



Executive Summary

Lupus Awareness Survey

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GfK Roper Public Affairs & Corporate Communications

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A recent survey of American adults conducted for the Lupus Foundation of America by GfK Roper Public Affairs & Corporate Communications finds that:

- **Awareness of lupus is broad, but not deep.**
 - The majority of Americans (81%) have at least heard of lupus, but the survey identifies a large opportunity for continued public education about the disease. More than three-fifths overall (61%) say they know *little or nothing* about lupus, or have never heard of lupus at all. About a quarter (27%) say they are *somewhat* familiar with the disease, but only a little more than one-in-ten (12%) report being *very* familiar with it.
 - Nearly three out of four (74% of) Hispanics and more than half (57%) of African-Americans say they have either never heard of lupus or know *little or nothing* about the disease. Meanwhile, only 6% of Hispanics and 18 percent of African-Americans report being *very* familiar with lupus and its symptoms.
- **These measures of general awareness closely mirror responses about personal experience with lupus.**
 - More than half (57%) do not know anyone with the disease, 28% know someone other than a family member with lupus, and 10% say a family member has the disease. Less than 1% self-identify as having lupus, while 4% prefer not to answer this personal question. Significantly more males than females decline to answer the question.
- **Awareness of lupus is particularly weak among younger and lower-income Americans.**
 - Nearly three-quarters of Americans age 18-34 (72%) have either never heard of lupus or know little or nothing about the disease beyond its name. More specifically, about three-in-ten Americans age 18-34 (29%) say they have never heard of lupus, compared to 19% in the population as a whole. In addition, people with household incomes below \$50,000 a year are significantly more likely than those with household incomes of \$50,000 or more to report no knowledge of lupus.

- **Lupus is widely recognized as a potentially fatal disease, yet the majority also believe that it is treatable.**
 - About seven-in-ten (69%) overall believe that lupus can be fatal; only one-in-ten (11%) do not believe so.
 - Nearly six-in-ten (59%) believe that lupus is a treatable disease; only one-in-five (22%) do not believe so.

- **Most Americans do not believe that lupus can be prevented or that it is an illness with few complications.**
 - More than half (56%) overall do not agree with the statement that lupus can be prevented, while only 18% say the statement is true. Men (23%) and younger Americans 18-34 (28%) are significantly more likely to say the statement is true than women and older Americans, respectively.
 - 61% of Americans do not agree that lupus is an illness with few complications, compared to only 20% who think this is true.

- **Americans are split on how disabling lupus is, but they are more clear about the risk of heart attacks and strokes.**
 - Americans do not seem to be clear on how disabling lupus is: about two-fifths believe that the statement that lupus is sometimes a difficult disease but not disabling is true (42%) and a similar proportion believe that the statement is false (38%).
 - Nearly half (48%) agree that people with lupus have a higher risk for having heart attacks and strokes, while only a fifth (21%) disagree with this statement.

- **Few misidentify lupus as a disease that mostly affects men.**
 - About two-thirds (65%) say it is false that lupus mostly affects men. Only one-in-ten (11%) think this is true.
 - Here again, younger and lower-income individuals show the least awareness of lupus, being significantly more likely to agree with the false statement that lupus mostly affects males: 17% of 18-34 year-olds and 19% of those with income less than \$20,000 agree with this false statement.

- **A majority believe that lupus can affect any organ in the body.**
 - Overall, 55% believe this to be true, and 15% think this is a false statement.
 - Significantly more women (61%) than men (49%) believe that this is a true statement.

- **Americans are less certain about other aspects of the disease.**
 - Three-in-ten (30%) think it is true that most people with lupus develop the disease after age 45, compared to 44% who say this is false.
 - By a similar margin, 41% believe that lupus can be diagnosed with a single blood test, compared to 26% who do not. Older Americans age 65+ (29%) are the least likely to believe that lupus can be diagnosed with a single blood test.

- **The majority of Americans are not sure what kinds of treatments are generally prescribed to treat lupus.**
 - Nearly six-in-ten (58%) do not know how lupus is treated. Older Americans 65+ (72%) are more likely than younger Americans to say they do not know.
 - About a fifth (22%) say corticosteroids, like Prednisone, are generally prescribed for lupus, while one-in-ten or fewer say medications to treat malaria (9%), chemotherapy (8%), organ rejection drugs (7%), or something else (11%) are used to treat lupus.

Methodology

The questions were asked as part of OMNITEL, a weekly national telephone omnibus service of GfK Custom Research North America. The results contained in this report are based on interviews conducted from October 12-14, 2012 with U.S. residents 18 years of age and over. A total of 1,000 interviews were completed. Data from the completed interviews are weighted by a custom-designed computer program, which automatically develops a weighting factor for each respondent to ensure proportional representation by five variables: age, sex, education, race and geographic region. The margin of error on weighted data is +/- 3 percentage points for the full sample.

Each OMNITEL study is based on a random digit dialing (RDD) probability sample of all telephone households in the continental United States. The RDD sampling system is totally computer based and provides an equal probability of selection for each and every household with a landline telephone. Thus, the sample represents landline telephone households with both listed and unlisted phones in their proper proportions. All sample numbers selected by this procedure are subject to an original and at least four follow-up attempts to complete an interview.

Appendix: Full Text of Survey Questions

- 1. I'm going to read you a list of statements. Please tell me which of the following statements best describes your level of familiarity with the disease called lupus?**

INTERVIEWER: READ LIST. SELECT ONLY ONE RESPONSE.

- 1 You are very familiar lupus and its symptoms
- 2 You are somewhat familiar with lupus and its symptoms
- 3 You have heard of lupus but you know little or nothing about the disease
- 4 You have never heard of lupus

- 2. As far as you know, are the following statements true or false. How about...?**

INTERVIEWER: READ LIST. SELECT ONLY ONE RESPONSE FOR EACH.

PROGRAMMER: RANDOMIZE LIST.

	True	False	(DO NOT READ) Don't Know
Lupus can affect any organ in the body	1	2	dk
Most people with lupus develop the disease after age 45	1	2	dk
Lupus can be fatal	1	2	dk
Lupus mostly affects males	1	2	dk
People with lupus have a higher risk for having heart attacks and strokes	1	2	dk
Lupus can be diagnosed with a single blood test	1	2	dk
Lupus can be prevented	1	2	dk
Lupus is a treatable disease	1	2	dk
Lupus is sometimes a difficult disease, but it's not disabling	1	2	dk
Lupus is an illness with few complications	1	2	dk

3. Of the following statements, please tell me which best describes your connection to lupus.

INTERVIEWER: READ LIST. SELECT ONLY ONE RESPONSE.

- 1 You have lupus yourself
- 2 You have a family member or relative with lupus
- 3 You know some other person with lupus, other than a family member
- 4 You do not know anyone with lupus
- 5 You would prefer not to say

4. As far as you know, what kinds of treatments are generally prescribed to treat lupus?

INTERVIEWER: READ LIST. SELECT ALL THAT APPLY.

PROGRAMMER: RANDOMIZE LIST, ANCHORING 4 AND 5. MULTIPLE RESPONSE, EXCEPT 5 IS EXCLUSIVE.

- 1 Chemotherapy
- 2 Organ Rejection Drugs
3. Corticosteroids, like Prednisone
- 3 Medications to treat malaria
- 4 Something else
- 5 Don't know