



I AM ALS

2021 Tracking Research

October 2021

Methodology

In this survey, **we interviewed 1,000 respondents in the US from October 7th through October 15th.** This survey was of the general population and we used demographic quotas to ensure a sample that is representative of the population, using census data.

There were four major sections of the survey:

1. **Awareness of ALS and other life-threatening diseases**
2. **Knowledge of ALS**
3. **Donation propensity for organizations working to cure ALS and other life-threatening diseases**
4. **COVID-19 and its impact on how people view and consider donating to life-threatening diseases**

Key Findings

- **As in 2018, about a third of people are at least somewhat aware of ALS**
- **67% of respondents know that there is currently no cure for ALS**
- **Just 6% respondents could name an organization working on a cure for ALS**
- **While the majority of donations to ALS remain one-time donations, the number of people making occasional (repeat) donations has increased over 40% from 2018**
 - “Knowing someone personally affected by the disease” and “knowing how devastating the disease is” are the two most effective ways to increase the odds of someone donating to an organization
- **More good news: the fundraising environment is ripe in the wake of the COVID-19 pandemic**
 - People are more likely to donate to life-threatening diseases after seeing the effectiveness of the medical response to the COVID-19 pandemic



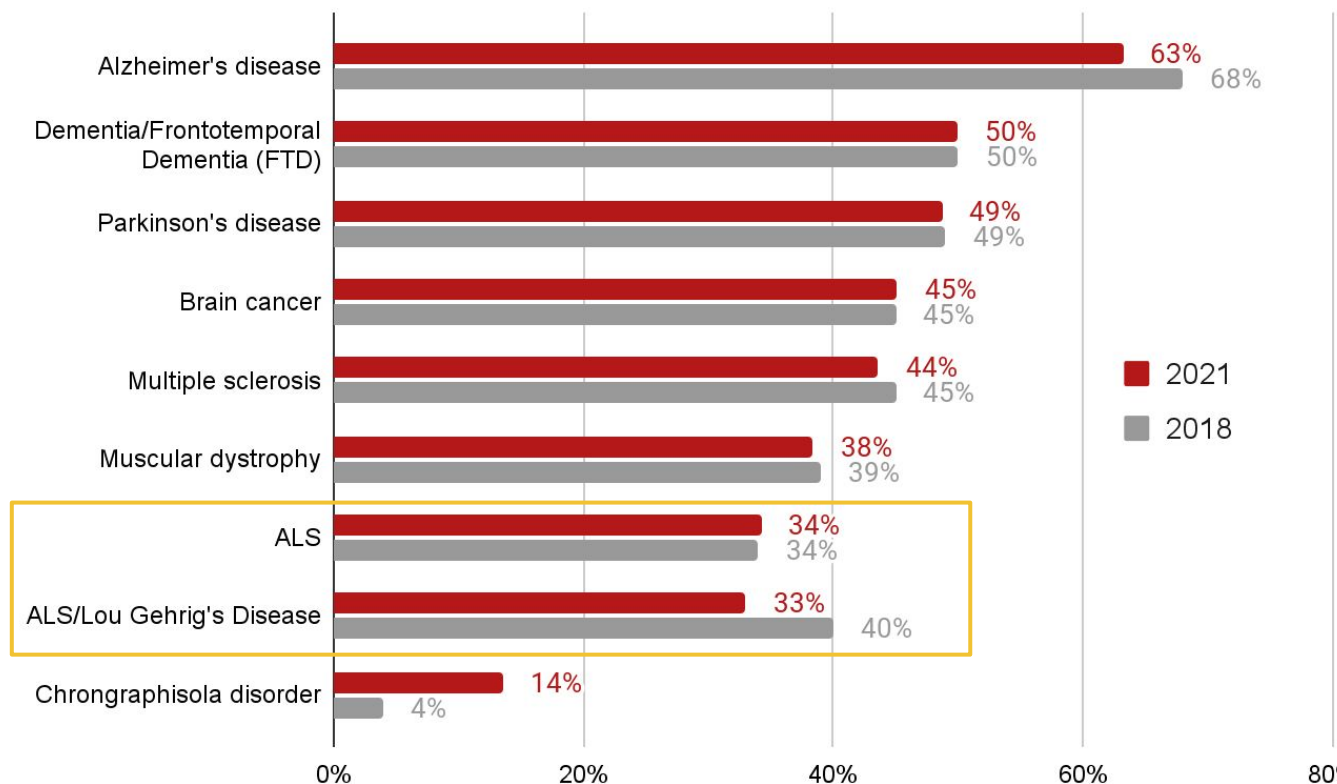
Awareness

As in 2018, about a third of people are at least somewhat aware of ALS

Awareness has remained roughly constant despite a 15 point decrease in awareness of purpose of the Ice Bucket Challenge (see slide 6).

This suggests that awareness of ALS goes beyond this social media fundraiser.

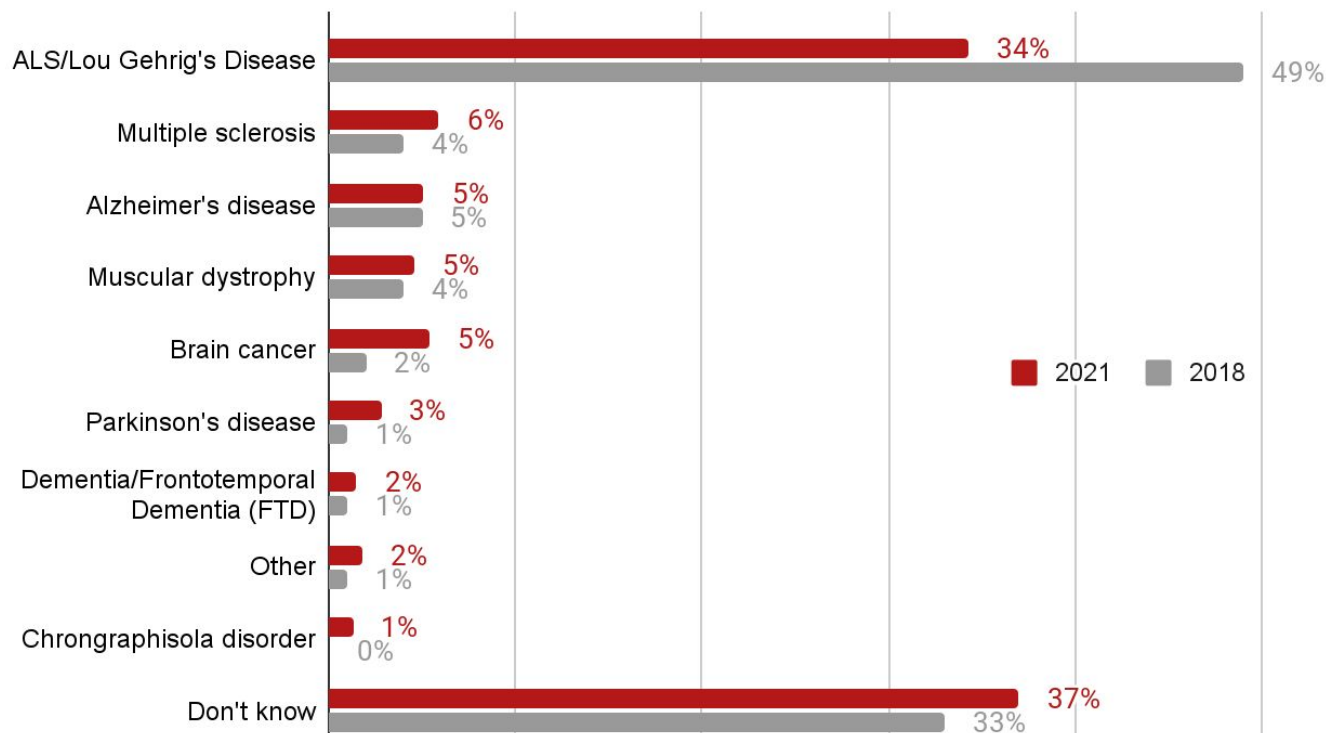
Awareness: "I know a great deal" + "I know something"



Unsurprisingly, the number of respondents who know the Ice Bucket Challenge was for ALS has dropped 15 points since 2018

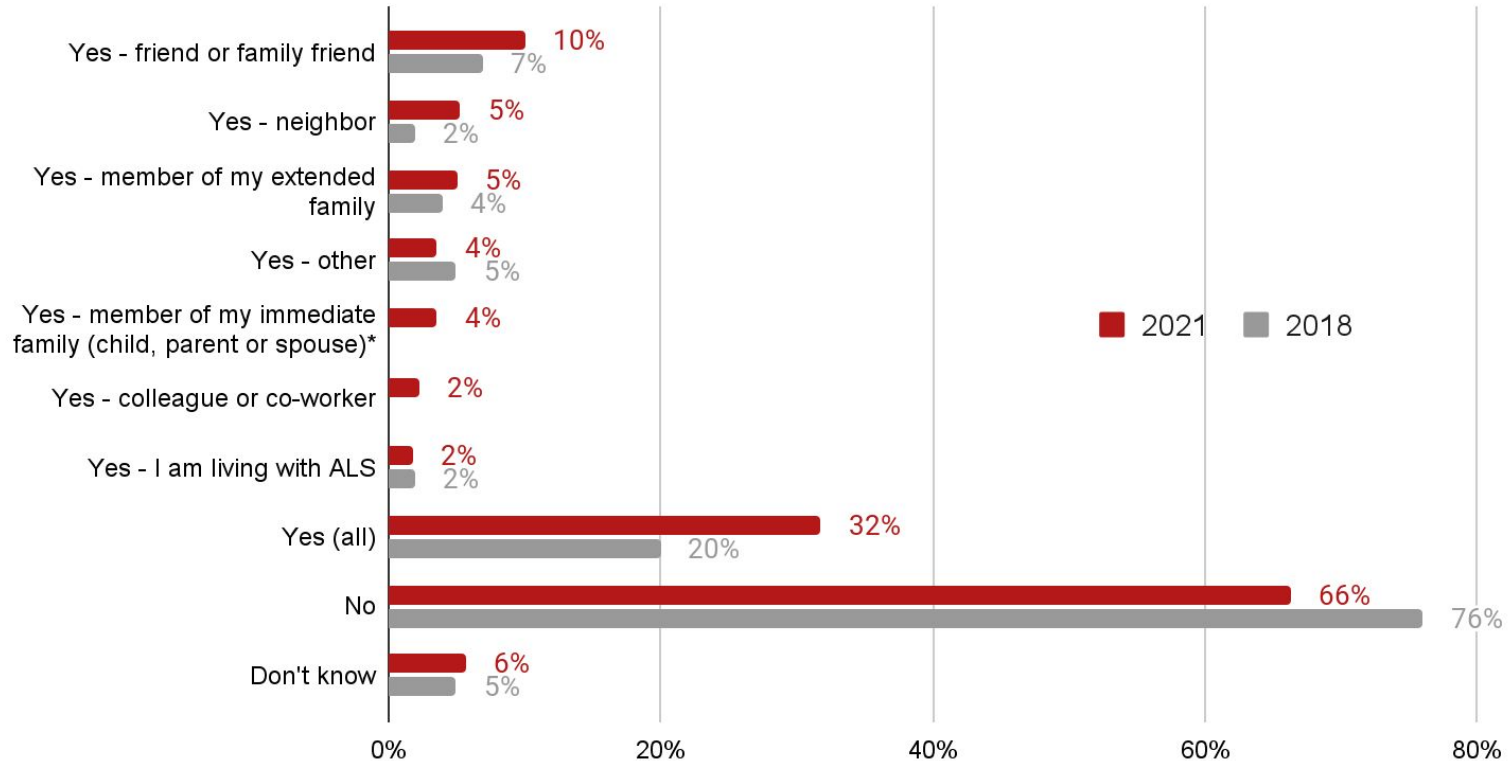
Awareness of the purpose of the Ice Bucket Challenge has **dropped from 49% in 2018 to 34% in 2021.**

The Ice Bucket Challenge was to benefit which of the following?



Almost a third of respondents know someone living with ALS, up 12 points since 2018

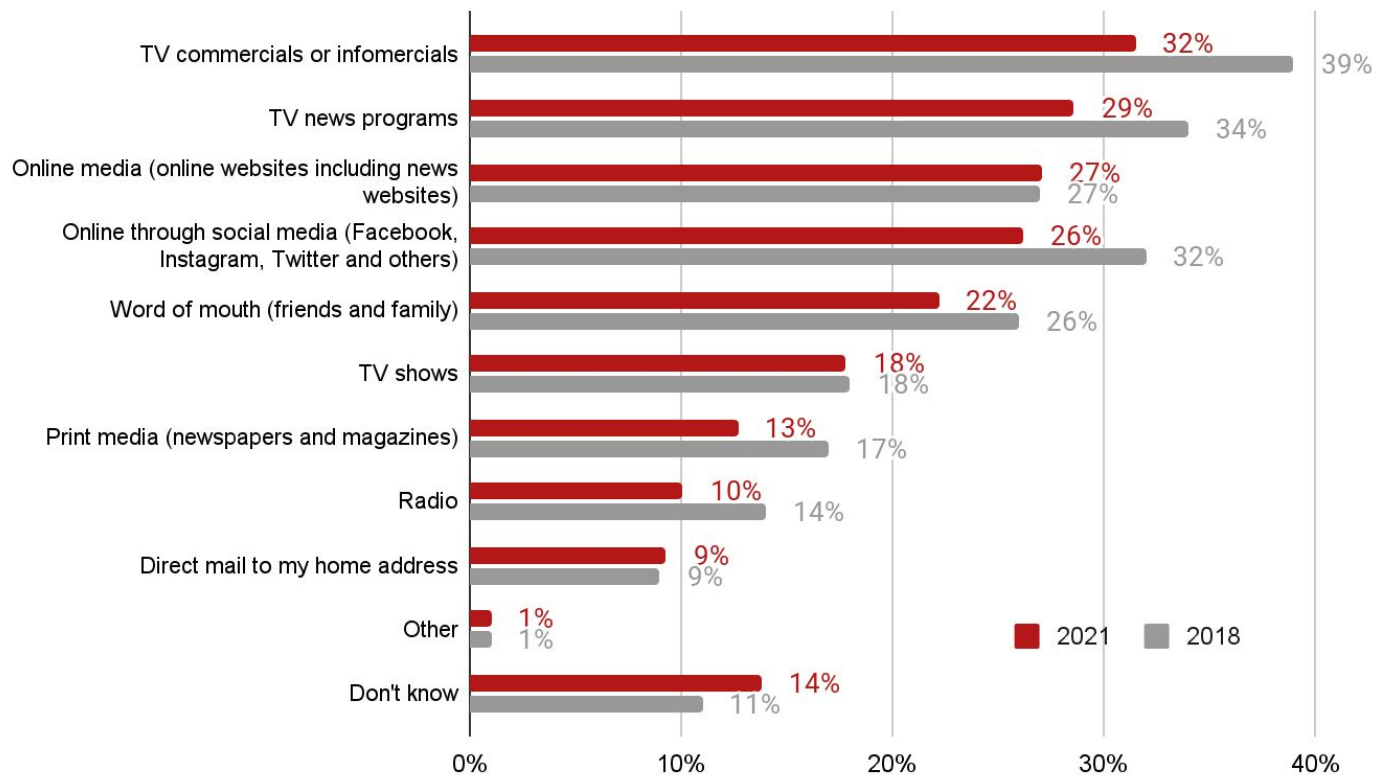
Do you personally know anyone who has been diagnosed with ALS?



TV commercials, TV news programs, online and social media are the most effective channels for spreading awareness about efforts to cure diseases

People rarely learn about efforts to cure diseases through more traditional media, like direct mail, radio, newspapers, or magazines.

Where do you most often hear about efforts to cure diseases?



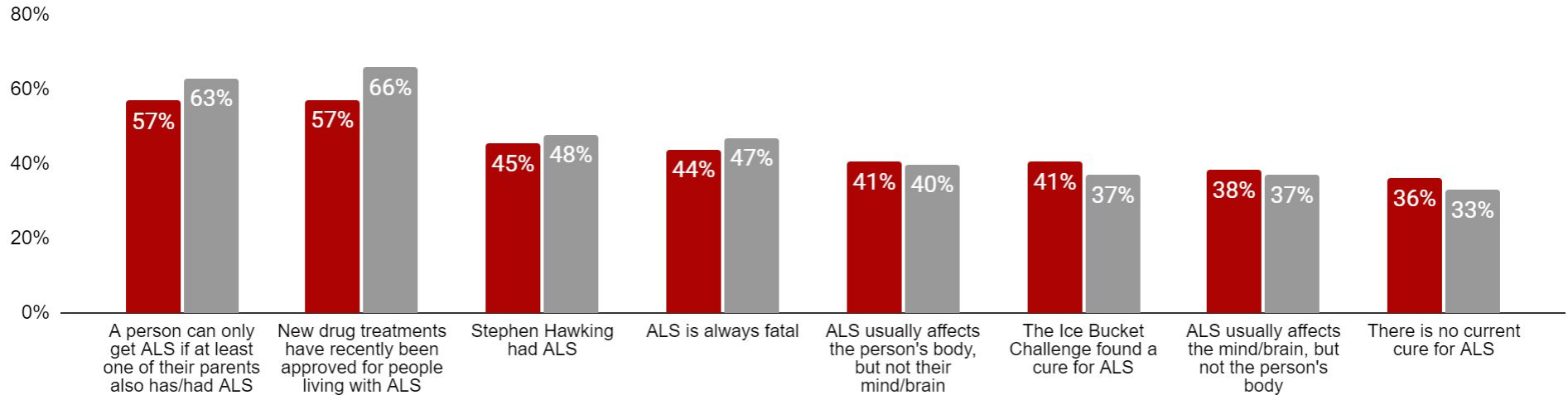


Knowledge

Uncertainty about the specifics of ALS has remained relatively steady since 2018

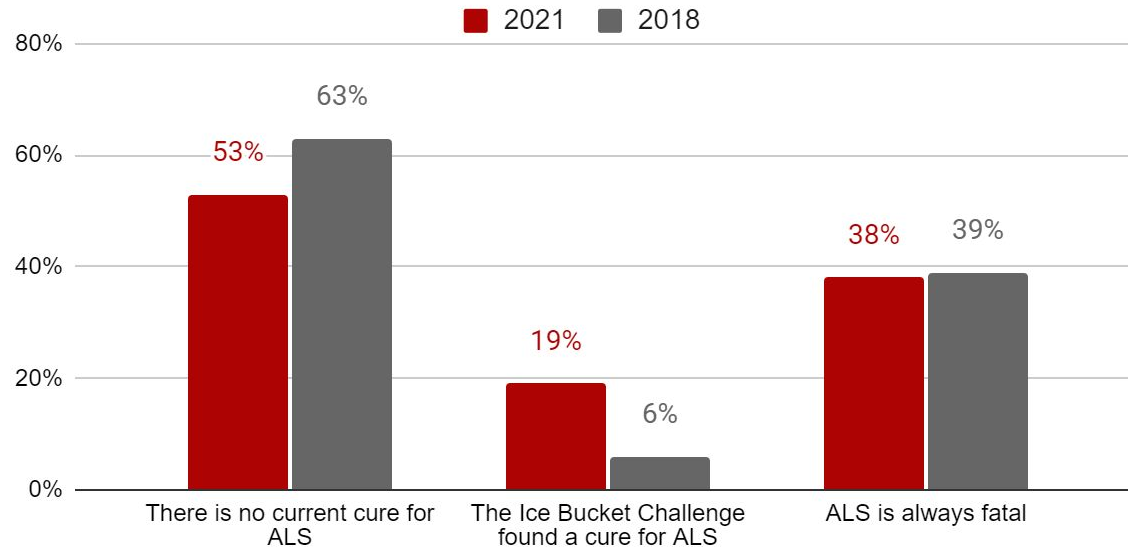
Are the below statements regarding ALS true or false? Showing % Don't know

■ 2021 ■ 2018



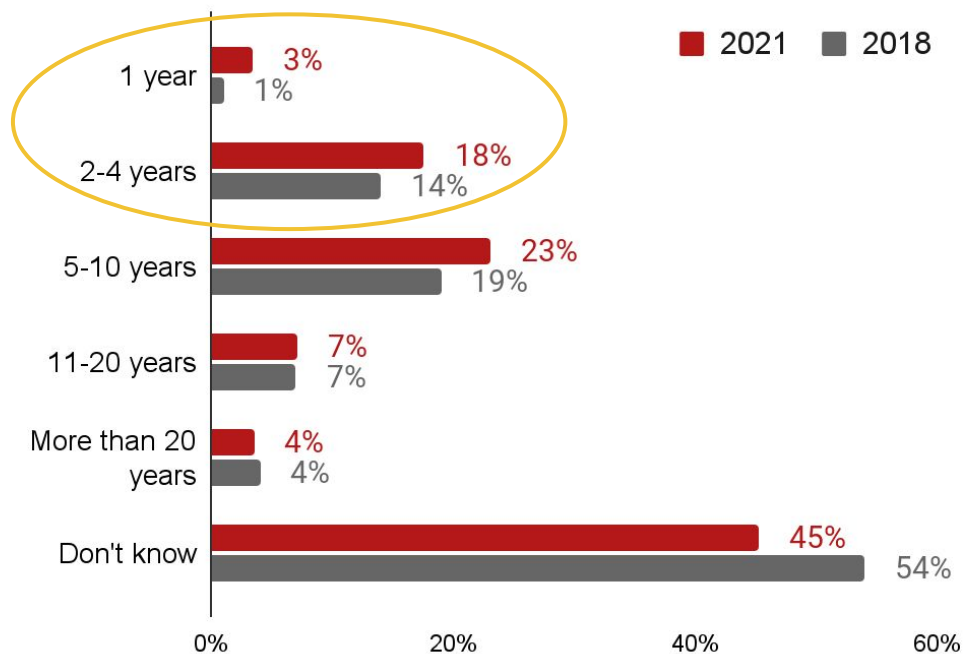
The number of people who correctly know there's no cure for ALS has decreased, while the number of people who incorrectly think that the Ice Bucket Challenge found a cure for ALS increased

To the best of your knowledge, are the below statements regarding ALS true or false? Showing % True



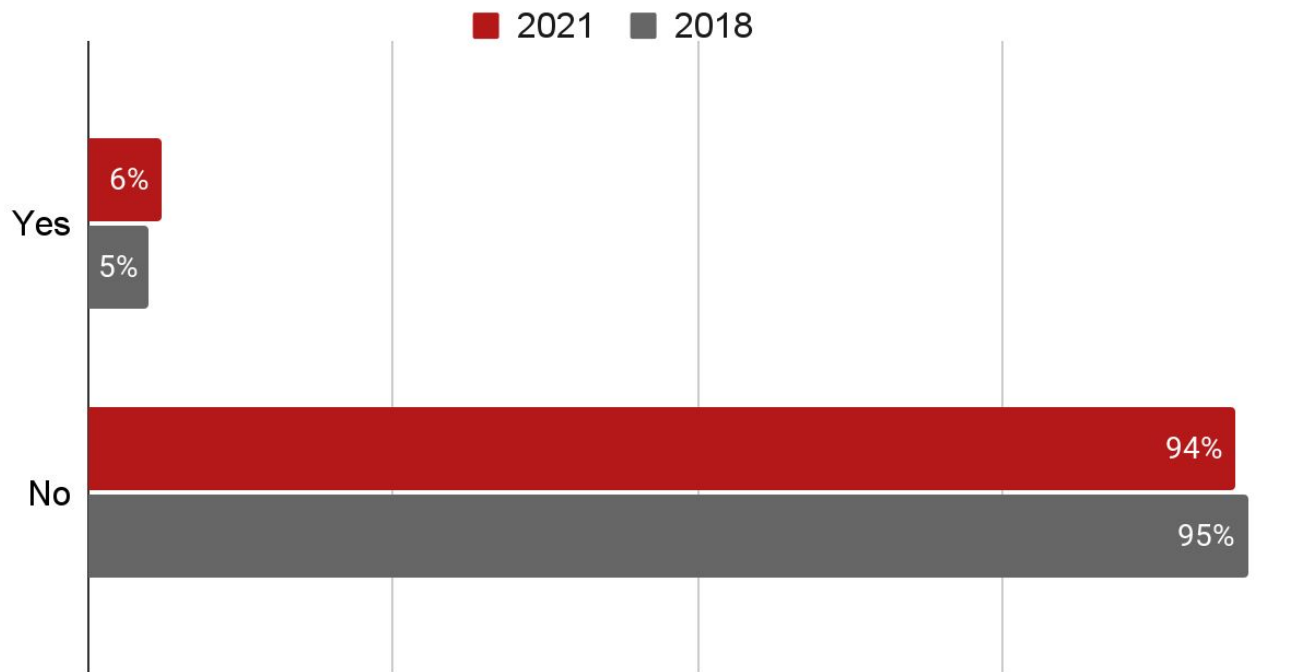
While knowledge of the severity of ALS has increased by 6 points, it is still relatively low

Approximately how long do most people diagnosed with ALS live after being diagnosed?



The number of people who know of any organizations working to find a cure for ALS remains very low, at 6%

Do you know of any organizations working to find a cure for ALS?

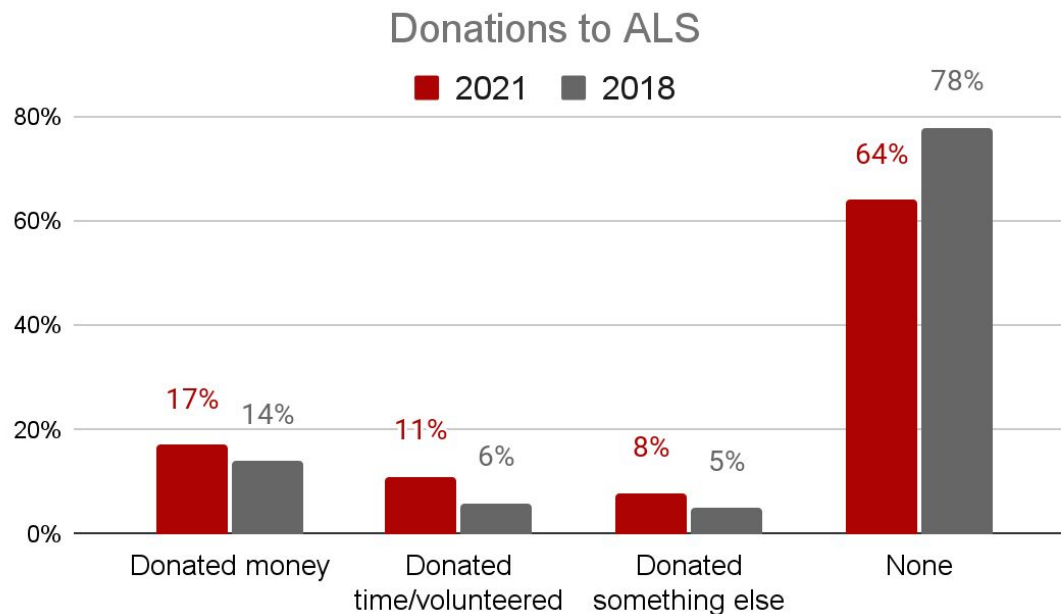




Donations

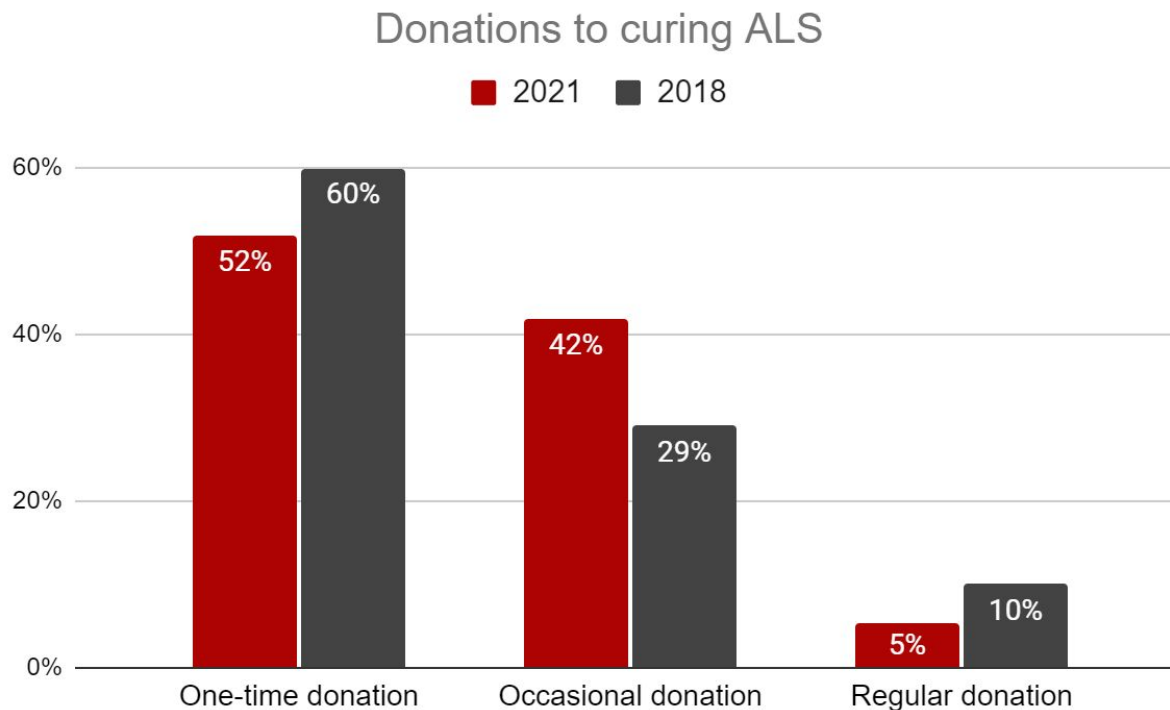
Over a third of respondents have donated to finding a cure for ALS in some capacity, up 11 points since 2018

- Monetary donations to finding a cure for ALS are the most common
- Across diseases, rates of donations have gone up over the past 3 years



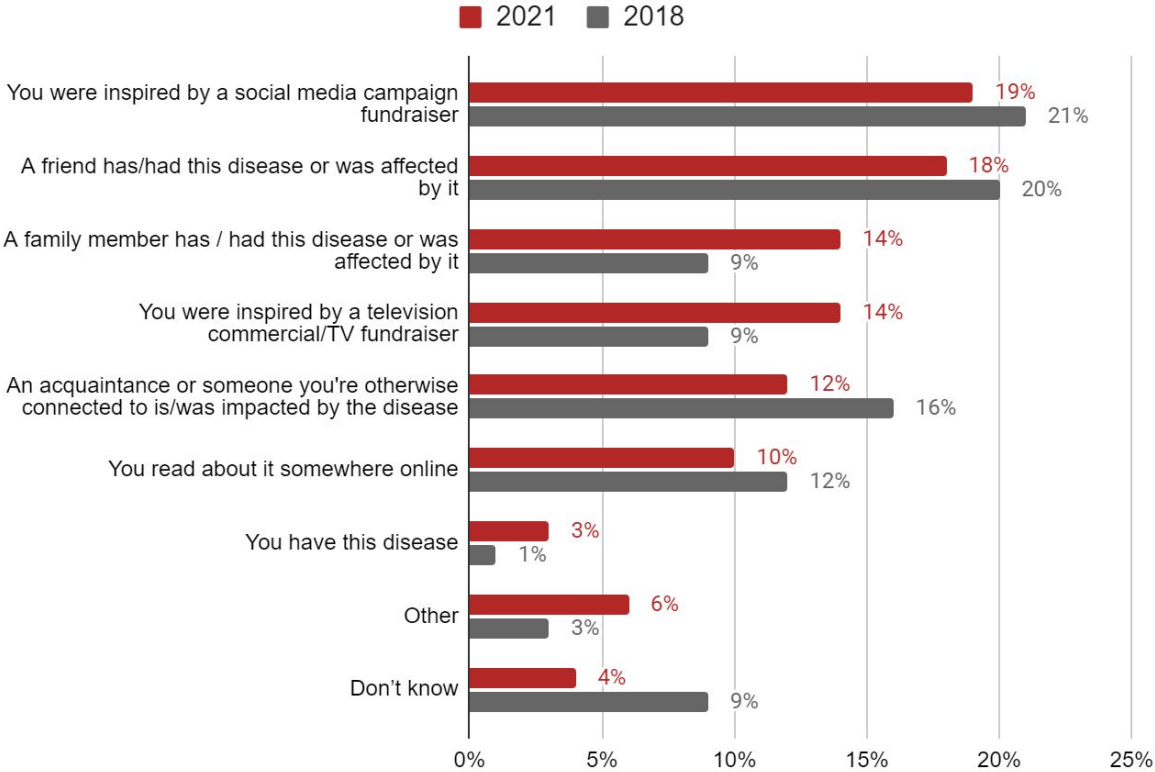
Occasional donations among those who donate to ALS have increased 13 points since 2018, to 42%

- The majority of monetary donations remain one-time donations, but the trend since 2018 is towards more sustained contributions



The two main reasons for donating to finding a cure for ALS are a connection to someone who has it, or inspiration from a social media campaign

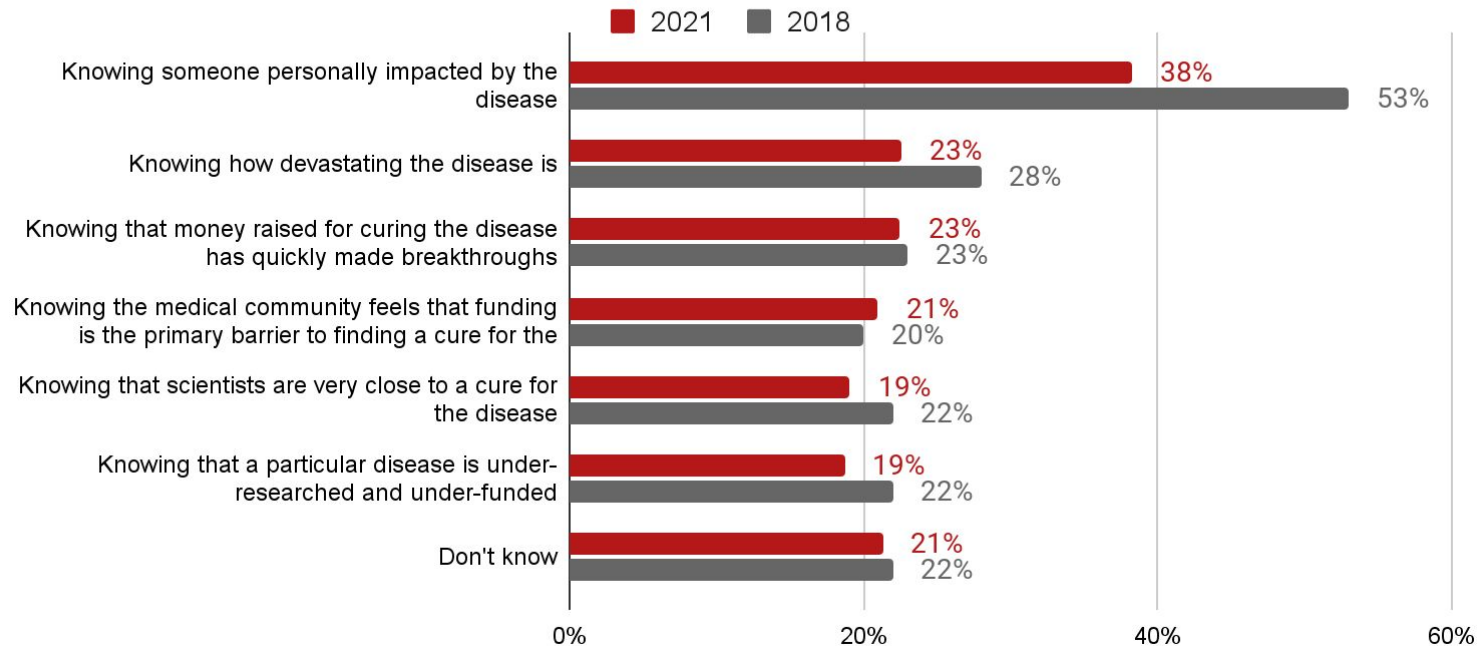
You indicated previously that you gave to a campaign to find a cure for ALS. Which reason best captures why?



Knowing someone personally impacted by a disease makes most people more likely to donate to finding its cure

- Beyond knowing someone impacted by the disease, the other causes have roughly even impact

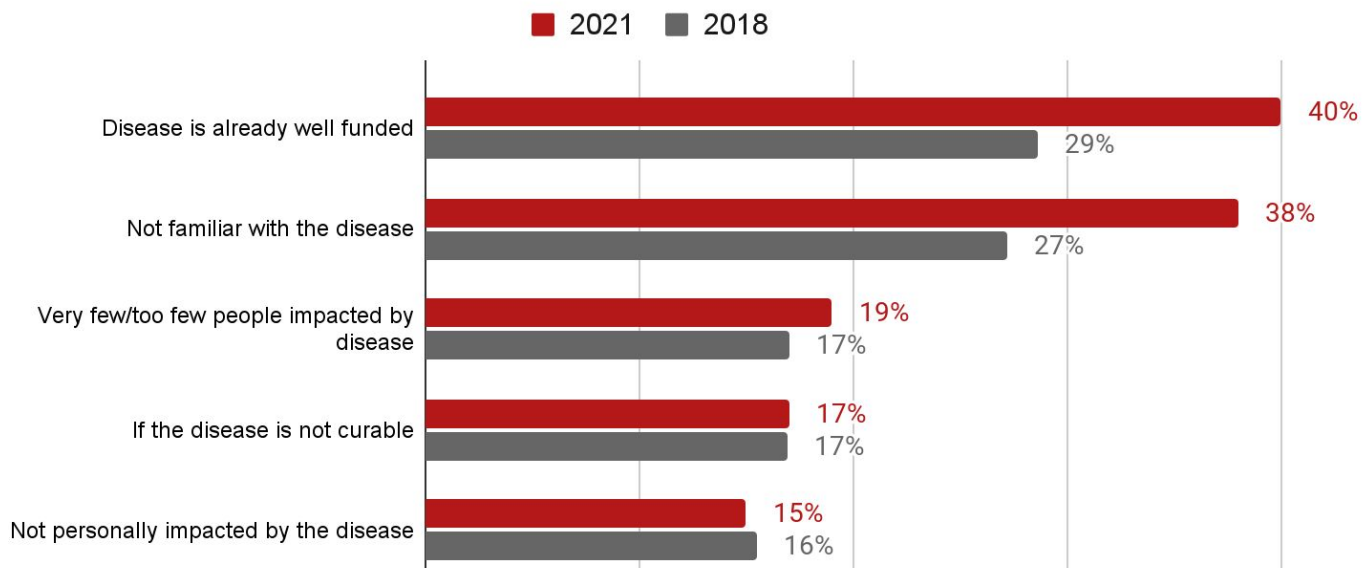
What would make you MOST likely to donate to an organization working to find a cure for a specific disease?



People are hesitant to donate to diseases that are perceived as already well funded or that they do not recognize

- While funding needs are not the most persuasive reason TO donate, they are a persuasive reason NOT to donate. And given the overall lack of knowledge the poll demonstrates people have about ALS, it is important that potential donors know ALS needs more funding.

What would make you LESS likely to donate to an organization working to find a cure for a specific disease?

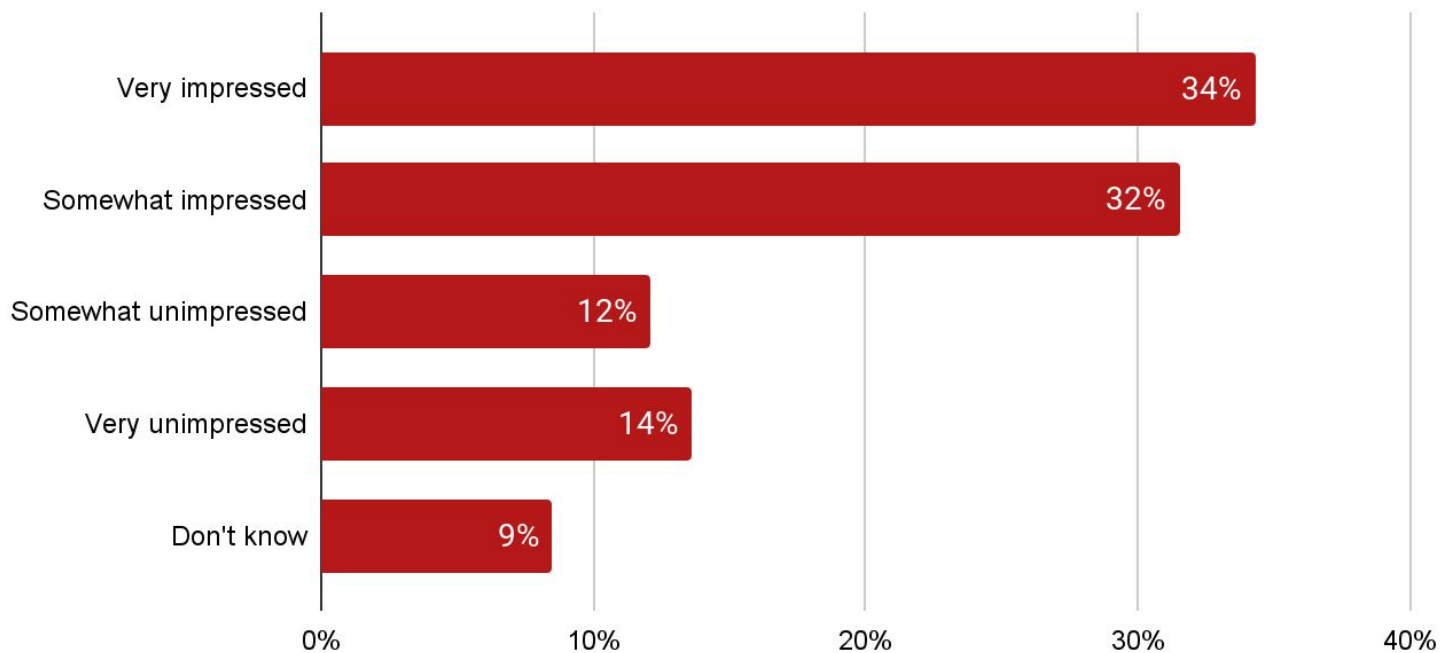




Impact of COVID

Two-thirds of respondents have been impressed by the vaccines and treatments for COVID-19

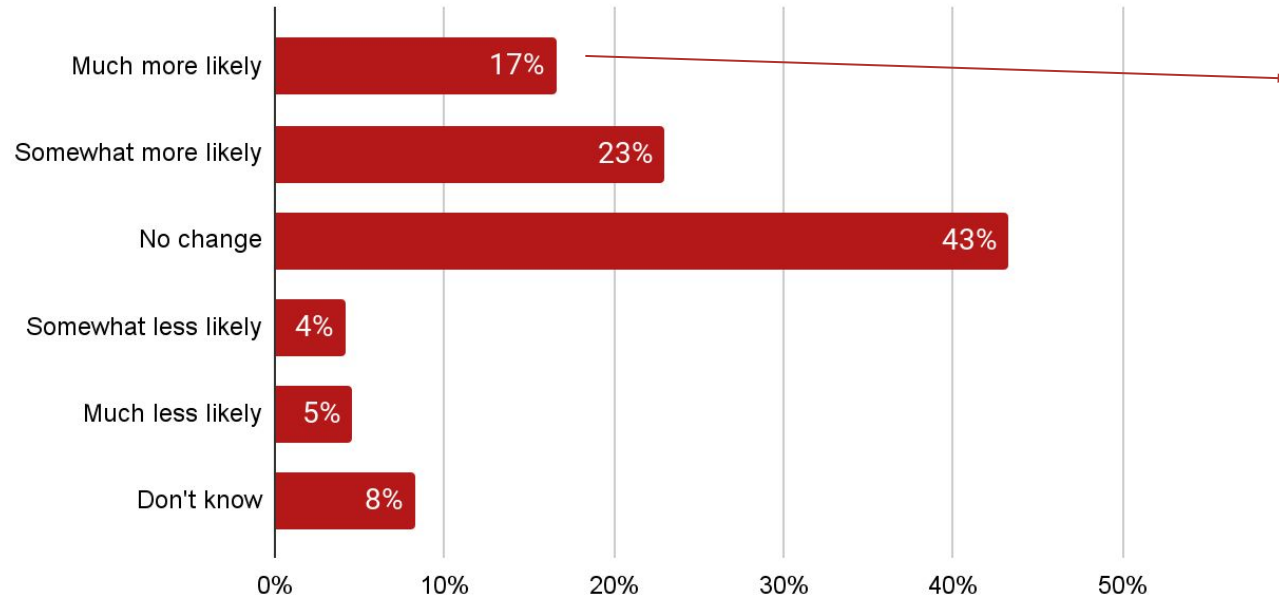
How impressed or unimpressed have you been by the development of vaccines and treatments for COVID-19?



And the pandemic has made 17% of respondents much more likely to donate to organizations working to find a cure for diseases

- Those who are much more likely to donate skew young, non-white, college-educated, employed, and Democratic.

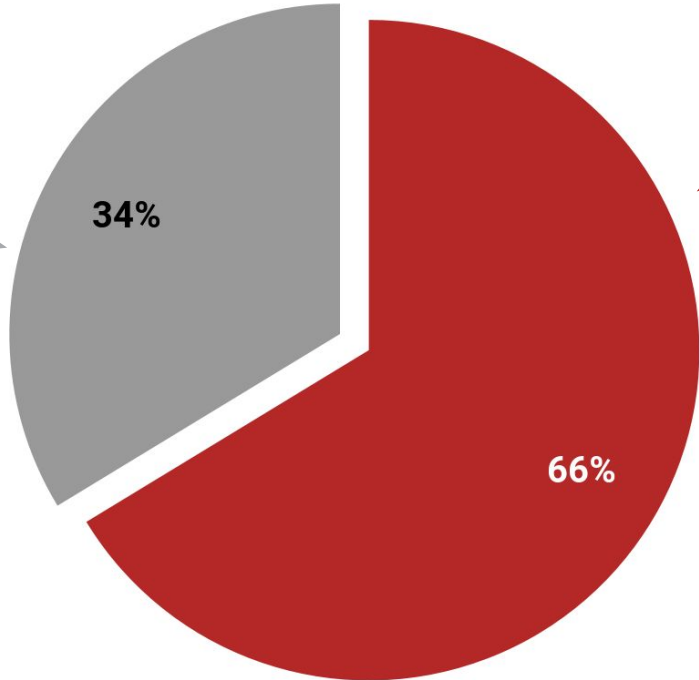
Has the COVID-19 pandemic made you more or less likely to donate to organizations working to find a cure for life threatening diseases?



	Much more likely to donate (17%)	Overall GP %
Under 45	66	57
45+	34	43
White	64	75
Non-white	37	25
Less than college	58	66
College or higher	42	34
Employed full-time	61	42
Democrat	55	42
Independent	17	22
Republican	27	33

Two-thirds of respondents say that the speed of COVID-19 vaccine development makes them more likely to fund research on other life threatening diseases

Seeing the devastating impact of the COVID-19 pandemic makes me wish we'd focus our resources more on developing vaccines and remedies for the next pandemic, instead of using resources to cure rare diseases that impact only a fraction of the population.



Seeing how quickly we were able to develop the COVID-19 vaccines when so many resources were focused on finding a solution has made me realize how important it is to further fund research on diseases like ALS.

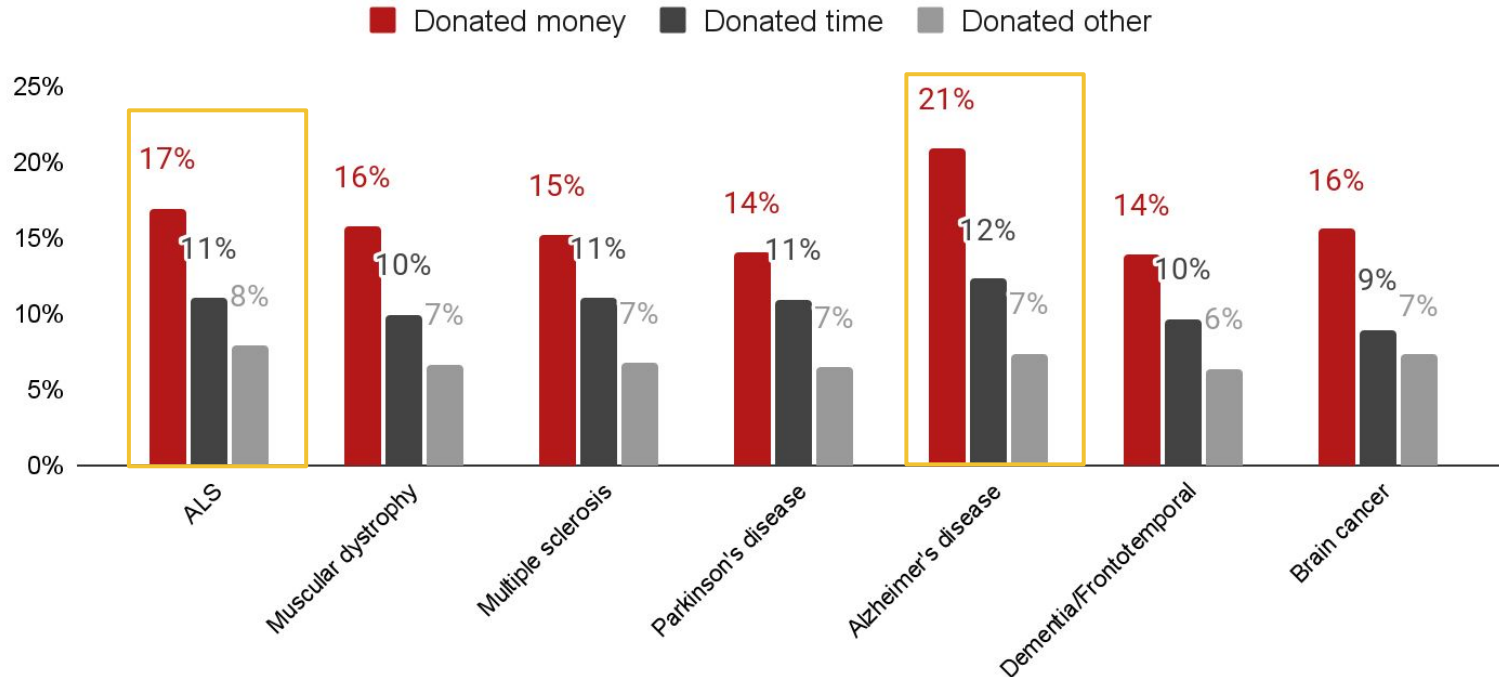


Appendix

Over a third of respondents have donated to finding a cure for ALS in some capacity, up 11% since 2018

- Across diseases, rates of donations for finding a cure have gone up over the past 3 years
- Alzheimer's has received the most monetary donations, followed by ALS

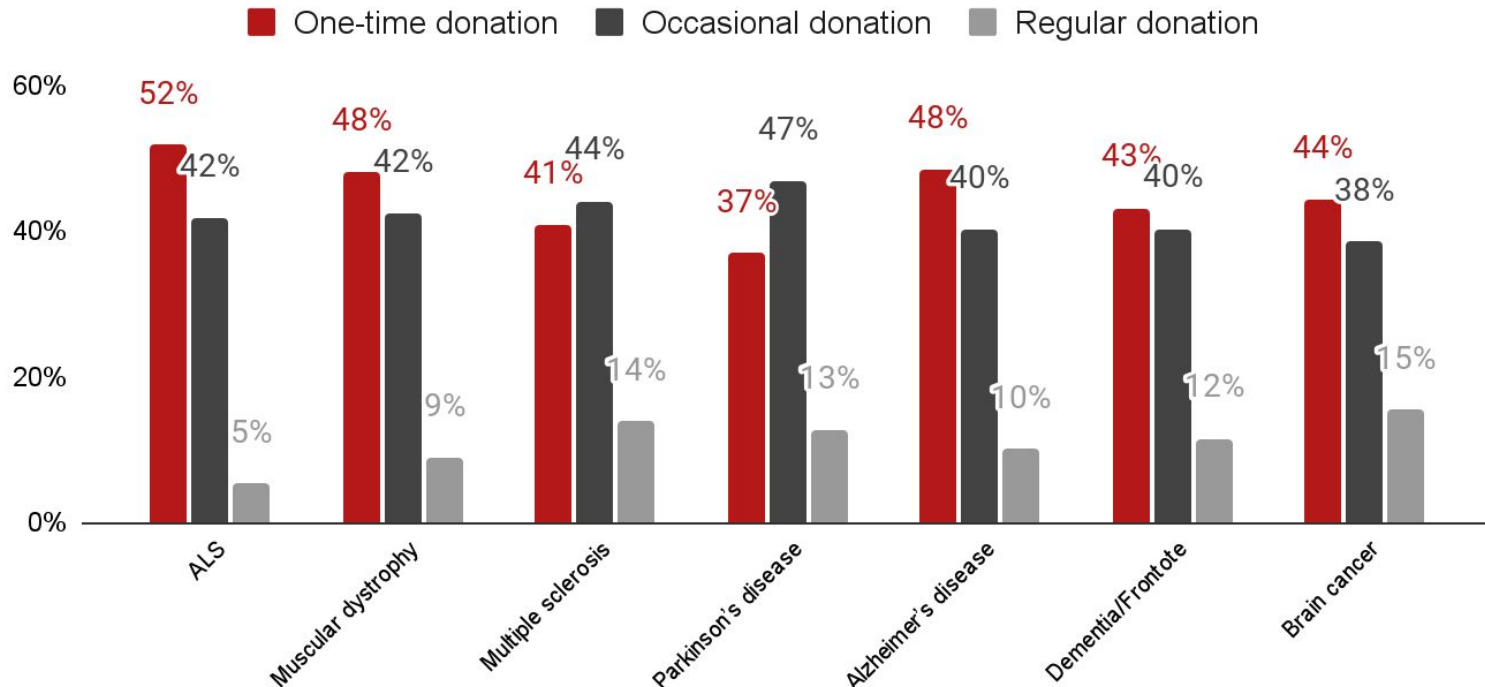
Which, if any, of the following diseases have you contributed time or money to finding a cure for?



Among those who donate to ALS, the majority of monetary donations are one-time donations

- However, occasional donations among those who donate to ALS have **increased 13% since 2018, to 42%**

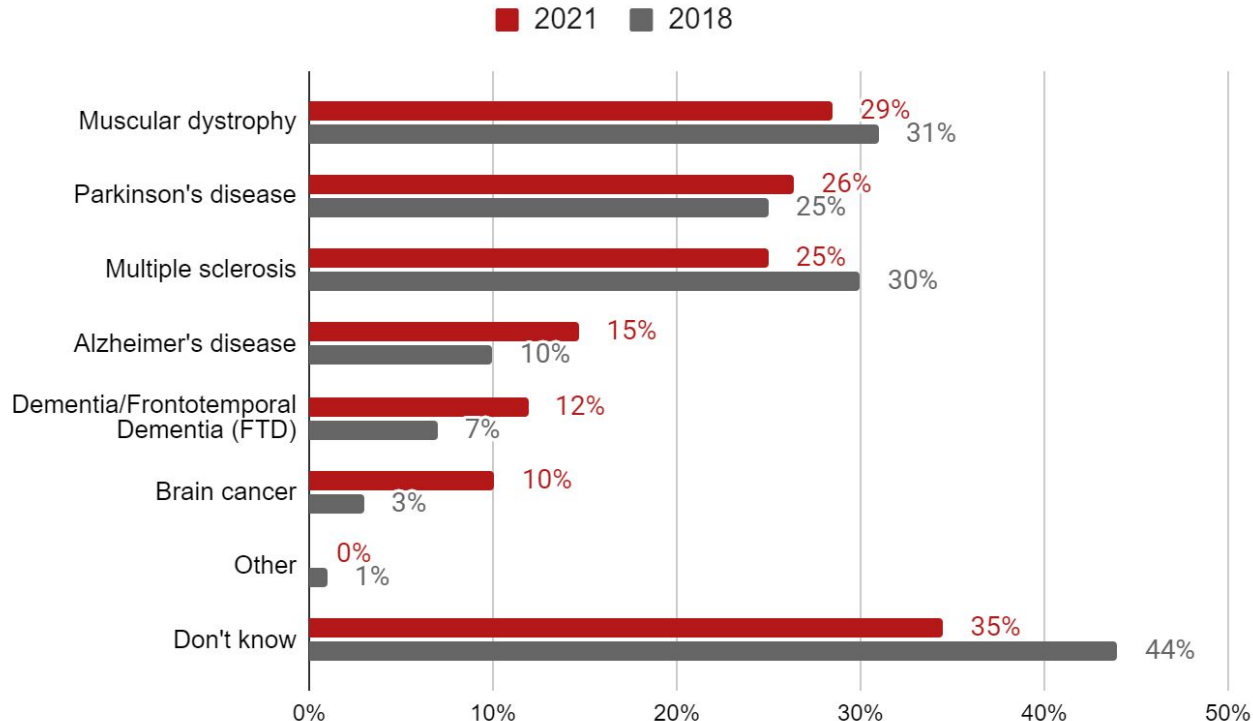
Was your contribution a one-time donation?



Muscular dystrophy and Parkinson's were most commonly selected as being closely related to ALS

- Respondents feel slightly less unsure about this than in 2018

Which of the following diseases are closely related to ALS?



The most common reason overall for donation to a disease is a family member being affected by it

You indicated previously that you gave to a campaign to find a cure for X disease. Which reason best captures why?

	ALS	Muscular dystrophy	Multiple sclerosis	Parkinson's disease	Alzheimer's disease	Dementia/ Frontotemporal Dementia (FTD)	Brain cancer
A family member has / had this disease or was affected by it	14%	15%	16%	17%	32%	25%	18%
An acquaintance or someone you're otherwise connected to is/was impacted by the disease	12%	15%	14%	16%	14%	10%	11%
A friend has/had this disease or was affected by it	18%	16%	18%	12%	12%	14%	14%
You read about it somewhere online	10%	14%	13%	14%	11%	11%	13%
You were inspired by a television commercial/TV fundraiser	14%	17%	15%	12%	11%	13%	15%
You were inspired by a social media campaign fundraiser	19%	11%	11%	15%	11%	16%	14%
You have this disease	3%	3%	2%	3%	2%	3%	1%
Other	6%	5%	6%	6%	3%	4%	8%
Don't know	4%	5%	5%	5%	4%	4%	6%