



Welcome

To the Healey Center for ALS at Mass General
An MDA Care Center of Excellence



Healey Center

Sean M. Healey & AMG Center
for ALS at Mass General



MASSACHUSETTS
GENERAL HOSPITAL



Healey Center

Sean M. Healey & AMG Center
for ALS at Mass General

Merit E. Cudkowicz, MD, MSc

Chief, Neurology Department

Director, Sean M. Healey & AMG Center for ALS

Massachusetts General Hospital

Julianne Dorn Professor of Neurology

Harvard Medical School



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/) 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



MASSACHUSETTS
GENERAL HOSPITAL



HARVARD
MEDICAL SCHOOL



Healey Center

Sean M. Healey & AMG Center
for ALS at Mass General

James D. Berry, MD, MPH
Chief, Division of ALS and
Motor Neuron Diseases
Massachusetts General Hospital



I'd like to welcome you to our ALS Multidisciplinary Clinic in the Healey Center for ALS at Mass General. All of us are truly glad you've chosen to visit and look forward to seeing you very soon. Whether you are coming for an initial evaluation, or a second opinion, or to learn about our research opportunities, feel comfortable in knowing that at the heart of everything we do in clinic are two driving principles — 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. In our multidisciplinary clinic, we assembled a team of people with a broad array of expertise to cover all the bases in a single stop — from speech, physical and respiratory therapists, a genetic counselor, nurses and nurse practitioners, to our palliative care

doctor, several ALS neurologists, a physical medicine and rehab physic physician, affiliated pulmonologists, and our research team. We are also excited about our other programs: ALS Parenting at a challenging time (ALS PACT), Virtual Visits, and ALS House Call.

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. 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 the way we think it should be provided, 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 Berry, MD



MASSACHUSETTS
GENERAL HOSPITAL

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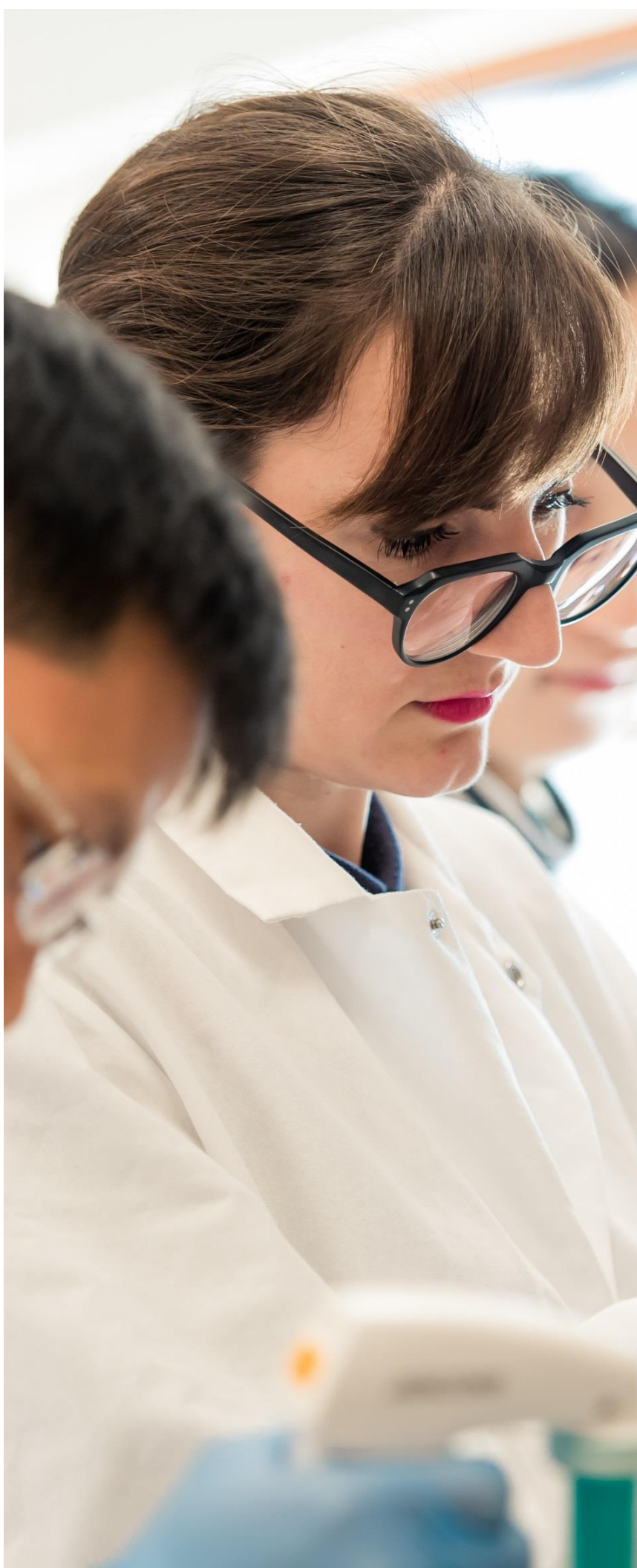
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How do YOU become a New Patient?

Step 1

Patient Registration

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/

Scheduling Appointment

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**.

Step 2

Step 3

Follow-up Communications

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.

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 and general questions so that we can best 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: <https://www.massgeneral.org/als/about/als-faqs.aspx>



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



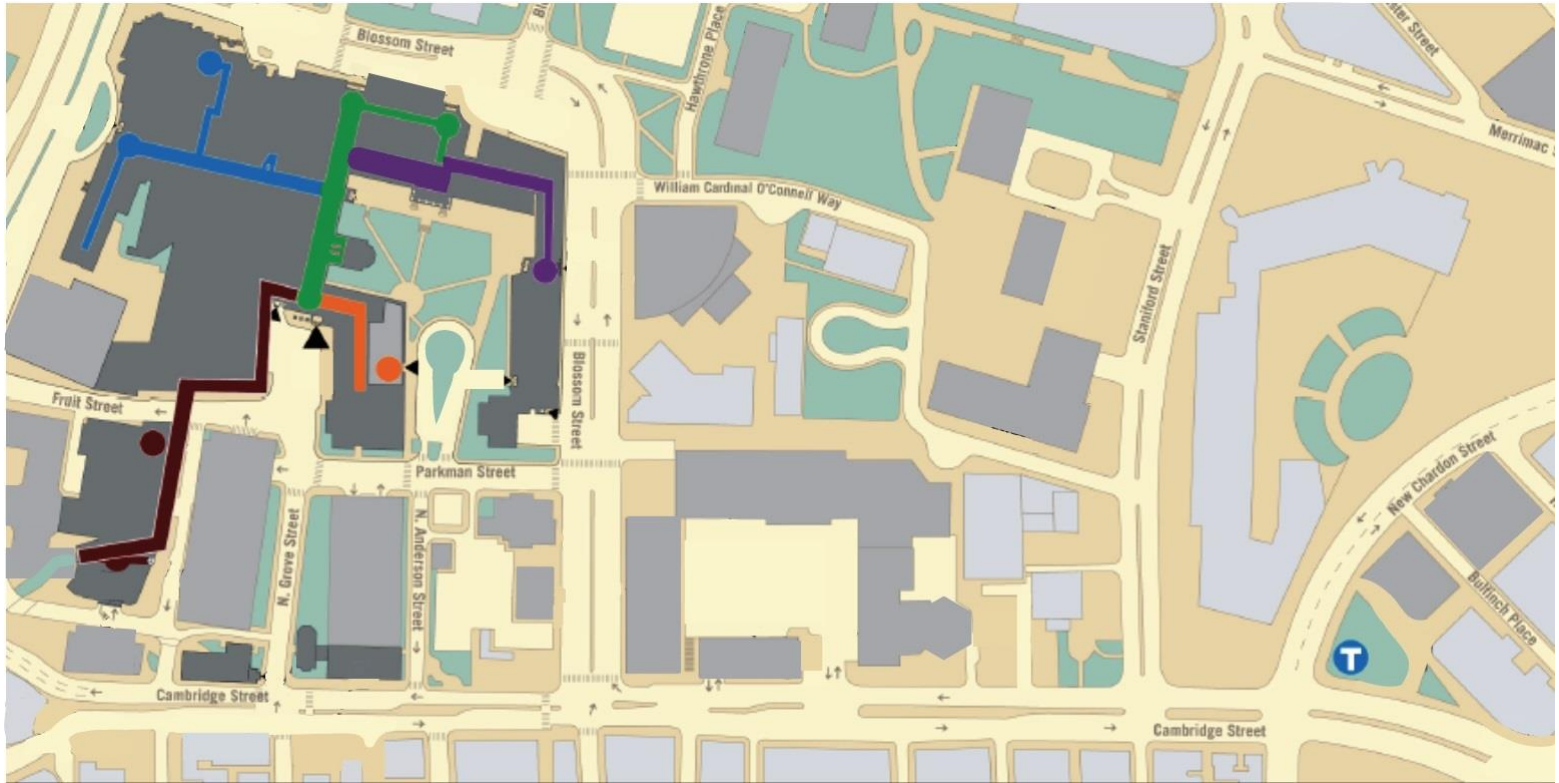
Arrive
Early

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.

MGH Campus Map



Our Locations

- ① **Wang Ambulatory Care Center**
15 Parkman Street, Boston MA 02114
 - ALS Clinic Visits, (on Tuesdays)... 8th floor
 - Labs for Blood Draws..... 2nd floor
 - EKGs..... 2nd floor
 - Occupational Therapy and Orthotics 1st floor
- ② **Sean Healey Center**
165 Cambridge Street, Boston MA 02114
 - Research Visits..... 6th floor
 - ALS Clinical Visits..... 6th floor
- ③ **Neuromuscular Clinic Institute**
165 Cambridge Street, Boston MA 02114
 - EMG Infusion Suite..... 8th floor
 - ALS Botox Injections..... 8th floor
- ④ **Ellison Building**
55 Fruit Street, Boston MA 02114
 - Outpatient Surgeries, Room 210... 2nd floor

Parking

For detailed direction to the hospital, please visit our website:

<https://www.massgeneral.org/visit/directions/>

- **Fruit Street Garage**
Preferred parking lot for Family/Friends visiting the emergency room or inpatient units.
- **Parkman Street Garage**
Preferred parking lot for Patients visiting the Wang Ambulatory Care Center or main campus. (Valet Parking available upon request)
- **Charles River Plaza Garage**
Preferred parking lot for Patients visiting the Sean Healey Center. Underground parking is available at 207 Cambridge Street.

Pharmacy

- ⑤ **Mass General Outpatient Pharmacy**
55 Fruit Street, Boston MA 02114... Lobby
Phone Number: (617) 724-2100
Monday-Friday, 9am-5:30pm
- ⑥ **CVS Charles River Plaza**
191 Cambridge Street, Boston MA 02114
Phone Number: (617) 367-0441
Monday-Friday, 9am-8pm
Saturday, 10am-5pm
- ⑦ **CVS Charles River Plaza**
155 Charles Street, Boston MA 02114
Phone Number: (617) 523-1028
Monday-Friday, 9am-8pm
Saturday, 10am-5pm

Banking

- ATM's (BoA and Citizens) are located:
- White Building, 1st floor main corridor
 - Ellison Building, 1st floor main corridor
 - BoA Center at 161 Cambridge Street
 - Wang Ambulatory Care Center, basement level

More Information

Lost & Found

- Contact the MGH Police and Security department center at (617) 726-2121

Wi-Fi

- For free Wi-fi please join the "PHSPIAGUEST" network

Cafeterias & Cafés

- ⑧ **Tea Leaves and Coffee Beans**,
15 Parkman Street, Boston MA 02114... Lobby
Monday-Friday, 7:30am-3pm
- ⑨ **Coffee Central**,
55 Fruit Street, Boston MA 02114... Lobby
Monday-Friday, 24/7 hours
- ⑩ **Eat Street Café**,
55 Fruit Street, Boston MA 02114... Basement
Monday-Friday, 7am-8pm
- ⑪ **Riverside Café**,
327 Cambridge St, Boston, MA 02114... Lobby
Monday-Friday, 8am-4:30pm
- ⑫ **Coffee South**,
327 Cambridge St, Boston, MA 02114... Lobby
Monday-Friday, 8am-4:30pm
- ⑬ **Whole Food Market**
Monday-Friday 7am-10pm
www.wholefoodsmarket.com/stores/charlesriver

Retail Shop

The General Store and Flower Shop
Monday-Friday, 8:30am-7:30pm
Weekends and Holidays, 10am-6pm

The General Store at Yawkey
Yawkey Center for Outpatient Care
Monday-Friday, 8:30am-7:30pm
Weekends and Holidays, 10am-6pm

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

ALS Physicians



Merit Cudkowicz
MD, MSc
Chief, Neurology Department
Director, Sean M. Healey & AMG Center



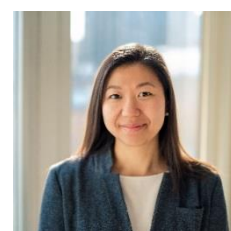
James D. Berry
MD, MPH
Chief, Division of ALS and
Motor Neuron Diseases



Nazem Atassi
MD, MMSc



Suma Babu
MBBS, MPH



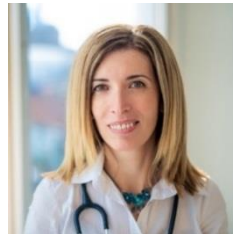
Sheena Chew
MD



William David
MD, PhD



**Katharine
Nicholson** MD



Sabrina Paganoni
MD, PhD



Haatem Reda
MD

ALS Nurse Practitioners



Darlene Sawicki,
MSN, NP-BC
617-724-3914



Jennifer Scalia, NP
617-724-3914



Sarah Luppino, NP
617-724-3380



Debra Skoniecki, NP
House Call Program
617-643-0422



Alexandra McCaffrey, NP
617-724-6024

To communicate with your ALS Care Team: Patient Gateway is the best way to communicate non-urgent matters (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 Nurses



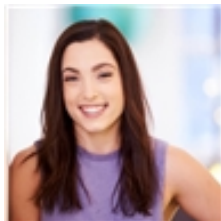
Maggie Bruno, RN
Clinical Nurse Caring
for Patients of Dr. Babu
& Dr. Atassi
617-643-7561



Judi Carey, RN
Research Access Nurse
617-724-8995



Kristen Kingsley, RN
House Call Program Nurse
617-504-1011



Ally Hochman, RN
Clinical Nurse Caring for
Patients of Dr. Chew



Margot Rohrer, RN
Clinical Research Nurse



Danica Sanders, RN
Clinical Nurse Caring for
Patients of Dr. Pagoni
& Dr. David
617-643-6249



Hannah Zivalic, RN
Clinical Nurse Caring for
Patients of Dr. Nicholson
& Dr. Reda
617-643-2060



Alexandra Mucci, RN
Clinical Nurse Caring for
Patients of Dr. Berry

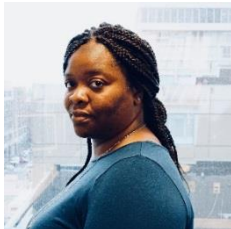
Patient Service Coordinators



Mayra Alvarado
House Call Coordinator &
Radicava Specialist
617-643-7290

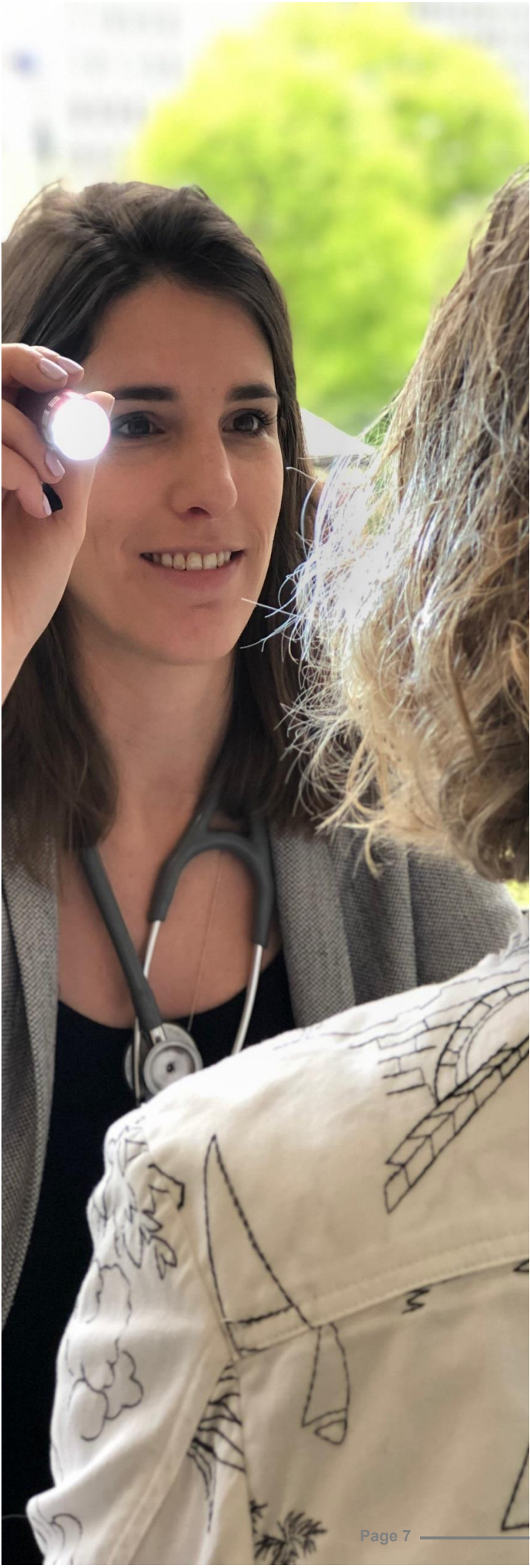


Daisy Feliciano
Patient Service
Coordinator II
617-724-3914



Larissa Jackson
Team Lead Patient
Service Coordinator III
617-724-3914

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Allied Health Providers and Affiliated Specialists



Katherine Burke
DPT, PT, NCS
Physical Therapist



Amy Swartz Ellrodt
PT, DPT
Clinical Services Manager
Physical Therapist



Paige Nalipinski
MA, CCC, SLP,
Speech Language
Pathologist



Stacey Sullivan
MS, CCC, SLP,
Speech Language
Pathologist



Julie MacLean
OTR/L
Occupational
Therapist



Purris Williams, RRT
Respiratory Care
Coordinator



Diane Lucente, MS
Genetic Counseling
Manager



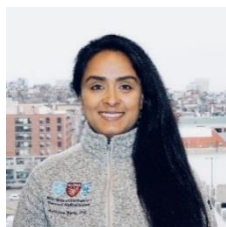
Joe Meekins
Spiritual Care Provider
jmeekins@mgh.harvard.edu



Kate T. Brizzi, MD
Neuropalliative Care
Physician



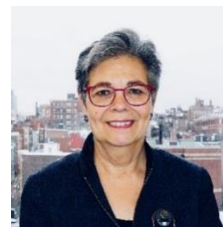
Victoria Siddall
Resource Specialist



Archana Basu, PhD
Psychologist ALS PACT Program
mghalspact@partners.org



Cynthia Moore, PhD
Psychologist ALS PACT Program
mghalspact@partners.org



Paula Rauch, MD
Psychiatrist ALS PACT Program
mghalspact@partners.org

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Clinical Research Coordinators



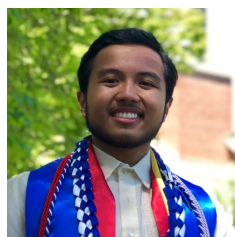
Grace Addy



Isabel Anez



Reagan Church



Ross Cimagala



Yuriko Fukumara



Dario Gelevski



Daniel Hevert



Katherine Holmberg



Ann Hu



Gabriel Jacobs



Mackenzie Keegan



Anthony Kostov



Austin Lewis



Kush Mehta



Mia Resendes

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Clinical Research Coordinators cont.



Zoe Schier

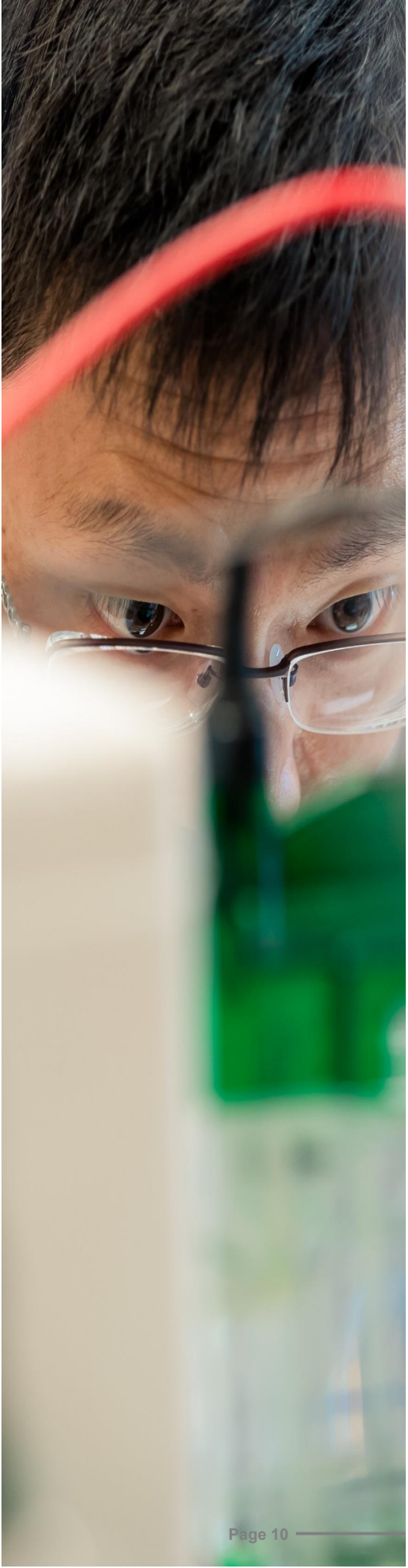


Simon Shulman



Megan Yerton

To communicate with your ALS Care Team: Patient Gateway is the best way to communicate non-urgent matters (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.



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. **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.
- **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.
- **Radicava Specialist:** Upon referral from your Physician to help obtain insurance approval for Radicava and coordinates administration of Radicava with local infusion companies. **This process can take 10-12 weeks to establish. Main Contact Number: 617-643-7290**
- **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.
- **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



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 do I schedule a clinic visit?

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 Cafés 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/cafeterias.aspx>

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.

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 Clinic in the Healey Center for ALS 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 **617-726-2787** for further assistance.

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/>

Q. Where do I park for my appointment?

A. Valet parking is available at the entrance for the Wang Ambulatory Care 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/maps-and-directions/>

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**.

Please visit our main campus interactive map to find the building where your appointment is located:

<https://www.massgeneral.org/visit/maps-and-directions/>

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/) 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 travelling 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/visit/>



Research

ALS Research at MGH Healey Center

(<https://www.massgeneral.org/als/research/?display=clinical-trial-list>) is our clinic's website that was developed to help people with ALS, their families and friends to understand what ALS is, how it is diagnosed, what research is being done to understand ALS and develop better treatments, and how we at Mass General address some of the important issues that are related to the disease.

ALS Untangled

Scientific effort investigating alternative and off-label ALS treatments, while bringing together patients, clinicians, and scientists via Twitter, a social networking tool.

<http://www.alsuntangled.com/index.html>

ClinicalTrials.gov

(<https://clinicaltrials.gov/>) is a website that provides patients, family members, health care professionals, and other members of the public easy access to information on clinical studies on a wide range of diseases and conditions. Information is provided and updated by the sponsor or principal investigator of the clinical study and the website is maintained by the U.S. National Library of Medicine (NLM) at the National Institutes of Health (NIH).

fALS Connect

fALS Connect is an online registry for people with familial ALS with the stated goal of facilitating research in ALS to develop treatments and ultimately a cure for this disease. By creating an online account, participants agree to be contacted about potential research opportunities. No identifying information is shared. <https://fals.patientcrossroads.org/>

Northeast ALS Consortium (NEALS)

(<http://www.neals.org>) is a website that provides comprehensive ALS clinical trial database, clinical trials 101 information, and blog to keep patient and caregiver communities well-informed about clinical research, trial opportunities, and scientific advancements world-wide.

National ALS Registry

Visit the page (www.cdc.gov/als) to participate in the registry or biorepository is the Center for Disease Control's (CDC) growing registry of ALS patients to help improve understanding of who gets ALS and factors that affect disease.



Community Resources

ALS Association (ALSA) (www.alsa.org)

Leading the fight to treat and cure ALS through global research and nationwide advocacy while also empowering people with Lou Gehrig's Disease and their families to live fuller lives by providing them with compassionate care and support.

- 1) Click on “In Your Community”
- 2) Select “State” under “*Find your local chapter*”
- 3) **To register for the Massachusetts Chapter:**
 - E-mail info@als-ma.org
 - Call 1-781-255-8884
 - Call 1-888-CURE-ALS

ALS Charitable Foundation (<http://alsfamily.org>)

Organization dedicated to raising funds for research to cure ALS in the future and providing patient services in support of those living with Amyotrophic Lateral Sclerosis today.

ALS ONE (www.alsone.org)

An organization is an unprecedented partnership of the top leaders, researchers, doctors and caretakers in ALS from MGH, UMass Medical School, Harvard Medical School, ALS Therapy Development Institute, and Compassionate Care ALS. Together, this team has identified the strongest therapeutic opportunities in ALS and has developed a plan with the goal of bringing a treatment or cure to patients.

ALS Information at the National Institute of Health (NIH)

www.nlm.nih.gov/medlineplus/amyotrophiclateralsclerosis.html

Comprehensive overview of ALS provided by MedlinePlus, a service of the U.S. National Library of Medicine. Materials are also available in Spanish.

ALS Therapy Development Institute (TDI)

(<http://www.als.net/als-community/>)

The ALS TDI's community page includes events, an online forum, and social networking opportunities.

Compassionate Care ALS (CCALS)

(<http://www.ccals.org>)

Organization dedicated to supporting ALS and their families through direct services, education, and equipment, while maintaining a holistic presence.

To register: E-mail info@ccals.org or call 508-444-6775



Everything ALS (<https://www.everythingals.org>)

This organization's mission is to support efforts to care for ALS patients and work to find a cure by creating a platform for direct engagement with patients, caregivers, advocates, and researchers.

I Am ALS (<https://iamals.org/>)

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

Muscular Dystrophy Association (MDA)

(<https://www.mda.org/>)

The MDA's website contains sections on advocacy, clinical trials, support groups, research news, and more.

To connect to MDA/ALS:

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

- To register: Sign a registration paper at clinic with your nurse or MDA representative
- Or contact the MDA Resource Center: 1-800-572-1717, option 1

PatientsLikeMe (<http://www.patientslikeme.com/>)

PatientsLikeMe® creates new knowledge by charting the real-world course of disease through the shared experiences of patients. While patients interact to help improve their outcomes, the data they provide helps researchers learn how these diseases act in the real world and accelerate the discovery of new, more effective treatments.

- Follow company news on [Twitter.com/PatientsLikeMe](https://twitter.com/PatientsLikeMe) and <http://blog.patientslikeme.com>

Podcasts

Connecting ALS Podcast

(<https://www.connectingals.org/>)

ALS Pathways Podcast Series

(https://www.alspathways.com/als-resources/?utm_source=email5&utm_medium=email&utm_campaign=resources&utm_content=patient#podcast-series-patient)

National Organization for Rare Disorders Podcast

(<https://rarediseases.org/nordpod/>)





"Our greatest privilege is caring for you and your loved ones!"

Supporting ALS Research and Care

"There's never a better time than now, for action in our quest to cure ALS." – At the Sean M. Healey & AMG Center for ALS at Mass General, we are deeply grateful for the outpouring of financial support from MDA ALS Care Center, ALS One and the generosity of individuals like you.

Your generous gifts, coupled with patient participation in clinical trials, place our research center at the forefront of innovative ALS research. With your support, it is possible to push progress, move innovation forward quicker, and challenge our determined experts to cure ALS. We are at an exciting and critical time in our ALS research, with a pipeline of promising therapies to bring forward to clinical trials for people with ALS. Utilizing new tools and technologies available to scientists, we are accelerating the discovery of therapies into action for people with ALS.

Your contributions span beyond helping to fund research by also supporting our multidisciplinary clinic and allowing us to provide comprehensive care for our patients through the expertise of physical and speech therapists, occupational therapists, respiratory therapists, a genetic counselor, nurse and nurse practitioners, to our palliative care doctor, several ALS neurologists, a physical medicine, rehab physician, affiliated psychiatrist, pulmonologists, psychologists, and our research team too.

In addition, we are able to offer ALS House Calls, tailoring physical and medical support to meet needs of our patients at home; TeleHealth, providing coordinated patient care in a way that is most convenient and best suited to the patient's needs through virtual technology; and ALS PACT, (Parenting at a Challenging Time), which offers guidance for parents addressing the disease related challenges faced by their children.

Now more than ever, we depend increasingly on philanthropic partnerships with our sponsors, patients, families, friends and people like you to ensure we can continue to train the leaders in neurology to explore new pathways and discover effective approaches to treating, reversing and ultimately preventing ALS. By making your contributions to Mass General, we sincerely thank you for believing in us and inspiring every member of our team to work tirelessly to break down barriers, accelerate research, and bring light to hope to many patients previously without access to new, innovative, and personalized therapeutics. ***(Please read the next page for a list of the many ways to support ALS research.)***

Now more than ever, your support makes our work possible.

Thank you.



To make a donation or learn more about ways to give, visit massgeneral.org/als/healeycenter or checks may be made out to: Massachusetts General Hospital Healey Center and mailed to: Mass General Development Office
Attn: Healey Center/Department of Neurology 125 Nashua
Street, Suite 540 Boston, MA 02114

To make a donation:

giving.massgeneral.org/donate/healey-center/

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Thank You to Our Supporters:



And the many generous Donors like YOU!

————— We are humbled by your support. —————



