

Smell Test Partner Toolkit

Smell loss is linked to Parkinson's disease (PD). The Michael J. Fox Foundation for Parkinson's Research is asking everyone age 60 and older without Parkinson's in the United States to take a simple scratch-and-sniff test. This could help scientists learn more about risk of brain disease and develop new treatments.

You can help spread the word and encourage your community to get involved in this important initiative. In this toolkit, we share an email/letter template, newsletter blurbs, talking points, social media posts, and creative assets (i.e., flyer, social media image, postcard, etc.).

Please make these items your own — especially if you can add your own connection to PPMI! You'll see places where you can customize and add your name or a friend's name, for example.

Email/Letter Template

Dear **[Friend]**,

I'm reaching out because I need your help! Today, there is so much information out there to help us understand how to best care for our brain. Now, emerging science is pointing to a healthful practice you can add to your routine: monitoring your sense of smell.

Smell loss may be one of the most important signs of risk for brain disease. A study from The Michael J. Fox Foundation for Parkinson's Research is exploring this link. They are asking everyone age 60 and older without Parkinson's to take a simple scratch-and-sniff test. You can get started by requesting a free test at mysmelltest.org/partners.

They'll mail you a test, which takes about 15 minutes to complete. Then you'll be asked to enter your answers online. Your results may mean you're a good candidate for a brain health study.

Please take the smell test and help spread the word! Share the link — mysmelltest.org/partners — with family, friends and others in your community.

There is so much we can do to protect our magnificent brains. I hope you'll join me and contribute to this important research.

Sincerely,

[YOUR NAME]

P.S. If you have any questions throughout the process, please reach out to ppmi@iu.edu.

Newsletter Blurbs

Long Version:

Your Nose Knows: Smell Loss and Brain Health

Many may be surprised to learn that our sense of smell is linked to brain health. Although one in two people over age 60 may be living with smell loss, many do not know it until they are tested. Monitoring your sense of smell could give you important information on your brain health as you age. Unlike temporary smell loss associated with COVID-19, ongoing smell loss can be a signal of cell damage associated with brain disease. In fact, smell loss may be one of the most important signals of risk for Parkinson's disease. (Not everyone with smell loss develops Parkinson's.)

A study from The Michael J. Fox Foundation for Parkinson's Research (MJFF) is exploring this link. A simple scratch-and-sniff test could help scientists learn more about risk and develop new treatments. MJFF is asking everyone age 60 and older without Parkinson's disease to take a free smell test.

Visit mysmelltest.org/partners to request a test. You'll receive your test in the mail and it'll take about 15 minutes to complete. Then you'll be asked to enter your answers online. Your results may mean you're eligible to join a brain health study.

Please help spread the word. Tell everyone you know over age 60 — family, friends, neighbors, community members — to monitor their brain health and contribute to this important research at mysmelltest.org/partners.

Short Version:

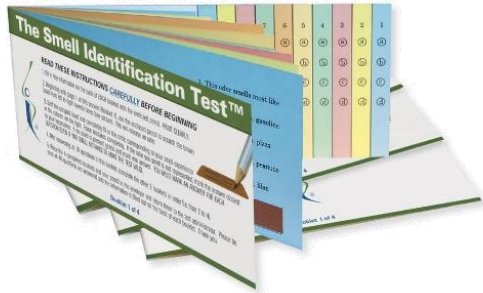
Your Nose Knows: Smell Loss and Brain Health

Loss of smell is an important signal of risk for brain disease, including Parkinson's. A landmark research study is exploring this link toward prevention. A simple scratch-and-sniff test could help scientists learn more about risk of brain disease and develop new treatments.

The Michael J. Fox Foundation for Parkinson's Research is asking everyone age 60 and up without Parkinson's disease to take a smell test.

Request your free scratch-and-sniff test at mysmelltest.org/partners.

Description of Smell Test



The UPSIT (University of Pennsylvania Smell Identification Test) is a simple, safe, scratch-and-sniff test that you can do in the comfort of your own home. This smell test is a validated and reliable tool trusted by doctors and scientists. It is considered the “gold standard” to check your sense of smell.

The smell test consists of four 10-page booklets with 40 questions total. Each page has a different scratch-and-sniff strip and the scent (such as gasoline or pizza) is released by using a pencil. There are four multiple-choice options to choose from. The test is scored out of answers to the 40 items. The score determines sense of smell function with different levels (e.g., from mild to severe). The smell test takes about 15 minutes to complete.

How-to

1. Complete smell test with multiple-choice options
2. Enter answers online
3. Study team will review your results
4. Results may mean you're a good candidate for a brain health study

References and Image Credit

1. Doty, Richard L., Kamath, Vidyulata, The influences of age on olfaction: a review. *Frontiers in Psychology*. doi: 10.3389/fpsyg.2014.00020. [Link to source](#).
2. Sensonics International. Smell Identification Test™ (UPSIT®). [Link to source](#).

Talking Points

- Monitoring your sense of smell could give you important information on your brain health.
- Sense of smell does naturally diminish as we get older. And many people have smell loss.
- Smell loss may be one of the most important indicators of risk to brain health as we age.
- In fact, ongoing smell loss may be one of the most important signs of risk for Parkinson's disease.
- **Not everyone with smell loss develops Parkinson's.**
- A study from The Michael J. Fox Foundation for Parkinson's Research is exploring this link.
- The Michael J. Fox Foundation is asking everyone age 60 and older without Parkinson's to take a free scratch-and-sniff test.
- This simple test could help you monitor your brain health and help scientists learn more about risk of brain disease.
- How to get started:
 - Visit mysmelltest.org/partners.
 - Answer a few brief questions to receive your smell test in the mail.
 - You'll take the test, which takes about 15 minutes to complete.
 - You'll enter your answers online.
 - Your results may mean you're eligible for a brain health study.

Questions to Anticipate:

- Who is eligible to take the test?
 - People age 60 and up who do not have Parkinson's in the U.S. are eligible.
- Do my results mean that I will get PD?
 - No — not everyone who has smell loss will develop PD. It is one of many factors linked to higher risk of Parkinson's.
- Does the test diagnose Parkinson's?
 - No, the test does not diagnose Parkinson's. The test is being done for research — to help scientists understand the role of smell loss in brain disease, including Parkinson's. Understanding how Parkinson's starts will get us closer to one day preventing it. If you're concerned about smell loss, please talk to your doctor.

- Will I get my results back from the study?
 - You will not receive the results from your smell test. This is being done for research, not for diagnostic or clinical purposes. The act of taking the test, though, may show you a deficit in your smell ability. If you are concerned about smell loss and brain disease risk, please talk to your doctor.
- Why am I not eligible to take the test?
 - Most likely: Age. Only people age 60 and up in the U.S. are eligible to take this smell test.
 - Otherwise: If you have Parkinson's, or live outside the U.S., you will not be eligible to take the smell test at this time.

Social Media Posts

- Join me to help advance better brain health for all. A landmark research study from The Michael J. Fox Foundation is exploring the link between smell loss and risk for Parkinson's disease. If you are age 60 or older without Parkinson's, take a simple scratch-and-sniff test today. mysmelltest.org/partners
- A critical research study is exploring the link between smell loss and risk of Parkinson's disease. Join me and help scientists working toward prevention! If you're over age 60 and not living with Parkinson's, take a simple scratch-and-sniff test today. mysmelltest.org/partners
- Did you know smell loss is linked to Parkinson's disease? A landmark study is exploring this link toward prevention. The Michael J. Fox Foundation is asking everyone age 60 and older without Parkinson's to take a simple scratch-and-sniff test. mysmelltest.org/partners

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