



# Welcome

To the ALS Clinic at the Healey & AMG Center  
at Massachusetts General Hospital

An MDA Care Center of Excellence



Welcome to the Sean M. Healey & AMG Center for ALS at Mass General. Our mission is to provide excellence in care for people with ALS while accelerating the development of effective treatments. We are at an inflection point in ALS, where there are great leaps forward in understanding the disease and many more options around treatments and clinical trials. We hope that the information the Healey faculty staff provide in-person and what is found on our website ([www.massgeneral.org/als/](http://www.massgeneral.org/als/)) will increase understanding of ALS, and the research we and others are doing to understand ALS and develop better treatments.

We want to provide critical and up-to-date information that will enable you to maintain control over the issues that might affect your life and to have a greater understanding of approaches to ALS's medical management and options for new treatments. Our ALS Multidisciplinary Team partners with researchers all over the world to accelerate discoveries for our patients. Our clinic is supported by the Muscular Dystrophy Association and through the generous support of individual contributions to our Mass General ALS Fund, which focuses on patient care improvements and acceleration of research to cure ALS. Our research efforts are funded by several foundations, the federal government and through the generous support of individuals.

We hope your experience in our clinic is a positive one and provides you with the information you need to make good decisions about ALS. We welcome your feedback and ideas for how we can keep improving how we care for you. It is our pleasure to serve you.

**Merit Cudkowicz, MD, MSc**

I'd like to welcome you to our ALS Multidisciplinary Clinic in the Healey Center for ALS at Mass General. We are all truly glad you've chosen to visit and look forward to doing everything we can to help you. Whether you are coming for an initial evaluation, or a second opinion, or to learn about our research opportunities, know that two principles drive everything we do in clinic — we care deeply and we aim to provide hope.

From diagnosis, to symptom management, to exploring research opportunities, we are deeply committed to providing you with the best possible care.

With multidisciplinary care, people with ALS live better and longer. We have assembled a team of experts with a broad array of skills to provide comprehensive care in a single stop —speech, physical and respiratory therapists, genetic counselors, nurses and nurse practitioners, to our neuropalliative care specialist, ALS physicians, affiliated pulmonologists, and our comprehensive research team. We have developed innovative programs to support ALS care, as well. ALS Parenting at a challenging time (ALS PACT), Virtual Visits, and the ALS House Call Program are all aimed at broadening our support for people with ALS and caregivers even more.

Our ALS Clinic Team is thoroughly integrated with our ALS Research Team at the Sean M. Healey & AMG Center for ALS at Mass General Hospital. We view research as a key part of clinical care for those who are interested, and our goal is to provide opportunities to participate in research to all people with ALS. With all this going on, you should not be surprised to hear that your visit to our clinic could take some time. Plan to spend several hours with us.

We are constantly innovating to provide care for people with ALS the way they need it, not just the way insurance reimburses it. We hope you are as excited to visit our clinic as we are to see you!

Sincerely,

**James D. Berry, MD, MPH**



# Welcome to the ALS Multidisciplinary Clinic in the Healey Center for ALS at Mass General

## ALS Physicians



**James D. Berry**

**MD, MPH**

**Chief, Division of ALS and  
Motor Neuron Diseases**



**Sabrina Paganoni**

**MD, PhD**

**Co-Director, Neurological**



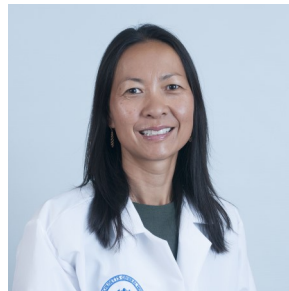
**Merit Cudkowicz**

**MD, MSe**

**Chief, Neurology Department**



**Suma Babu**



**Doreen Ho**



**Nazem Atassi**



**Haatem Reda**



**Mark Garret**



**Sheena Chew**

To communicate with your ALS Care Team: Patient Gateway is the best way to communicate non-urgent matters ([www.patientgateway.partners.org](http://www.patientgateway.partners.org)). Our Patient Service Coordinators are also available from 8:30 am - 5:00 pm EST, Monday - Friday, to assist you please dial 617-724-3914. For emergency matters after 5:00 pm EST or on weekends, dial 617-726-2000, and ask the Page Operator to page your Physician. For medical emergencies, please call 9-1-1.

## ALS Nurse Practitioners



**Sarah Luppino, NP**



**Jennifer Scalia, NP**

**617-724-3914**



**Darlene Sawicki,**

**MSN, NP-BC**

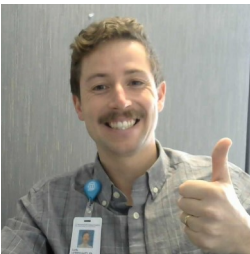


**Alexandra McCaffrey, NP**



**Pravin Pant, MSN, NP**

**617-724-8468**



**Carl Lewenhaupt, House  
Call NP**

## Patient Service Coordinators



**Daisy Feliciano**

**Patient Service**

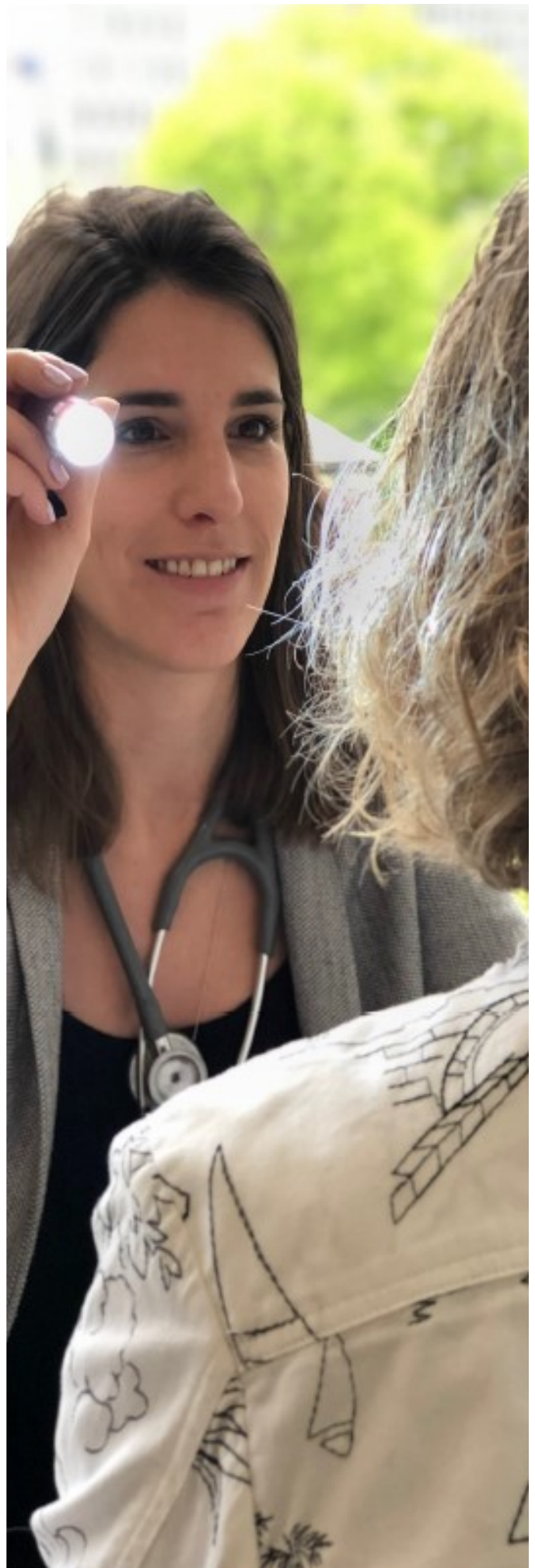


**Larissa Jackson**

**Team Lead**

**Patient Service**

**Coordinator III**



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# ALS Nurses



Judi Carey, RN  
Research Access Nurse



Catherine Chin, RN  
Clinical Nurse Caring for  
Patients of Dr. Babu



Erin Clampffer, RN  
Clinical Nurse Caring for  
Patients of Dr. Berry



Emily Hegel, RN Clinical  
Nurse caring for Patients of  
Dr. Reda and Dr. Chew



Kristen Kingsley, RN  
House Call Program Nurse



Devin McClain, RN  
Clinical Nurse Caring for  
Patients of Dr. Garret and Dr.  
Atassi



Kiersten Pease, RN  
Clinical Nurse Caring for  
Patients of Dr. Ho



Aimee Roderick, RN  
Clinical Nurse caring for  
Patients of Dr. Cudkowicz



Margot Rohrer, RN  
Clinical Research Nurse  
Specializing in Expanded  
Access



Danica Sanders, RN  
Clinical Nurse Caring for  
Patients of Dr. Paganoni & Dr.  
Berry



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# Allied Health Providers & Affiliated Specialists



Amy Swartz Ellrodt  
PT, DPT



Katherine Burke,  
PT



Clarie MacAdam  
PT, NCS



Kendall Carney  
PT



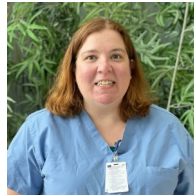
Stacey Sullivan  
MS, CCC-SLP



Elizabeth Christiansen  
MS, CCC-SLP



Christopher Piccuito  
RRT  
Respiratory Care



Karla Schlichtmann  
RRT



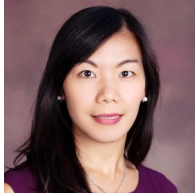
Archana Basu, PhD  
Psychologist ALS PACT  
Program



Cynthia Moore, PhD  
Psychologist ALS PACT  
Program



Kate T. Brizzi, MD  
Neuropalliative Care  
Physician



Helen Jin Yun Chen  
Genetic Counseling



Diane Lucente, Genetic  
Counseling Manager



Julie MacLean OTR/L  
Occupational Therapist



Jaime Cormier, Genetic  
Counseling



## Clinical Research Coordinators



**Grace Addy**



**Gaby Casagrande**



**Daniel Sullivan**



**Gavi Forman**



**Rachel Freedman**



**Dario Gelevski**



**Kylie Graves**



**Munaf Hateem**



**Grace Laber**



**Miji Kim**



**Lisa Lichtenegger**



**Mary McCormack**



**Chrysthie Mline**



**Sean Morgan**



**Chloe Noll**



**Megan Okoro**

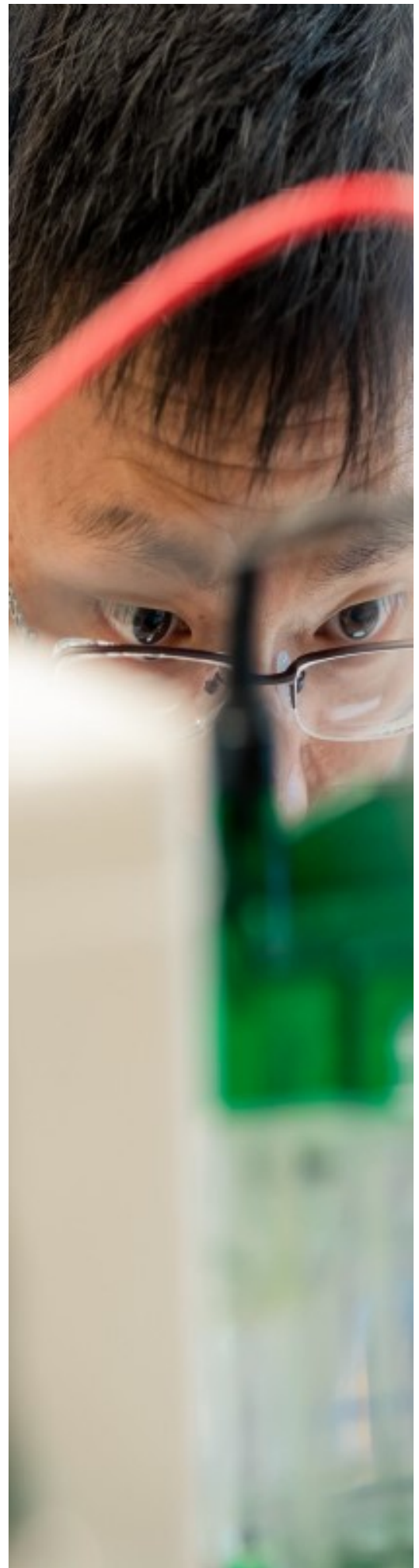


**Ludjie Pierre**



**Arian Pilja**

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## Clinical Research Coordinators cont.



**Ethan Riddell**



**Erica Scirocco**



**Tom Royse**



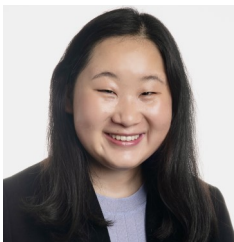
**Jacqueline Topping**



**Courtney Uek**



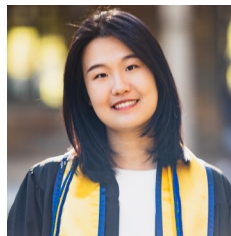
**Lily Walker**



**Anne Williams**



**Allison Wheeler**



**Jingqi Zhu**



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# How Members of Our Team Help to Take Care of You

- **Physicians** lead your evaluation and management plan. Your ALS Physician can be reached for **non-emergencies** by sending a message through Patient Gateway or calling clinic (**8:30am- 5pm**) at **617-724-3914**. Please ask the operator to be connected with your physician or physician's primary nurse to ask any questions related to your care or to help with medication refill questions. **For an emergency, please call the Page Operator at 617-726-2000** and ask to *"please have your physician paged."* **For extreme emergencies, please call 911 for immediate medical care.**
- **Patient Service Coordinator (PSC):** Serves as the team lead and point person for day-to-day clinic operations. The PSC provides comprehensive administrative support to the ALS providers functioning as the primary interface between the patient and physicians. The PSC assists in scheduling procedures, diagnostic testing, coordinating referrals, procedures and managed care related issues. The PSC can also help obtain insurance approval for Radicava and coordinate administration of Radicava with local infusion companies. **Main Contact Number: 617-724-3914**
- **Nurse Practitioner:** Works in collaboration with our physicians to manage your care. Our NPs conduct clinic visits, see patients for individual health concerns and urgent matters that develop in between regular clinic visits.
- **Clinical Nurse:** Works closely with physicians to assist with providing care to patients, both in clinic and between visits. The nurse is the primary member of your care team for health concerns and medication questions and refills, and is **available Monday-Friday, 8:30 am-5 pm ET. (Please contact your nurse via patient gateway or by phone).**
- **Research Access Nurse:** Meets with patients to talk about current and upcoming research trials and then works with you to determine what trials may be right for you to consider participating in. **Main Contact Number: 617-724-8995**
- **Physical Therapist:** Evaluates mobility and overall function for patients and makes suggestions to improve mobility and safety, optimize function, and enhance participation in daily activities, including recreational activities, for as long as possible. Assists with family training for functional mobility or recommendations to referrals to other specialists, such as an occupational therapist or orthotist.
- **Speech Language Pathologist:** Evaluates speech and swallowing issues caused by ALS and recommends techniques for maximizing communication and swallowing safety and efficiency.
- **Occupational Therapist:** Helps the patient maintain the highest level of independence in activities of daily living along with work, community, and leisure tasks.
- **Respiratory Therapist:** Assists in evaluating breathing concerns, educating patients about supportive respiratory equipment and making appropriate recommendations.
- **Orthotist:** Specialist in bracing, works with patients and MD/PT to create custom braces and supports, including ankle, neck, and shoulder braces. Talk to your physical therapist if you need a recommendation for a local orthotist.
- **Genetic Counselor:** Provides clinical care to patients and families with neurodegenerative conditions, including diagnostic testing for patients with symptoms and pre-symptomatic testing for individuals with a 50% chance of inheriting a genetic condition. Also provides genetic counseling and testing to ALS patients and their families who are participating in research.
- **Neuropalliative Care Provider:** Brings an approach to care that is appropriate at any stage of illness and focuses on helping patients live well. The goal is to improve quality of life for both patients and their families. The palliative care provider works together with the multidisciplinary team to manage physical and emotional symptoms, while also helping patients navigate treatment choices.
- **Clinical Research Coordinator:** Brings patients to clinic rooms for visits and assists patients with tasks requested by your physician including completing various questionnaires and performing vital capacities.
- **ALS Parenting at a Challenging Time (PACT) Program:** A psychologist or psychiatrist provides parent guidance to individuals diagnosed with ALS who have children (infants through young adults). The team is available to meet parents during clinic visits, or work with them through phone or virtual appointments. **Main Contact Number : 617-724-3914**
- **ALS House Call Team:** Supplements care provided at the ALS Multidisciplinary Clinic. The House Call team delivers timely, responsive and personal targeted care for patients living with ALS. Face to face visits provide an opportunity to assess for disease progression, optimize symptom management, assess the home environment for safety and DME needs and to provide support.

# How do YOU become a New Patient?



## Patient

**Step 1:** If this is the first time you are seeing a physician at Mass General Hospital or within the Partners HealthCare Network, please call Mass General Registration at **1-866-211-6588** to obtain an MRN (Medical Record Number).

If you **live internationally** and are interested in coming to our Multidisciplinary Clinic, dial **617-726-2787** or visit: [www.massgeneral.org/international/](http://www.massgeneral.org/international/)



## Scheduling

**Step 2:** Please call our ALS Multidisciplinary Clinic at **617-724-3914**

Provide your MRN (Medical Record Number)

You will be given helpful information about becoming a patient in our clinic

Within a few business days, one of our Patient Service Coordinators will contact you about scheduling a New Patient appointment.

The fax number to send your Medical Records to our clinic is **617-724-7290**.



## Follow-up

**Step 3:** You will receive a Reminder Letter of your appointment in the mail or via email with helpful information for the day of your visit.

For future communications with your ALS team you have the option of setting up a **Patient Gateway** account once you have your MRN by visiting: [www.patientgateway.partners.org](http://www.patientgateway.partners.org)

*If patients do not wish to have this, they can call **800-745-9683** and ask to have it disabled on their account.*

If you have urgent or immediate needs, it is best to reach out to your team by calling the clinic at **617-724-3914**



# Preparing for your first visit



**Q+A**

## Write down your Questions



On the day of your appointment, please **bring a list of all your medical & general questions** so that we can address all your concerns.

To assist you, our team has compiled a Q+A list of the most frequently asked questions. Please look in your Welcome Folder or visit our website at:

## Plan for Visit



Our multidisciplinary team combines **multiple specialists' appointments in one clinic visit.**

We want you to know that your time with us in clinic may be **several hours, especially if it's your first visit.**

We hope this information helps you with planning your day to allow for enough time to spend with us in clinic.



**Plan  
for Visit**



**Arrive  
Early**

## Arrive Early



**Peak traffic times are unpredictable in and around Boston.**

To lessen your stress, allow for extra travel time in order to arrive **15 minutes before your appointment**, find parking and then make your way to our clinic.



## **About Appointments & Scheduling**

### **Q. How long can I expect to be in clinic**

**A.** Our multidisciplinary team combines multiple specialists' appointments in one clinic visit. We want you to know that your time with us in clinic may be several hours, especially if it's your first visit.

### **Q. Can I request to be seen by a certain Provider?**

**A.** We understand that a certain provider in our clinic may have been recommended to you. We will try our best to schedule you with that ALS provider. We do aim to have you seen in our clinic as quickly as possible and this may mean that you are seen by a different provider in order to expedite your care. We are a close-knit Care Team that collaborates in order to provide you with our best care.

### **Q. How long can I expect to be in Clinic?**

**A.** Call **617-724-3914** and speak with one of our ALS Patient Service Coordinators who will assist you with scheduling a clinic visit. If you reside outside the United States, to request an appointment with the MGH-ALS Multidisciplinary Clinic, call the Mass General International Office at **1-617-726-2787** or visit our website for international patients: <https://www.massgeneral.org/international/>

### **Q. What do I need to bring to my clinic visit?**

**A.** If this is your first visit to the MGH-ALS clinic, please bring your insurance card, photo identification, current medication list, medical records and imaging on disk, and your co-payment. To update your insurance and contact information prior to your appointment, please call Patient Registration at **1-866-211-6588**.

### **Q. Could I bring snacks or beverages to my visit?**

**A.** Yes, you can bring your own bag of snacks. However, Mass General has tasty assortment of food stations and Cafes in the hospital. If you or your accompanying care giver want to step away from clinic to purchase food or a drink, there are several cafeterias and coffee shops located throughout the hospital. Please visit our cafeteria webpage: <https://www.massgeneral.org/services/visitor-cafeterias>

### **Q. What do I do if I am going to be late for my clinic appointment or need to cancel it?**

**A.** For those unforeseen circumstances that may require you to be late for your appointment, call us at **617-724-3914** and provide us with your estimated time of arrival. If you have to cancel your clinic appointment, please call us 24 hours in advance, so we may be able to offer that visit to another patient.

### **Q. Are interpreter services available?**

**A.** Yes, let one of our ALS Patient Service Coordinators know that you will need an interpreter at the time you schedule your appointment.

## **Traffic, Parking, & Clinic Location**

### **Q. How is the traffic to and from Mass General Hospital?**

**A.** Peak traffic times are unpredictable in and around Boston. To lessen your stress, allow for extra travel time to arrive 15 minutes before your appointment. We do understand sometimes being late for an appointment cannot be helped, please call us at **617-724-3914** and provide us with your estimated time of arrival. For driving directions to Mass general Hospital, walking instructions and public transportation options, please visit: <https://www.massgeneral.org/visit/maps-and-directions/locations-and-parking-guide>

### **Q. Where do I park for my appointment?**

**A.** Valet parking is available at the entrance for the Wang Ambulatory Carey Center. Visit the webpage for main campus locations, nearby parking garages, and reduced visitor parking rates at MGH parking garages. Please visit: <https://www.massgeneral.org/visit/parking-and-shuttles/parking>

### **Q. Where are the multidisciplinary clinic visits located?**

**A.** Most clinic visits are located in the Wang Ambulatory Care Center on the 8th Floor Neurology Suite. The location of your visit is listed on your appointment letter. If you are unsure of location, please call one of our Patient Service Coordinators at **617-724-3914**

### **Q. Where is the multidisciplinary clinic in Waltham?**

**A.** Our Waltham location is located at Mass General Waltham, 52 2nd Ave, Waltham, MA 02451. The location of your visit is listed on your appointment letter.

### **Q. Where do I park for my appointment at Mass General Waltham?**

**A.** Mass General Waltham offers ample free parking. The patient parking garage can be located by turning onto 2nd Ave and turning into garage for Mass General Waltham located across the street from Costco. We do understand sometimes being late for an appointment cannot be helped, please call us at **617-724-3914** and provide us with your estimated time of arrival.

## Communicating with the Team

### **Q. How can I communicate with my ALS physician and other members of my care team?**

**A.** For **emergencies**, dial **911** or go to your local Hospital for immediate medical care.

**Patient Gateway** ([patientgateway.partners.org/login/](https://patientgateway.partners.org/login/)) is a convenient and secure way to communicate with your Physician and ALS Care Team for non-urgent matters. **Please allow up to 24 hours for a response back from your Provider.** By logging into your account, you can send a descriptive message to most members of your Care Team, request prescription refills, or to review visit notes, lab results and medication refills.

For urgent concerns or questions during weekdays, from 8:30-5 pm EST, dial **617-724-3914** to speak to a Patient Service Coordinator. Our Coordinators can help put you in touch with a member of your Care Team to better assist you. Also, for any urgent concerns throughout the week you can also dial **617-726-2000** and ask the Page Operator to page your Physician.

For **urgent concerns or questions after normal business hours** (8:30-5 EST) or on the weekends, dial **617-726-2000** to speak to an MGH Page Operator and ask to have your Physician paged.

## Hotels

### **Q. Are there hotel accommodations nearby?**

**A.** If you are traveling a considerable distance to get to Mass General Hospital and want to stay overnight at a local hotel, please visit our Visiting Boston webpage for information on nearby hotel accommodations. [https://www.massgeneral.org/assets/mgh/pdf/social-service/accommodations-list.pdf?](https://www.massgeneral.org/assets/mgh/pdf/social-service/accommodations-list.pdf?TRILIBIS_EMULATOR_UA=aqkljlpwmmkitx%2Caqkljlpwmmkitx)

[TRILIBIS\\_EMULATOR\\_UA=aqkljlpwmmkitx%2Caqkljlpwmmkitx](https://www.massgeneral.org/assets/mgh/pdf/social-service/accommodations-list.pdf?TRILIBIS_EMULATOR_UA=aqkljlpwmmkitx%2Caqkljlpwmmkitx)

## Insurance & International Patients

### **Q. Do I need a referral?**

**A.** If you reside in the U.S., check with your insurance company about your coverage requirements. If you need a referral, we can guide you through the process to obtain a referral. Generally, the MGH Multidisciplinary ALS Care Clinic doesn't require a Doctor's referral. However, obtaining one can help the ALS Team better determine your specific care needs. If you reside outside the U.S., contact our International Office at 1-**617-726-2787** or visit our website for international patients: <https://www.massgeneral.org/international/> for further assistance.

# Connecting to Research Resources

## ALS Research at MGH Healey Center

Review our trials for opportunities to participate in investigational medication trials and observational studies at the Healey Center at Mass General.

→ <https://www.massgeneral.org/neurology/als/research/als-clinical-trials>

## ALS Research Paper Review (RPR)

ALS RPR hosts seminars where patients interview researchers about their work with the intent of providing a deeper understanding of the scientific principles and research processes that go into finding a treatment for an extremely complex disease.

→ <https://rarediseases.org/rare-diseases/amyotrophic-lateral-sclerosis/#:~:text=ALS%20is%20a%20rare%20disorder,new%20cases%20diagnosed%20each%20year>

## ALS Therapy Development Institute (TDI)

TDI's Lab focuses on drug discovery, research, and therapeutic development for ALS. Its website hosts information about research, news, & webinars.

→ <https://www.als.net/als-research/>

## ALS Untangled

Read scientific reviews about alternative and off-label treatments (AOTs) for management of ALS to help make better informed decisions about them. This website is managed by Dr. Richard Bedlack, ALS Neurologist at Duke University.

→ <https://www.alsuntangled.com/completed-reviews/>

## ClinicalTrials.gov

Access a database of privately and publicly funded clinical studies conducted around the world. Information is provided and updated by the sponsor or principle investigator of the clinical study and the website is maintained by the U.S. National Library of Medicine (NLM) at National Institutes of Health (NIH).

→ <https://clinicaltrials.gov/>

## I Am ALS's ALS Signal: Clinical Research Dashboard

This dashboard is a tool designed for and by patients and caregivers to provide an overview of treatments and supplements that are being tested for use in ALS from around the world. This website also hosts a list of common research terms.

→ <https://iamals.org/get-help/als-signal-clinical-research-dashboard/>

## National ALS Registry

Participate in surveys to help provide a picture of who gets ALS and risk factors for the disease. Researchers can use the Registry data to look for disease pattern changes over time and help identify any common risk factors among individuals with ALS.

→ <https://www.cdc.gov/als/>

# Podcast

# Resources

## **ALS Pathways Podcast Series**

This podcast covers a range of topics relating to ALS. There are episodes on caregiving, symptom management, and the basics of ALS including the history and science of the disease as well as various tests that monitor progression.

→ <https://www.alspathways.com/als-resources/>

## **ALS Therapy Development Institute's Endpoints Podcast**

This series has a research section as well as an ALS Stories section in which individuals with ALS share their story. The research podcast focuses on the current ALS research by breaking down different therapies and trials while the ALS Stories podcast focuses on individuals and their journeys.

→ <https://www.als.net/endpoints/>

## **Connecting ALS Podcast**

This all encompassing podcast covers everything from advocacy and research to mobility and home modifications. The 20 minute episodes include weekly guests that may be researchers, volunteers, and people with ALS.

→ <https://connectingals.org/podcasts/>

## **National Organization for Rare Disorders Podcast**

Raring: The Voice of Rare Disease podcast has created a forum for medical professions, patients, and their families to discuss rare disorders. This podcast focuses on creating a community for those with a rare disorder to learn and share their story.

→ <https://rarediseases.org/nordpod/>



# Connecting to Community

# Resources

## ALS Association (ALSA)

ALSA is an organization that serves, advocates for, and empowers people living with ALS to live their lives to the fullest, and works to discover treatments and a cure for ALS.

→ <https://www.als.org/>

## ALS Charitable Foundation

Dedicated to providing patient services in support of people living with Amyotrophic Lateral Sclerosis (ALS) in the New England area and raising funds for research efforts to find better treatment options and a cure.

→ <https://alsfamily.org/>

## ALS Information at the National Institute of Health (NIH)

Comprehensive overview of ALS provided by MedlinePlus, a service of the U.S. National Library of Medicine.

→ <https://medlineplus.gov/amyotrophiclateralsclerosis.html>

## ALS ONE

ALS ONE is an organization dedicated to improving the care of people living with ALS, and expediting treatments that lead to a cure for ALS through collaboration.

→ <https://alsone.org/>

## ALS Ride for Life

ALS ride for Life is a charity that supports research and offers grants for ALS patients who do not have healthcare coverage for respite care. This organization gives the family caregiver an opportunity to take a break and offers grant for legal services related to ALS.

→ <https://alsrideforlife.org/about-rfl/our-story/>

## ALS Therapy Development Institute (TDI)

Provides resources designed to get you answers quickly keep you up-to-date, and connect you with others in the ALS community through forums, virtual town hall meetings, and podcasts.

→ <https://www.als.net/resources/>

## Compassionate Care ALS (CCALS)

CCALS provides resources including equipment, educational opportunities, Medicare/Medicaid assistance, communications assistance, guidance and awareness with regards to living with ALS, caregiving, and exploring end-of-life when invited.

→ <https://ccals.org/>

## Everything ALS

A non-profit organization that offers people with ALS a platform for direct engagement with other patients, caregivers, researchers, and drug companies. Everything ALS hosts bi-monthly community meetings designed to provide support and information to patients & caregivers.

→ <https://www.everythingals.org/>

## HARK ALS

HARK ALS is a non-profit that runs a wheelchair accessible van donation program and assists with travel expenses for people with ALS to attend important family events.

→ <https://hark-als.org/>

## Mary Beth Benison Foundation

The Mary Beth Benison Foundation is a non-profit that offers financial aid to people with ALS and their families to obtain medical equipment and transportation. The foundation helps organize and fun family vacations for families facing medical challenges.

→ <http://www.mbbloves.com/>

# Additional Community Resources

## HealthWell Foundation

HealthWell assists with insurance premium costs and co-pays of drug prescriptions. This program is for individuals who have health insurance that covers part of the cost of treatments.

→ <https://www.healthwellfoundation.org/fund/amyotrophic-lateral-sclerosis/>

## I Am ALS

An organization dedicated to reshaping the public understanding of ALS and connecting patients, family, and friends to community resources whose mission is to educate and motivate all about ALS. I Am ALS is a platform for patients living with ALS to take lead in the fight against ALS and search for a cure.

→ <https://iamals.org/>

## Muscular Dystrophy Association (MDA)

MDA supports the largest network of clinical care centers including MGH's ALS Multidisciplinary clinic and information specialists and educational resources are available to offer guidance and support. The website contains information on advocacy clinical trials, support groups, and research news.

→ <https://www.mda.org/disease/amyotrophic-lateral-sclerosis>

## PatientsLikeMe

PatientsLikeMe's mission is to improve the lives of patients through new knowledge derived from shared real-world experiences and outcomes. While patients share their health experiences to help others, the data they share brings real patient perspectives to the healthcare industry and drive necessary change.

→ <https://www.patientslikeme.com/>

## Peter Frates Foundation

The Peter Frates Foundation is a non-profit with the mission to assist progressed ALS patients and their families with the costs of home health care.

→ <https://petefrates.com/contact/>

## Project Main Street

Project Main Street is a non-profit organization that aims to support and care for ALS patients until there is a cure. Project Main Street offers grants for eye-gaze equipment, renovations to make homes ADA accessible, home care, and life expenses.

→ <https://projectmainst.org/>

## Your ALS Guide

An online guide to help those recently diagnosed with ALS walk through the most important things to know about your diagnosis to planning ahead.

→ <https://www.youralsguide.com/newly-diagnosed.html>

## Roon

Roon the place online for people navigating complex health conditions. Today we are focused on helping people with Glioblastoma and ALS

→ <https://www.roon.com/>

# Grants

# Resources

## **ALS Association — Massachusetts Chapter**

This grant program assists individuals with ALS or PLS with expenses incurred that are not traditionally covered by insurance such as private insurance, Medicare, Medicaid (Mass Health), and other assistance programs. It will cover respite, travel costs related to ALS clinics or research, generators, durable medical equipment repairs, and personal emergency response systems, and other ALS related expenses.

→ <https://www.als.org/massachusetts/local-care-services/grants-assistance>

## **ALS Foundation For Life**

The ALS Association Massachusetts Chapter maintains the ALS Foundation for Life's webpage as a service to those who have contributed to the foundation. The Massachusetts Chapter shall continue to maintain this page to honor the legacy the Foundation's two decades working to support persons with ALS and their families.

→ <https://www.als.org/massachusetts/local-care-services/grants-assistance>

## **The Assistance Fund - Amyotrophic Lateral Sclerosis (ALS) Financial Assistance Program**

This programs provides financial assistance to patients who have been diagnosed with ALS for the following out-of-pocket costs: prescription drug assistance (copays, deductibles, and coinsurance) on FDA-approved treatment, health insurance premiums, therapy administration costs, and treatment-related ground travel costs.

→ [https://enroll.tafcares.org/TAF\\_ProgramInformation?Id=S5PkZIFzIN%2FVosCPzFQfxfm5qD9fGk4wAflQWeYvQdUVs5TKzuvaLMFCsIE%2Bq%2BKg](https://enroll.tafcares.org/TAF_ProgramInformation?Id=S5PkZIFzIN%2FVosCPzFQfxfm5qD9fGk4wAflQWeYvQdUVs5TKzuvaLMFCsIE%2Bq%2BKg)

## **Edward T. Strauss Memorial Fund - "With Eddie's Help", Inc.**

Provides financial assistance for medical equipment and/or supplies to individuals who have, or to families where an individual has Amyotrophic Lateral Sclerosis (ALS).

→ <https://witheddieshelp.org/about-us/our-mission/>

## **HARK - Financial Assistance Program**

HARK provides assistance to alleviate the financial burdens faced by families battling ALS.

→ <https://hark-als.org/>

## **HealthWell Foundation - Amyotrophic Lateral Sclerosis Fund**

Provides financial assistance for insurance co-payments and premium for the prescription drugs and biologics used in the treatment amyotrophic lateral sclerosis.

→ <https://www.healthwellfoundation.org/fund/amyotrophic-lateral-sclerosis/>

## **Project Main Street**

Helping those who are experiencing financial challenges as a direct result of ALS.

→ <https://projectmainst.org/>

## **Team Gleason**

Helps financially with respite care, communication devices and adventure travel.

→ <https://teamageason.org/>

# Benefits

# Resources

## U.S. Department of Veterans Affairs (VA)

The U.S. Department of Veterans Affairs (VA) has recognized ALS as a service-connected disease, which means that the VA provides financial and medical support to veterans with at least 90 continuous days of active duty. If you qualify for these benefits, they can provide significant assistance in obtaining medical care, assistive devices and financial support. The Paralyzed Veterans of America (PVA) can guide you through the process of connecting with the VA.

→ <https://www.pvanewengland.org/contact/>

## Social Security Disability (SSDI) and Medicare

**Social Security Disability Insurance (SSDI)** is a program that provides monthly income for people who become unable to work due to a disability. The amount you receive each month depends on how much you earned and paid into Social Security over the years.

**Medicare** is a national health insurance program for seniors and some disabled people. It covers the bulk of medical and equipment expenses for most people living with ALS.

SSDI and Medicare are two separate programs, but you apply for them together.

Most people living with ALS qualify for Medicare and Social Security Disability Insurance—regardless of age. Medicare can cover the bulk of your healthcare costs and SSDI provides a monthly income.

→ <https://www.youralsguide.com/ssdi--medicare.html>

## FMLA (Family Medical Leave Act)

The Family and Medical Leave Act (FMLA) provides certain employees with up to 12 weeks of unpaid, job-protected leave per year. It also requires that their group health benefits be maintained during the leave.

→ <https://www.dol.gov/general/topic/benefits-leave/fmla>

## PFML (Paid Family Medical Leave)

Learn more about Massachusetts's Paid Family and Medical Leave (PFML), including how to apply, “leave” benefits, and approval timelines. Your employer may have responsibilities under both PFML and FMLA law, refer to your state government’s webpage for information. To check on other states’ PFML laws, refer to your state government’s webpage for more information.

→ <https://www.mass.gov/info-details/paid-family-and-medical-leave-pfml-overview-and-benefits>

## Disabled Parking Permit

If you would benefit from having a disabled parking permit, let us know if we can assist you with the application. Or for more information, please visit the website below.

→ <https://www.mass.gov/how-to/apply-for-a-disability-placard-or-license-plate>

## Mass Health (Medicaid)

Mass Health (Medicaid) is the state healthcare program that provides benefits based on state residency status and financial eligibility.

→ <https://www.mass.gov/how-to/apply-for-masshealth-the-health-safety-net-or-the-childrens-medical-security-plan>

# Connecting to Family Resources

## 5 Ways to Help Kids Cope with a Parent's ALS – ALS News Today

Kristin Neva, a mother of two whose husband Todd was diagnosed with ALS, provides a couple of points for parents to keep in mind while dealing with talking to their children, taking care of themselves, and caring for another family member.

→ <https://alsnewstoday.com/columns/help-kids-cope-death/>

## Talking with Children – ALS Worldwide

Sarah Byer conveys the importance of open and age-appropriate communication with children about ALS to help drive successful conversations. It also provides some books at the end of the article for children that have a parent of family member with ALS.

→ <https://alsworldwide.org/care-and-support/article/talking-with-children>

## Telling Children about ALS – ALS Connect

This blog post from ALS Association emphasizes not shielding children from the diagnosis and being open and honest to alleviate fears and establish trust and comfort, and also discusses things to keep in mind when telling others about a diagnosis.

→ <https://als-connect.org/2017/11/02/telling-children-about-als/#:~:text=Explain%20that%20it%20is%20hard,know%20exactly%20what%20causes%20ALS.>

## Supporting Kids and Teens through ALS – I Am ALS

I Am ALS provides a list of many tips for parents dealing with ALS while taking care of children. They also provide a list to resources for children, teens, and adults.

→ <https://iamals.org/get-help/supporting-kids-and-teens-through-als/>

## Families and ALS – ALS Association

This guide from the ALS Association dives into talking with children, caregiving for children, impacts at school, and loss, while providing sources and types of resources. It is filled with information, which may be overwhelming, but chapters and headings make it easy to pick and choose what's looked at.

→ <https://www.als.org/navigating-als/resources/Families-and-ALS-Resource-Guide>

## Talking to Your Kids about ALS – MDA

Aimee Chamerik, who lives with her husband and three kids while being diagnosed with ALS, reiterates a lot of the talking and parenting points from other resources, but provides a perspective of someone directly affected who knows what it's like to deal with it day to day.

→ <https://www.mda.org/alsn/article/talking-your-kids-about-als>

## Discussing ALS with Children – ALS Association

Another ALS Association resource provides a couple of communication points for parents to keep in mind while telling their children, as well as talks through helpful practices while living with the progressive disease and caring for children.

→ [https://secure2.convio.net/alsa/site/SPageNavigator/discussing\\_als\\_with\\_children.html;jsessionid=00000000.app277b?NONCE\\_TOKEN=80E2147E25AD56BD7E9B94ECC5F524A3](https://secure2.convio.net/alsa/site/SPageNavigator/discussing_als_with_children.html;jsessionid=00000000.app277b?NONCE_TOKEN=80E2147E25AD56BD7E9B94ECC5F524A3)

## Parenting through Terminal Illness – NYT

Kelsie Snow, a mother of two whose husband is diagnosed with ALS, and psychotherapist Andrea Warnick discuss honest communication with children, and how adult reactions towards things that arise with ALS shape some of children's feelings.

→ <https://www.nytimes.com/2021/08/04/parenting/terminal-illness-sick.html>

## Supporting Children When Someone Has a Terminal Illness – Marie Curie

This guide is similar to the one compiled by the ALS Association, but it is more general in terms of conversations about disease. They have a lot of good similar information, though the resources they provide outside of the guide are only relevant to patients in the UK.

→ <https://www.mariecurie.org.uk/globalassets/media/documents/how-we-can-help/booklets-pdfs-only/supporting-children->

# Caregiver Resources

## ALS Pathways—Caregiver Support

ALS Pathways provides support and resources to ALS caregivers as well as information aimed to assist in understanding and monitoring the disease.

→ <https://www.alspathways.com/caregiver-support/>

## ALS Care Connection

ALS Care Connection lets caregivers start a care team to post request for support, give updates, and streamline communication to keep their community in the loop.

→ <https://www.als.org/navigating-als/for-caregivers/als-association-care-connection>

## ALS Caregiving Toolkit

From I Am ALS, their caregiving toolkit provides first steps for coping with a diagnosis and communicating with providers. They include resources for navigating work and financial decisions/changes and finding in-home support.

→ <https://iamals2dev.wpengine.com/get-help/caregivers-start-here/>

## Family Caregiver Alliance

The FCA compiles resources for caregivers of adults with physical and cognitive impairment including support groups, financial planning, research updates, and navigating familial relationships. Their CareNav tool connects caregivers to local resources and a resource specialist that can help with unique needs.

→ <https://www.caregiver.org/>

## SimpliHere

SimpliHere is an application that helps people with ALS and their caregivers communicate, manage daily activities, and stay connected. The app features a voice assistant that helps to communicate basic needs, contact providers, find equipment and get ALS news.

→ <https://www.simplihere.com/>

## The Susie Foundation

The mission of the Susie Foundation is to provide assistance to young caregivers and families struggling with the family challenges of living alongside ALS. They provide financial assistance and host events to connect families.

→ <https://www.thesusiefoundation.org/>

## MDA Guide for Caregivers

This comprehensive guide delves into the many aspects of caring for an individual with a neuromuscular disease and discusses topics from daily care and ventilation to quality of life.

→ <https://www.mda.org/sites/default/files/Guide-For-Caregivers-2018.pdf>

## Caring for Persons with ALS

This document was created by the Les Turner ALS Foundation and discusses home health and activities of daily living. It also includes helpful questions to ask when hiring a caregiver for persons with ALS.

→ <https://lesturnerals.org/section-5/>

## Taking Care of YOU: Self-Care for Family Caregivers

This resource created by the Family Caregiver Alliance discusses the importance of caregivers not only caring for their loved one, but also for themselves. The importance of self-care and well-being are emphasized in this article, as well as techniques and skills to help reduce stress

→ <https://www.caregiver.org/resource/taking-care-you-self-care-family-caregivers/>

# Health & Wellness

# Resources

## **Medical Psychology Group**

ALS Pathways provides support and resources to ALS caregivers as well as information aimed to assist in understanding and monitoring the disease.

→ <https://www.mpc.care/>

## **Center for Healthy Aging**

ALS Care Connection lets caregivers start a care team to post request for support, give updates, and streamline communication to keep their community in the loop.

→ <https://www.beverlyhospital.org/center-for-healthy-aging>

## **ALS Parenting At a Challenging Time (PACT) Program**

The ALS PACT Program provides parent guidance to support parents in addressing the illness-related challenges faced by their children and adolescents.

→ <https://www.massgeneral.org/neurology/als/services/als-parenting-pact>

## **MGH Dental Group**

This dental group has offices in Boston and Danvers and may offer home visits for patients not on ventilators. This is also the Mobile Dental Hygiene group if patient is on MassHealth

→ <https://www.mobiledentalhygiene.com/>



### **MGB Neurology Clinic - Boston**

15 Parkman St #835 (Wang Building, 8th Floor)  
Boston, MA 02114

### **Healey & AMG Research Center for ALS**

165 Cambridge St Suite 600  
Boston, MA 02114

### **MGB Neurology Clinic - Waltham**

52 Second Ave, Suite 3100  
Waltham, MA 02451

*(Some of our providers see patients in both Boston and Waltham)*

### **The ALS Clinic at the Healy & AMG Center**

phone #- 617-724-3914  
fax# - 617-724-7290

Join the MGH ALS Link  
Your reliable resource for ALS



<https://lp.constantcontactpages.com/su/saTzwlp/ALSLink>