Mass General Brigham

Healey & AMG Center
Sean M. Healey & AMG Center for ALS
at Massachusetts General Hospital

Updated May 2024

Study of Dominant Inherited ALS (DIALS)

Join our Study for Families Affected by ALS and Find Answers for your Family

How can I benefit by participating in the DIALS study?

- Receive free, confidential genetic testing for currently known genes that cause ALS
- Periodic monitoring of your health from our ALS specialized study team, consisting of neurologists, nurse practitioners, genetic counselors, and clinical research coordinators
- Be a part of research that helps us understand ALS and may lead to the discovery of new treatments
- Get started with clinical care and connect to other research studies if you should develop symptoms of ALS while in the DIALS study

Who can participate?
Adults over the age of 18 who:
1) do not have symptoms of ALS, and,
2) have an immediate relative with an ALS causing gene mutation

How often do I have to come in for visits?
Study visits may occur every 6-12 months for at least five years. If you decide to learn your genetic results, you will have two phone call visits, and a return of results visit (in-person or via Zoom) with our genetic counselor within eight weeks of your screening visit.

What happens at a DIALS visit?
Some of the activities that may occur at a visit include collection of blood and urine and optional spinal fluid, vital capacity (breathing) test, neurological exam, strength testing, genetic counseling, speech recording, and cognitive assessments.

Where are the DIALS study sites located?
There are two DIALS study sites – Massachusetts General Hospital, Boston, MA and Washington University/Barnes Jewish Hospital, St. Louis, MO.

Will I be reimbursed for my participation?
The study currently does not reimburse you for travel costs outside of the cost of parking at the garage located outside our research center.

What is the purpose of collecting my samples of blood and spinal fluid (optional)?
These samples can be analyzed for promising potential indicators of early disease onset for ALS, and may benefit future biomarker research.

What happens with my samples?
Your samples are stored in our on-site ALS Sample Repository and shared upon request with collaborators looking for novel biomarkers.

Principal Investigator: James Berry, MD, MPH Sponsor: ALS Finding a Cure, ALS Association, and Philanthropy.
Enrollment Contacts: **DIALS@mgh.harvard.edu**
or call Courtney Uek at 617-724-0783
or Rachel Freedman at 617-724-3268

Sign up for the MGH ALS Link to Stay Connected to Research:

https://lp.constantcontactpages.com/su/saTzwIp/ALSLink

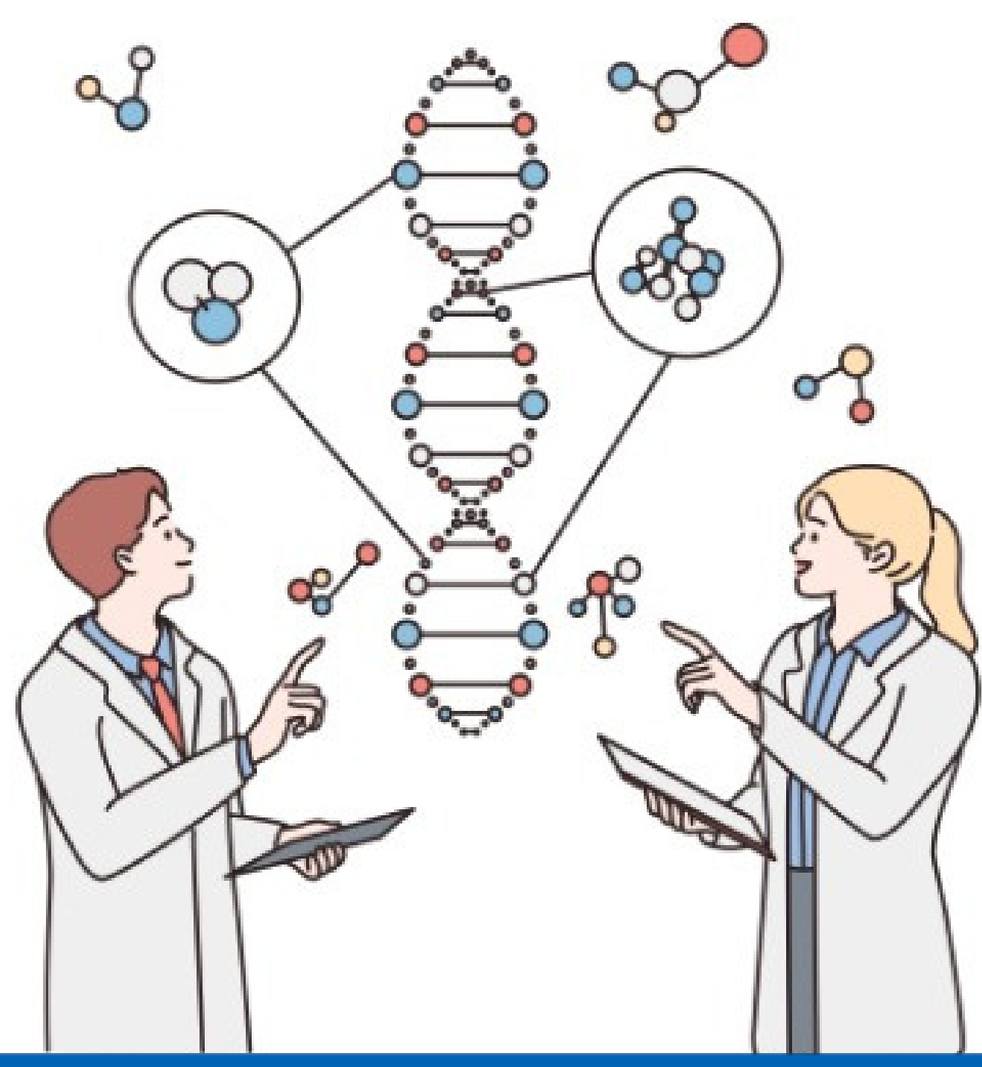
Genetic Testing and Counseling in the DIALS Study

What is the genetic testing process?
A sample of your blood is collected at the screening visit and sent to a lab that specializes in genetic testing. You'll have the option to learn your results in about 8 weeks. By having genetic testing through DIALS, you'll receive continuous support from our genetic counselor and your medical information is protected by the confidentiality measures we take. Testing is paid for by the DIALS study.

Is my genetic testing confidential?
Yes, maintaining confidentiality of your genetic testing results is one of our main priorities. Your samples are de-identified and your genetic test results will never be placed in your medical records unless you make this request.

Can I be in the study if I choose not to learn my genetic results?
Yes, you can be in the study if you choose not to learn your genetic test results. The study team remains blinded to your results unless you change your mind. You can discuss your questions and concerns with our genetic counselor at any time.

If I test negative, can I continue my participation in the study?
You may choose to continue in the study as a healthy participant, which provides valuable data to compare to the gene carrier data. We currently see healthy participants once a year.



Other Familial ALS Studies

ATLAS

This research study is looking to enroll people with fast-progressing variants of the SOD1 mutation that causes ALS (SOD1- ALS). Eligible participants must not have any signs or symptoms of ALS at the time of screening.

The purpose of this study is to investigate whether the study drug, BIIB067 also known as Tofersen, delays the onset of signs and symptoms of ALS and/or slows the progression of the disease if signs and symptoms appear.

If interested, contact: ATLAS@mgb.org or call Courtney Uek at 617-724-0783 or Rachel Freedman at 617-724-3268