The Louise Wilcox ALS Clinic at Rhode Island Hospital: 25th Anniversary (1999–2024)

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Image 1. The late **Louise Wilcox**, an accomplished chef who was the inspiration and motivator for the establishment of the ALS clinic at Rhode Island Hospital that now bears her name.

It is with great pride that we announce that the Louise Wilcox ALS Clinic at Rhode Island Hospital is celebrating its 25th anniversary. Inaugurated in 1999, the clinic has grown substantially over the course of a quarter century, while implementing advances in the diagnosis and treatment of Amyotrophic Lateral Sclerosis (ALS) here in Rhode Island.

The clinic was named for Louise Wilcox, a graduate of the Culinary Program of the Rhode Island School of Design and an accomplished executive chef and cookbook author, who started developing symptoms of ALS at age 33 (**Images 1–3**). She continued to cook at a high level, despite her progressive debility, even adapting her kitchen to allow the use of her motorized wheelchair.[1] A resident of Westport, Massachusetts, Louise attended multidisciplinary ALS clinics in Boston and resolved that this level of care should be offered locally to Rhode Islanders with ALS. Her spirit and drive were instrumental in launching the clinic that now bears her name after her passing.

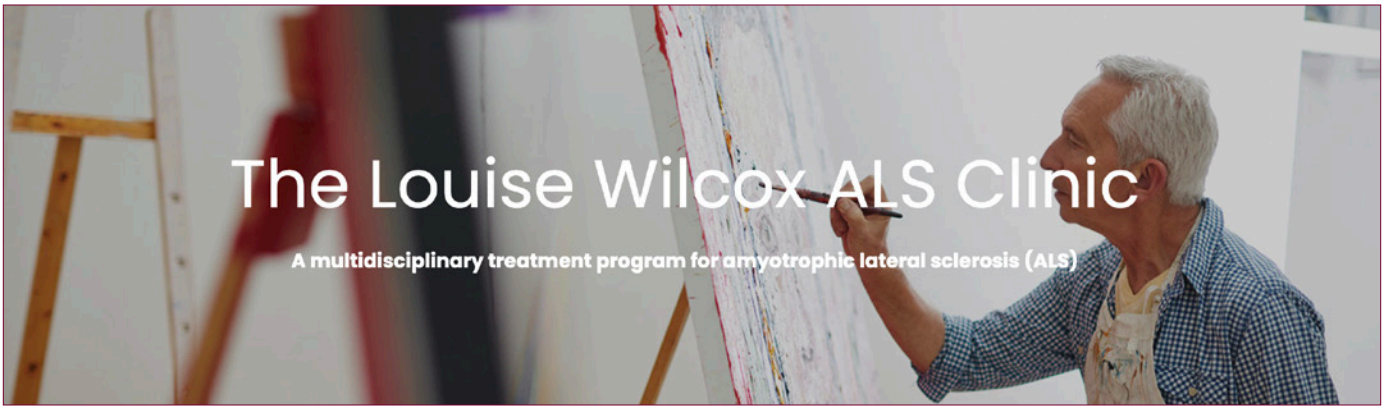
Although the passion and expertise of the clinic has not changed since 1999, the scope of the care provided certainly has grown over the years. The clinic started with a handful of patients during the first year, who were seen in a clinic on Dudley Street in Providence. The clinic then moved to its current, updated facilities in the Ambulatory Patient Center (APC) at Rhode Island Hospital in 2015. Registration records, as kept by ALS United Rhode Island, indicate that a total of 711 patients have been diagnosed with ALS in Rhode Island since 2013, many of whom have received care at the Louise Wilcox Clinic, with 55 patients seen in 2023 alone – certainly an uptick in numbers since the start of the clinic. With an estimated prevalence of 5.5 people per 100,000 living with ALS in the Northeast US, Rhode Island would, statistically, have about 50–60 people living with ALS.[2]

Image 2. Louise Wilcox, center, in a photo circa 1999, is shown with **Dr. Nicholas Hill** and **Ruth Dickinson, RN**.

Image 3. The clinical staff at the Louise Wilcox ALS Clinic at Rhode Island Hospital, in a photo from 2021, are, from left, **Erin Gill, RN**; **Michelle Cupolo, PT**; **Sarah Overy, OT**; **Dr. Vincent LaBarbera**, **Dr. George Sachs**, **Dr. Nick Hill**, **Robin Vales, RD**, and **Beth Baccari, SLP**. [PHOTOS COURTESY OF THE LOUISE WILCOX ALS CLINIC AT RHODE ISLAND HOSPITAL]

TREATMENT, TESTING, RESEARCH

Symptomatic and respiratory care, in addition to dietetics/nutrition, speech-language pathology and occupational and physical therapy services, were, and remain, the mainstays of treatment for this disease. In 1999, only one FDA-approved medication, riluzole, was available for the treatment of ALS. This medication initially was shown to modestly prolong lifespan among people with ALS,[3] although more recent real-world data[4] may suggest a more substantial lifespan prolongation with riluzole.



The ensuing years have seen the approval of the infusion edaravone in 2017, shown to further slow the progression of the disease,[5] followed by its oral formulation in 2022, making the treatment available to patients who could not utilize an IV port. More recently, the first approved treatment for familial ALS, the intrathecally- (via a spinal tap) administered tofersen for Superoxide Dismutase 1 gene (SOD-1)-positive ALS, became available.[6] Unfortunately, the medication sodium phenylbutyrate-taurursodiol, which had achieved conditional FDA approval in 2022, was recently pulled from the market (April 2024) due to unfavorable Phase III trial data.

The cost of these medications can prove to be a significant barrier to patients seeking their use. Thankfully, with a diagnosis of ALS, these medications are typically available and covered by commercial insurance, although certain inclusion criteria, namely duration of disease, pulmonary function parameters, and current functional status, are required (specifically for the use of edaravone). The respective pharmaceutical companies have programs which can help to defray cost as well. Additionally, ALS is an entity covered by Medicaid and Medicare. Without these programs, riluzole can cost approximately $7600 per year, edaravone approximately $173,000 per year, and tofersen approximately $199,200 per year.[7]

Over this time frame, advances in the availability of genetic testing have now afforded all patients with ALS the opportunity to undergo testing and, potentially, treatment of the most common gene mutations. Further genetic treatments are in the research pipeline. Currently, all patients with a diagnosis of ALS are offered genetic testing. Genetic testing is often covered by commercial insurance, but at present, sponsored testing from pharmaceutical companies is also widely used to defray out-of-pocket costs to our patients.[8]

CLINIC PROVIDERS

The medical providers who staff and coordinate the clinic, and the team members at ALS United who run the community services, including support groups, the durable medical equipment loan closet, transport services to and from medical appointments, among other services, are the glue that keeps the clinic together. Dr. George Sachs, the clinic's first and longest-serving medical director, was the sole neurologist of the clinic for more than 20 years before his retirement in 2022, preceding the arrival of the current clinic medical director and neurologist, Dr. Vincent LaBarbera in 2021. Dr. Nicholas Hill has served since the clinic's inception as its senior pulmonologist. Dr. Michael Stanchina and Dr. John Ladetto have volunteered time to the clinic, and currently, Drs. Hill and Ladetto alternate as pulmonologists to our patients. A multitude of neurology and pulmonology residents and fellows from the Brown University/Rhode Island Hospital and Tufts Medical Center systems have also gained invaluable educational experience while rotating through the clinic.

The therapy staff, including physical therapist Michelle Cupolo, occupational therapists Sarah Overy, Jean Fraize, and Angela Pucino, speech language therapists Elizabeth Baccari and Amy Muschiano, and dieticians Robin Vales and Barbara Santurri aim to help our patients maintain their optimal function, regardless of insurance or immigration status. At present, our clinic refers out to colleagues in the community for mental health/psychological therapy and social work, as well as to psychiatry and palliative care services.

The contributions of our clinic coordinators, starting with Ruth Dickinson, RN, whose father-in-law succumbed to ALS, and currently, Erin Gill, RN, and our volunteers, including, over the years, Linda Boudewyns and Linda Benish, cannot be overestimated. They assure the smooth functioning of the clinic and provide many services to our patients and their families, helping them obtain needed equipment and making connections with other providers such as outside physicians and durable equipment companies. The clinic is also deeply indebted to the loyal support of ALS United Rhode Island, formerly the ALS Association, Rhode Island Chapter.

SUMMARY

The Louise Wilcox clinic has seen tremendous growth in the past 25 years, and we are excited to see how the clinic can continue to thrive. With the promise of medications and new therapies in the pipeline, we hope that our services will be much less

needed at some point in the not-too-distant future. But until then, we aim to continue to serve this community of patients, to provide care, to educate patients, families, and the next generation of medical providers, such that our patients and families do not have to face this devastating diagnosis alone, and to maintain dignity and hope – as neurologist W. Bryan Matthews expressed it: "The best test of a physician's suitability for the specialized practice of neurology is not his ability to memorize improbable syndromes but whether he can continue to support a case of motor neurone disease, and keep the patient, his relatives and himself in a reasonably cheerful frame of mind."[9]

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Disclosure

The authors (VL, EG, NH, GS) report no conflicts of interest.

Disclaimer

The views expressed herein are those of the authors and do not necessarily reflect the views of Brown University/Rhode Island Hospital, Tufts Medical Center, or ALS United Rhode Island.

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