UMass HDSA COE Updates: October 2024

The UMass Huntington's Disease Society of America Center of Excellence (UMass HSDA COE) comprehensive care movement disorders clinic at UMass Chan and UMass Memorial Medical Center offers specialized care for Huntington's Disease patients and families.



"We are very excited to launch the first edition of our Huntington's Horizon newsletter! Special thanks to Sharon Velazquez for designing this. We hope this will be a source of information related to managing Huntington's disease, research updates and events. Our team is very passionate about care for HD patients and families, and we look forward to being a partner in your care!" - Anindita Deb, MD

Meet our UMass HSDA COE Team

Our team, led by Anindita Deb, MD, Director, UMass HSDA COE in partnership with Samuel Frank, MD, Director, HDSA COE at BIDMC provides a holistic approach to research and treatment opportunities.



Pictured from L to R:

Kelly Gaumond, RN, Nurse Navigator; Maria DelVecchio, LCGC; Rajavi Sanghavi, MA, CCC-SLP; Anindita Deb, MD, HDSA COE Director, Sarah Crombie, LICSW, Elisabeth Larrivee, LICSW; Jennifer Gomez, HD Clinic

We are focused on serving families in the Central and Western MA region to meet the individualized needs associated with Huntington's Disease.

You will have a supportive team to best assess and address your needs and concerns. Our team includes a fellowship-trained Movement Disorders neurologist, genetic counselor, nurse navigator, speech therapist, and social worker. We aim to have members of the team present during your initial evaluation and throughout your journey with Huntington's Disease.

Our team also collaborates with other specialists and experts through consultation services for areas such as

genetic testing, nutrition screening, rehabilitation therapies, palliative care, neuropsychology, and neuropsychiatry.

HD Current and Ongoing Research



Dr. Kara Smith from UMass is collaborating with researchers at Beth Israel Deaconess Medical Center to study speech problems in Huntington's Disease (HD). The team plans to explore innovative new ways to use speech and technology to better understand and monitor HD symptoms. The goal of this research is to learn more about the speech changes that occur in Huntington's disease and how they may be similar or different from other neurological conditions like Parkinson's disease, and then to develop tools that will use speech information gathered and analyzed by technology in order to monitor changes over time in patients with HD.

Learn about UMass HD COE clinical trials

HD research is on the rise, learn about current and ongoing focused support for patients and families at **HDBuzz - Huntington's disease research news**.

News for Patients and Families:

We are very excited to have our multidisciplinary HD clinic up and running. We have an experienced team able to provide specialized movement disorders evaluation, social support, resources, genetic counseling and testing. Our team of specialists looks forward to meeting patients and their families.

Speech Language Pathology and Huntington's Disease

You or your loved one with HD may have trouble with speech and/or swallowing. These are commonly referred to as

- Dysarthria (dis-AR-three-yuh): A condition that leads to slurred and difficult to understand speech, and
- Dysphagia (dis-FAY-juh): Difficulty swallowing. This can include difficulty coordinating muscles to keep food in the mouth, chewing and/or food/liquids "going down the wrong way".

Your doctor may refer you to see a Speech Language Pathologist to further assess these concerns and guide you with improving you/your loved one's ability to communicate and improve safety with eating and drinking.



Community News and Events:

This is the first edition of our HDSA COE Newsletter and with your feedback, we hope to continue to provide information related to HD resources and care in the region. In partnership with BIDMC-Lahey, we are organizing a virtual educational symposium for healthcare professionals across the state which we hope to hold in early 2025.

HD events to raise awareness and education for patients and families.

To learn more or become involved in local community events, click on the **Local HDSA Events** link or the **Education and Youth Day event in November 2024**.





In 2024, UMass Huntington's Disease Society of America Center of Excellence (UMass HDSA COE) has received reaccreditation from the Huntington's Disease Society of America (HSDA) as a partner site to Beth Israel Deaconess Medical Center (BIDMC).

Click the link to learn more about the **<u>Huntington's Disease Society of America (hdsa.org)</u>**.

Stay Informed:



Contact Jen Gomez or Anindita Deb regarding patient referrals for consultation or co-management for Huntington's patients.

Physician Referrals



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UMass Movement Disorders Team

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