge anniversary posts and #EveryAugustUntilACure donations

Expert Comments on ALS Organizations

Experts see the greatest change on the horizon for ALS organizations is an increased role in serving as the patient voice in research and drug development. They say that the patient voice has historically been excluded from scientific decisions but the advent of new treatments requires patients and supportive organizations to take a more active role moving forward.

Experts believe the ALS movement would benefit from focused and organized government affairs work. The ALS community should cultivate more champions in Congress or the Department of Defense who can advocate for increased research funding and help publicize advancements.

Key Quotes from In-Depth Interviews with ALS Experts

"We're on the brink of first treatments. How we think about doing things and rolling them out is a major topic. We're no longer the experts. We should have a way to plan out what the roles are." – ALS Expert

"[ALS patients] don't have a big enough voice in some of these policy decisions, but the FDA has massively changed its stance towards patient groups in recent years." – ALS Expert

"I think that government advocacy is something the field could use more of. We see the impact of that in Parkinson's and SMA, where genetic screening got approved within months. That used to take ten years." – ALS Expert

"[We need] a very direct public policy campaign… There are a lot of levers from a government affairs perspective but we're just sitting back and waiting for the status quo." – ALS Expert

Expert Comments on ALS Organizations

Experts suggest that fundraising, patient care, and research efforts have been hampered by the large number of ALS organizations who compete for resources and duplicate efforts. They believe increased communication and coordination between ALS organizations would allow them to more effectively divide and conquer.

There is broad agreement that large-dollar fundraising is the greatest logistical challenge for ALS. Experts say that ALS organizations need to increase the number of matching gifts and large donations because they lack a reliable base of repeat and lifetime donors.

Key Quotes from In-Depth Interviews with ALS Experts

"One of the things that I would love to see done is a really good matching gift program. There's never been a million dollar challenge grant. That's kind of sad." – ALS Expert

"I want us to put together teams of people that can focus on the different areas that are required to get work done. We have great organizations in the space that try to do it all and we have to change that." – ALS Expert

"[Communications between ALS organizations] are poor at best… People would like to see more happen. There's no defined or shared goals so we're not talking." – ALS Expert

"I think the crosstalk could be much better so there isn't duplication. People are applying for the same grants… Each group is funding the same studies… They could really do this all together and be more effective." – ALS Expert

ALS Landscape Summary

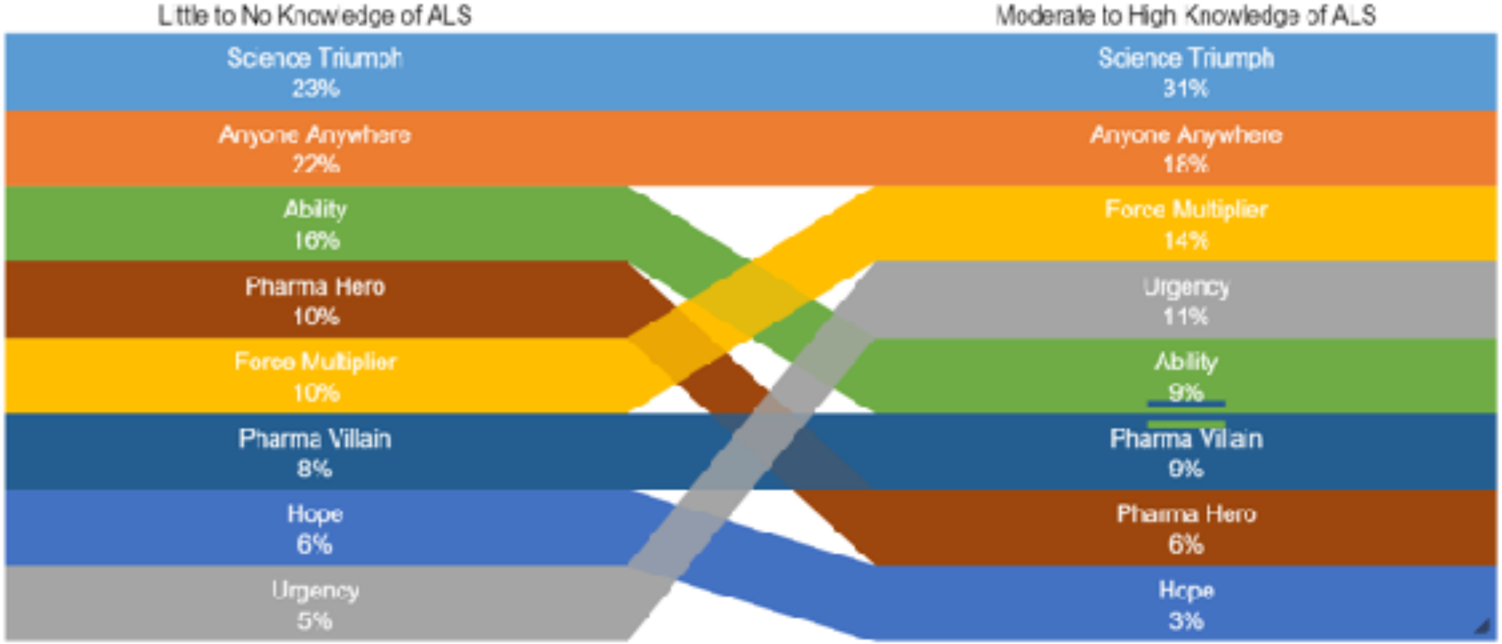
- **Media Landscape Analysis:**
    - Media coverage of ALS is primarily driven by celebrity diagnoses and deaths.
    - Stories focused on technology, affected populations, and scientist profiles are effective at generating interest.
    - Pete Frates and Steve Gleason rank as the most effective advocates at earning news and social coverage.
- **Legacy of the Ice Bucket Challenge:**
    - Awareness of the Ice Bucket Challenge is high and Americans view the fundraiser favorably.
    - Learning about the Challenges increases willingness to donate, but reactions to an anniversary event are mixed.
    - Recent “challenge” campaigns have struggle to reach large audiences or focus on the disease.
    - Experts are hesitant to makes claims about the impact on research and use of funds.
- **Challenges for ALS Organizations According to Experts:**
    - Sustained large-dollar fundraising campaigns,
    - Effective government relations outreach,
    - Coordination and optimization between organizations,
    - An active patient voice in medical and research decisions.

Messaging

Science Triumph and Anyone Anywhere are the most compelling messages for all audiences

This was consistent across all levels of knowledge of ALS, political affiliation, interest in donating, and more.

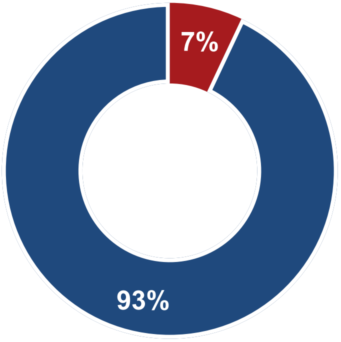
Of all the messages you read, which one made you the most interested in donating to or volunteering with an ALS non-profit or charity? *Showing % by level of prior ALS knowledge*



Emphasize themes from Force Multiplier as supporting points to encourage donations

Americans who donated to other causes in the past year indicated that Force Multiplier made them the most interested in supporting an ALS organization. They highlighted phrases such as "1 in 15 Americans alive today," movement, and "Parkinson's, Alzheimer's, and Huntington's," suggesting that the message was effective at motivating donors because it showed the broad impact of a donation to ALS research.

After reading this message, how much more or less likely are you to donate to an ALS non-profit or charity?
Showing % Among Donors to Other Causes



🟥 Somewhat or Much Less Likely

🟦 Somewhat or Much More Likely

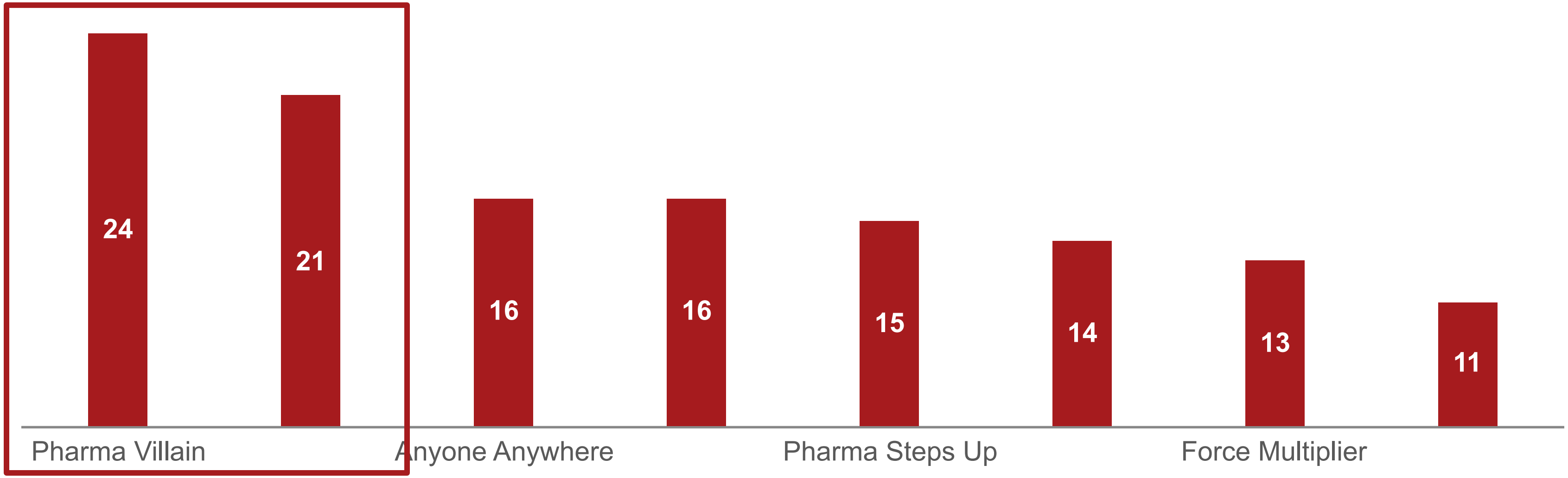
After reading this message, how much more or less likely are you to donate to an ALS non-profit or charity?
Showing % of Donors to Much More Likely

All Messages	% of Donors Much More Likely
Force Multiplier	**49%**
Ability	47%
Urgency	45%
Science Triumph	44%
Anyone Anywhere	43%

Provide optimistic statements rather than those focused on criticisms or fatalities

Messages such as Urgency (which highlights the 3-5 year lifespan of ALS patients and diagnoses every 75 minutes) and Pharma Villain (which says that drug companies "have not stepped up" and are putting "people over profits") made nearly one quarter of Americans less hopeful about finding a cure for ALS.

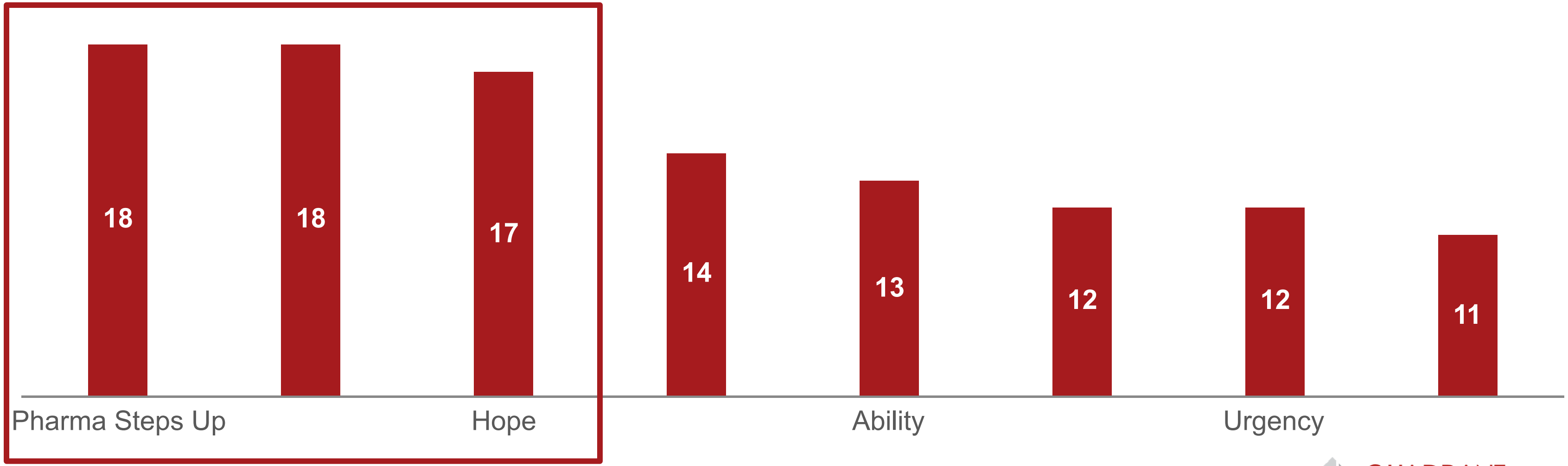
After reading this message, how much more or less hope do you have that scientists and researchers can find a cure for ALS within the next few years? *Showing % somewhat less hopeful or much less hopeful*



Avoid messages that suggest audience involvement is not necessary to make progress

Messages such as Pharma Steps Up and Hope, which feature references to "pharmaceutical companies… making a big push" and "a new movement… that will lead to breakthroughs," made nearly one-fifth of Americans less interested in donating to an ALS charity as they imply that important research and advocacy efforts will take place regardless of public contributions.

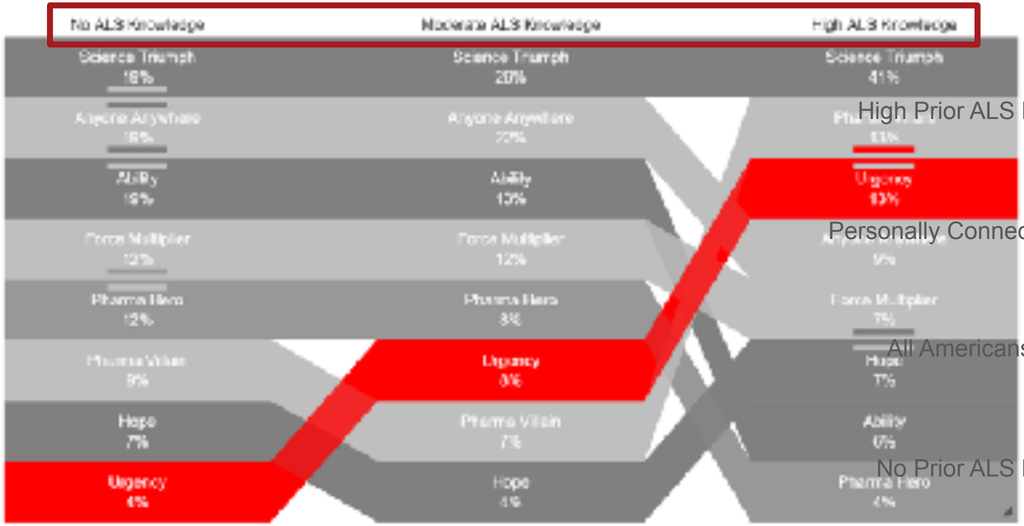
After reading this message, how much more or less likely are you to donate to an ALS non-profit or charity?
Showing % somewhat less likely or much less likely



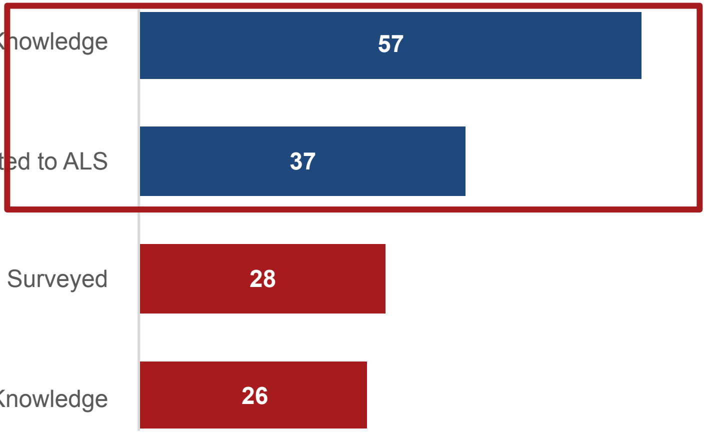
Use ‘Urgency’ with the ALS Community

The more Americans know about ALS the more they value messages such as Urgency that stress the immediate need to invest in ALS research and emphasize the short lifespan of patients. While these messages perform poorly with audiences who know little about ALS, they ranked as the second most effective message among Americans with a high amount of prior knowledge about (or a personal connection to) the disease.

Of all the messages you read, which one made you the most interested in donating to or volunteering with an ALS non-profit or charity? *Showing %*



After reading this message, how much more or less hope do you have that scientists and researchers can find a cure for ALS within the next few years? *Showing % much more hopeful*



QUADRANT STRATEGIES

Provide clarity on who is affected by ALS, such as veterans and professional athletes

Please read the following facts about ALS. After each, indicate how, if at all, each fact changes your interest in donating to an ALS non-profit or charity. *Showing % much more interested*

Facts	**% Much more interested**
More veterans have died from ALS since the start of the wars in Iraq and Afghanistan than have died in combat	**37%**
Those who serve in the military are 60 percent more likely to develop ALS at some point in their lives	**34%**
More than 90 percent of ALS patients have no family history with the disease.	33%
While ALS is diagnosed at the same rate as Multiple Sclerosis, ALS progresses far faster and receives less than half the funding for research compared to Multiple Sclerosis.	32%
More than 500,000 people living today will die from ALS	31%
On average, it costs more than $2 billion to bring a new drug to market and the largest ALS fundraiser to date raised just $220 million	29%
1 in 400 men and 1 in 600 women alive today will be diagnosed with ALS	29%
ALS affects 30,000 Americans every year	27%

When describing the prevalence of ALS, use the "500,000 people living today" statistic

Among the three prevalence statistics we tested, "more than 500,000 people living today will die from ALS" generated the most interest in donating to an ALS non-profit, especially among those with little or no prior knowledge of the disease. DC Insiders we interviewed also stressed the importance of using large statistics such as those featured in the Force Multiplier message about millions of lives.

Please read the following facts about ALS. After each, indicate how, if at all, each fact changes your interest in donating to an ALS non-profit or charity.
Showing % somewhat or much more interested among respondents with no prior knowledge of ALS

Facts	% more interested
More than 500,000 people living today will die from ALS	83%
1 in 400 men and 1 in 600 women alive today will be diagnosed with ALS	77%
ALS affects 30,000 Americans every year	74%

THANK YOU

Q21_4. Select the words or phrases that you found most compelling in this statement.

Total sample; Unweighted; base n = 500