



Press Release

ALS Survey

Awareness, Knowledge, Fundraising

Chicago, IL, January 23, 2019 – In June 2018 Ipsos undertook a survey of 1,005 American adults on behalf of I AM ALS, a patient-led movement to push for a cure for ALS launched in January 2019. The survey was undertaken pre-launch to assess awareness of and knowledge about the disease (and other related diseases), and to explore public awareness of and engagement with organizations and foundations fighting ALS and a range of other related diseases.

The study found that ALS awareness and knowledge is much lower than many similar diseases with comparable incidence and/or mortality rates, and that there is similarly little knowledge about organizations or efforts who are fundraising and fighting this disease.

Just 39% of Americans know that ALS is always fatal. Just over half did not know that the Ice Bucket Challenge (a fundraising campaign that went viral in 2014) was raising money for ALS. And just 5% can name an organization or foundation working to fight ALS.

These are the findings from an Ipsos study conducted June 4 - 5, 2018. For the survey, a sample of 1,005 adults ages 18 and over from the continental U.S., Alaska and Hawaii was interviewed online, in English. The precision of Ipsos online polls is measured using a credibility interval. In this case, the poll has a credibility interval of ±3.5 percentage points for all respondents surveyed.

1. How much, if anything, do you know about each of the following diseases? If you have not heard of a disease, just say so.

% Know a great deal/Know some	All Respondents
	(n=1,005)
Alzheimer's	68%
Dementia / Frontotemporal Dementia (FTD)	50%
Parkinson's	49%
Brain cancer	45%
Multiple Sclerosis	45%
ALS/Lou Gehrig's Disease [SPLIT SAMPLE WITH "ALS"]	40%
Muscular dystrophy	39%
ALS [SPLIT SAMPLE WITH "ALS/Lou Gehrig's Disease"]	34%
Chrographisola disorder*	4%

**Made-up disease to assess baseline overstatement on awareness*

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2. To the best of your knowledge, which of the following was the Ice Bucket Challenge raising money for?

	All Respondents (n=1,005)
ALS	49%
Alzheimer's	5%
Multiple Sclerosis	4%
Muscular dystrophy	4%
Brain cancer	2%
Parkinson's	1%
Dementia / Frontotemporal Dementia (FTD)	1%
Chrographisola disorder	*
Other	1%
Don't know	33%

3. Do you personally know anyone who has been diagnosed with ALS (Amyotrophic Lateral Sclerosis, also referred to as Lou Gehrig's Disease)?

	All Respondents (n=1,005)
Yes - member of my immediate family (child, parent, or spouse)	2%
Yes - member of my extended family	4%
Yes - friend or family friend	7%
Yes - neighbor	2%
Yes - colleague or co-worker	2%
Yes - other	5%
No	76%
Don't know	5%

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4. To the best of your knowledge, are the below statements regarding ALS (Amyotrophic Lateral Sclerosis) true or false?

Please choose “true”, “false”, or “don’t know” for each statement below:

A person can only get ALS if at least one of their parents also has/had ALS

	All Respondents
	(n=1,005)
True	7%
False	30%
Don't know	63%

Stephen Hawking had ALS

	All Respondents
	(n=1,005)
True	43%
False	10%
Don't know	48%

ALS usually affects the mind/brain, but not the person’s body

	All Respondents
	(n=1,005)
True	10%
False	54%
Don't know	37%



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ALS usually affects the person's body, but not their mind/brain

	All Respondents (n=1,005)
True	40%
False	20%
Don't know	40%

ALS is always fatal

	All Respondents (n=1,005)
True	39%
False	14%
Don't know	47%

The Ice Bucket Challenge found a cure for ALS

	All Respondents (n=1,005)
True	6%
False	58%
Don't know	37%

There is no current cure for ALS

	All Respondents (n=1,005)
True	63%
False	4%
Don't know	33%

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4. New drug treatments have recently been approved for ALS patients

	All Respondents (n=1,005)
True	30%
False	4%
Don't know	66%

5. To the best of your knowledge, approximately how long do most people diagnosed with ALS live after being diagnosed?

	All Respondents (n=1,005)
1 year	1%
2-4 years	14%
5-10 years	19%
11-20 years	7%
More than 20 years	4%
Don't know	54%

6. Some diseases that affect the brain and body are related, which means that scientific breakthroughs in one can help the other diseases. To the best of your knowledge, which of the following diseases are closely related to ALS? Choose all that apply.

	All Respondents (n=1,005)
Muscular dystrophy	31%
Multiple Sclerosis	30%
Parkinson's	25%
Alzheimer's	10%
Dementia / Frontotemporal Dementia (FTD)	7%
Brain cancer	3%
Other	1%
Don't know	44%

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7. Do you know of any organizations (non-profits, charities, or foundations,) who are working to find a cure for ALS?

	All Respondents (n=1,005)
Yes	5%
No	95%

8. And which, if any, of the following diseases have you contributed time or money to fighting? If you have not donated for this particular disease or cause, just say so.

Parkinson's

	All Respondents (n=1,005)
Donated money	8%
Donated time / volunteered	4%
Donated something else	5%
None	83%

Dementia / Frontotemporal Dementia (FTD)

	All Respondents (n=1,005)
Donated money	5%
Donated time / volunteered	7%
Donated something else	4%
None	85%

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ALS

	All Respondents
	(n=1,005)
Donated money	14%
Donated time / volunteered	6%
Donated something else	5%
None	78%

Brain cancer

	All Respondents
	(n=1,005)
Donated money	12%
Donated time / volunteered	6%
Donated something else	3%
None	81%

Alzheimer's

	All Respondents
	(n=1,005)
Donated money	20%
Donated time / volunteered	10%
Donated something else	4%
None	69%

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Multiple Sclerosis

	All Respondents (n=1,005)
Donated money	16%
Donated time / volunteered	6%
Donated something else	5%
None	75%

Muscular dystrophy

	All Respondents (n=1,005)
Donated money	19%
Donated time / volunteered	6%
Donated something else	3%
None	75%

9. And was your contribution a one-time donation, or have you contributed to fighting this disease more than once?

Parkinson's

	Those who Donated (n=86)
One-time donation	46%
Occasional donation	42%
Regular donation	11%
Never donated money to this disease	2%

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Dementia / Frontotemporal Dementia (FTD)

	Those who Donated (n=56)
One-time donation	56%
Occasional donation	28%
Regular donation	16%

ALS

	Those who Donated (n=134)
One-time donation	60%
Occasional donation	29%
Regular donation	10%
Never donated money to this disease	1%

Brain cancer

	Those who Donated (n=116)
One-time donation	44%
Occasional donation	40%
Regular donation	12%
Never donated money to this disease	4%

Alzheimer's

	Those who Donated (n=198)
One-time donation	47%
Occasional donation	38%
Regular donation	14%
Never donated money to this disease	1%

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Multiple Sclerosis

	Those who Donated (n=162)
One-time donation	47%
Occasional donation	45%
Regular donation	8%
Never donated money to this disease	1%

Muscular dystrophy

	Those who Donated (n=172)
One-time donation	44%
Occasional donation	44%
Regular donation	11%
Never donated money to this disease	1%

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

Parkinson's

	Contributed to Cause (n=169)
A family member has / had this disease or was affected by it	26%
An acquaintance or someone you're otherwise connected to is / was affected by the disease	17%
A friend has / had this disease or was affected by it	15%
You read about it somewhere online	11%
You were inspired by a television commercial / TV fundraiser	10%
You were inspired by a social media campaign fundraiser	6%
You have this disease	4%
Other	3%
Don't know	7%

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Dementia / Frontotemporal Dementia (FTD)

	Contributed to Cause (n=152)
A family member has / had this disease or was affected by it	47%
An acquaintance or someone you're otherwise connected to is / was affected by the disease	13%
A friend has / had this disease or was affected by it	11%
You read about it somewhere online	6%
You were inspired by a television commercial / TV fundraiser	5%
You were inspired by a social media campaign fundraiser	5%
You have this disease	2%
Other	5%
Don't know	6%

ALS

	Contributed to Cause (n=211)
You were inspired by a social media campaign fundraiser	21%
A friend has / had this disease or was affected by it	20%
An acquaintance or someone you're otherwise connected to is / was affected by the disease	16%
You read about it somewhere online	12%
A family member has / had this disease or was affected by it	9%
You were inspired by a television commercial / TV fundraiser	9%
You have this disease	1%
Other	3%
Don't know	9%

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Brain cancer

	Contributed to Cause (n=187)
A family member has / had this disease or was affected by it	23%
A friend has / had this disease or was affected by it	16%
You read about it somewhere online	16%
An acquaintance or someone you're otherwise connected to is / was affected by the disease	12%
You were inspired by a television commercial / TV fundraiser	12%
You were inspired by a social media campaign fundraiser	6%
You have this disease	3%
Other	4%
Don't know	8%

Alzheimer's

	Contributed to Cause (n=305)
A family member has / had this disease or was affected by it	44%
A friend has / had this disease or was affected by it	15%
An acquaintance or someone you're otherwise connected to is / was affected by the disease	9%
You were inspired by a social media campaign fundraiser	8%
You read about it somewhere online	5%
You were inspired by a television commercial / TV fundraiser	4%
You have this disease	1%
Other	9%
Don't know	4%

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Multiple Sclerosis

	Contributed to Cause (n=246)
A friend has / had this disease or was affected by it	26%
A family member has / had this disease or was affected by it	16%
An acquaintance or someone you're otherwise connected to is / was affected by the disease	14%
You were inspired by a television commercial / TV fundraiser	12%
You were inspired by a social media campaign fundraiser	7%
You read about it somewhere online	7%
You have this disease	3%
Other	6%
Don't know	9%

Muscular dystrophy

	Contributed to Cause (n=246)
You were inspired by a television commercial / TV fundraiser	28%
A friend has / had this disease or was affected by it	16%
An acquaintance or someone you're otherwise connected to is / was affected by the disease	12%
A family member has / had this disease or was affected by it	9%
You were inspired by a social media campaign fundraiser	8%
You read about it somewhere online	8%
You have this disease	1%
Other	9%
Don't know	9%

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11. From the list below, what do you think would make you MOST likely to donate money towards fighting a specific disease? Please choose up to three items from the list below.

	All Respondents (n=1,005)
Knowing someone personally affected by the disease	53%
Knowing how devastating the disease is	28%
Knowing that scientists are very close to a cure for the disease	22%
Knowing that a particular disease is under-researched and under-funded	22%
Knowing that money raised for fighting the disease has quickly made breakthroughs	23%
Knowing that medical community feels that funding is the primary barrier to finding a cure for the disease	20%
Don't know	22%

12. And, from the list below, what do you think would make you LESS likely to donate money towards fighting a specific disease? Please choose up to three items from the list below.

	All Respondents (n=1,005)
Disease is already well funded	40%
Not familiar with the disease	38%
Very few / too few people affected by disease	19%
If the disease is not curable	17%
Not personally affected by the disease	15%
Disease is already well funded	40%

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13. Thinking general, where do you most often hear about efforts to fight and cure diseases? Please choose those that apply from the list below.

	All Respondents (n=1,005)
TV commercials or infomercials	39%
TV news programs	34%
Online through social media (Facebook, Instagram, Twitter, and others)	32%
Online media (online websites including news websites)	27%
Word of mouth (friends and family)	26%
TV shows	18%
Print media (newspapers and magazines)	17%
Radio	14%
Direct mail to my home address	9%
Other	1%
Don't know	11%

About the Study

These are the findings from an Ipsos poll conducted June 4 - 5, 2018. For the survey, a sample of 1,005 adults ages 18 and over from the continental U.S., Alaska and Hawaii was interviewed online, in English. The precision of Ipsos online polls is measured using a credibility interval. In this case, the poll has a credibility interval of ± 3.5 percentage points for all respondents surveyed.

The sample for this study was randomly drawn from Ipsos's online partner online panel sources, and "river" and does not rely on a population frame in the traditional sense. Ipsos uses fixed sample targets, unique to each study, in drawing sample. After a sample has been obtained from the Ipsos panel, Ipsos calibrates respondent characteristics to be representative of the U.S. Population using standard procedures such as raking-ratio adjustments. The source of these population targets is U.S. Census 2016 American Community Survey data. The sample drawn for this study reflects fixed sample targets on demographics. Post-hoc weights were made to the population characteristics on gender, age, region, race/ethnicity and income.

Statistical margins of error are not applicable to online nonprobability sampling polls. All sample surveys and polls may be subject to other sources of error, including, but not limited to coverage error and measurement error. Where figures do not sum to 100, this is due to the effects of rounding. Ipsos calculates a design effect (DEFF) for each study based on the variation of the weights, following the formula of Kish (1965). This study had a credibility interval adjusted for design effect of the following (n=1,005, DEFF=1.5, adjusted Confidence Interval=5.0).

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About 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. Today, ALS is always fatal and patients typically live for 3 to 5 years after diagnosis. I AM ALS is working to push for a cure. Learn more and support at <http://www.iamals.org>.

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About Ipsos

Ipsos is an independent market research company controlled and managed by research professionals. Founded in France in 1975, Ipsos has grown into a worldwide research group with a strong presence in all key markets. Ipsos ranks fourth in the global research industry.

With offices in 89 countries, Ipsos delivers insightful expertise across five research specializations: brand, advertising and media; customer loyalty; marketing; public affairs research; and survey management.

Ipsos researchers assess market potential and interpret market trends. They develop and build brands. They help clients build long-term relationships with their customers. They test advertising and study audience responses to various media and they measure public opinion around the globe.

GAME CHANGERS

« Game Changers » is the Ipsos signature.

At Ipsos we are passionately curious about people, markets, brands and society.
We make our changing world easier and faster to navigate and inspire clients to make smarter decisions.
We deliver with security, speed, simplicity and substance. We are Game Changers.

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