



ALS Identified™

FREQUENTLY ASKED QUESTIONS (FAQs)

**For People Living with ALS
and Their Families**

ALS Identified is a no-charge testing program for amyotrophic lateral sclerosis (ALS), sponsored by Biogen and offered through Invitae.



PROGRAM INFORMATION



1. WHAT IS THE ALS IDENTIFIED PROGRAM?

The ALS Identified program, sponsored by Biogen and offered through Invitae, offers genetic testing to people with ALS and their families at no charge in order to help provide a deeper understanding of the disease.

Genetic testing may be helpful for:

- People currently living with ALS that have a known family history of ALS
- People currently living with ALS that have **NO** known family history of ALS
- People who do not currently have ALS but have a family member or family history of ALS



2. WHO CAN PARTICIPATE IN THE ALS IDENTIFIED PROGRAM?

The ALS Identified program is available to residents of the US and Puerto Rico, over the age of 18:



PATIENTS: People who have been diagnosed with ALS



FAMILY: People who do not have ALS but have a family history of ALS

Only a doctor can recommend whether genetic testing is appropriate for you.



3. WHAT DOES THE PROGRAM COVER?

The program covers the cost of genetic testing for ALS by Invitae—there is no charge to you or your family. The test must be ordered by a doctor.

This program does NOT cover treatment for ALS.



4. DOES THE PANEL SCREEN FOR ALL GENE MUTATIONS ASSOCIATED WITH ALS?

No. The test includes more than 20 genes that have been linked to ALS, and your doctor might also order tests for a few other genes that may or may not be linked to ALS. However, there are likely other genes that have not yet been discovered, and some cases of ALS may not be caused by a genetic mutation. Your doctor can share more information about the genes included in the Invitae testing.

ABOUT THE GENETIC TEST



1. WHY SHOULD INDIVIDUALS GET TESTED?

Genetic testing may help you and your doctor have a deeper understanding of ALS and its potential impact on you and your family.

- **If you have been diagnosed with ALS**, the results may help you understand if any genetic mutations may have contributed to your ALS. Genetic testing may also help you and your doctor make decisions about your care, including long-term care needs and the potential to participate in clinical trials
- **If you are a family member of someone with ALS**, the results may indicate whether you are at increased risk for developing ALS in the future
- **For people with ALS and family members**, genetic testing may help to inform life decisions and long-term lifestyle choices, including family planning



2. WHAT DOES THE PROGRAM TEST FOR?

The ALS Identified program offers testing for a range of genetic mutations, including more than 20 mutations that have been linked to ALS. Your doctor may also recommend additional tests as needed.



3. HOW DO I TAKE THE TEST?

Your doctor may have you take the test in the office, or they might have you take it at home.

- **If you take the test in the office**, your doctor will take a small sample from you and send it to the lab. The sample taken to test for your DNA may be saliva, blood, or a buccal swab (a small stick or pad that is rubbed on the inside of your cheek to collect a few cells)
- **If you take the test at home**, you will receive a sample collection kit in the mail. Follow the instructions included with the kit to provide a buccal swab or saliva sample and send it to the lab using the prepaid mailer provided



4. WHAT SHOULD I CONSIDER BEFORE HAVING A GENETIC TEST?

Genetic testing can provide limited but important information about ALS. If you have ALS, the results may help to inform your prognosis. For family members without ALS, genetic testing may help to determine if you are at increased risk for developing ALS but it cannot predict when or if a person without ALS may develop the disease.

Before choosing to undergo genetic testing, you should discuss the implications with your doctor or another professional, such as a genetic counsellor. They can explain in detail the potential benefits, risks, and limitations of the genetic testing.

ABOUT THE GENETIC TEST



5. HOW LONG WILL THE TEST TAKE?

Completing the test kit will only take you a few minutes. Test results will arrive at your doctor's office around 10 to 21 days (14 days on average) after the sample arrives at the lab.



6. HOW WILL I GET MY TEST RESULTS?

The results will be sent directly to your doctor (even if you do the test at home). Your doctor will then share and discuss the results with you. Afterwards, you can ask your doctor to give you direct access to your test results through a portal on the Invitae website.



7. HOW CAN I GET TESTED THROUGH ALS IDENTIFIED?

Only a healthcare professional can order testing through the program. Ask your doctor if you may be eligible for ALS Identified.



8. CAN I ORDER A TEST MYSELF?

No, your doctor must initiate and order the test on your behalf. The test can only be requested by a licensed doctor in the US.

ADDITIONAL QUESTIONS



1. WHERE CAN MY DOCTOR FIND MORE INFORMATION?

Your doctor can speak with a Biogen representative for more information.



2. WILL ANY GENETIC OR PERSONAL INFORMATION BE SHARED WITH BIOGEN?

Biogen will receive de-identified patient data and genetic testing results from ALS Identified, but at no time will they receive identifiable patient information. Biogen will receive contact information for healthcare professionals who refer patients to the ALS Identified program.



ALS Identified™

SPONSORED BY BIOGEN
AND OFFERED THROUGH INVITAE

REQUEST A TEST AND GAIN A DEEPER UNDERSTANDING OF GENETIC ALS



**Not all ALS
is the same:**

Genetic testing may
help you learn more
about ALS



**Knowledge is
essential** in the
fight against ALS



**No-charge
genetic testing**
for people with ALS
and their families

While third parties and commercial organizations may provide financial support for this program, tests and services are performed by Invitae. Healthcare professionals must confirm that patients meet certain criteria to use the program. Third parties and commercial organizations may receive de-identified patient data from this program, but at no time would they receive patient identifiable information. Third parties and commercial organizations may receive contact information for healthcare professionals who use this program. Genetic testing is available in the US only. Healthcare professionals and patients who participate in this program have no obligation to recommend, purchase, order, prescribe, promote, administer, use or support any other products or services from Invitae or from third parties or commercial organizations.