



16th Annual ALS Care and Research (Virtual) Symposium

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Disclosures/ Disclaimers

- › I, nor my family, have any financial or other relationship with the drug/ pharmaceutical companies mentioned, beyond participating in the clinical trials



ALS Clinic

- › Multidisciplinary Clinic- Froedtert Hospital, VAMC
 - ALS Physicians- Paul Barkhaus, Dominic Fee, David Shirilla
 - Nursing- Stacey Martinetti, Doris Lozano, Naya Fabian, Jamie Groh
 - Therapists
 - › Respiratory- Ellyn Newman, Jodi Morgan, Michelle Werner
 - › Physical and Occupational- Cody Halber, Peggy Hoyt, Rachel Larson, Bill Reinhard, Deb Romoren, Katie Schultz, Chris Wipperman
 - › Speech and Dietary- Suzi Bloedel, Peter Cummings, Aaron Feest, Libby Kelley, Michelle McDonagh, Jennifer Sargent
 - › Pharmacy- Michelle Maynard
 - › ALSA, Chaplain, Child Life, Psychology, Social Work- James Durnil, Mary Defrain-Jones, Megan Kilps, Amy Houston PsyD, Heidi Miranda, Robin Stanczyk; Sue Berg
 - Research- Lynn Wheeler, Marie Mejaki



ALS Clinic- 2019 Totals

- › MCW clinic at Froedtert Hospital
 - ALSA Certified Treatment Center of Excellence
 - Patients- 220 active
- › VA clinic
 - ALSA Certified Treatment Center of Excellence
 - Patients- 40 active



ALS Education

› Lectures

– Therapists

› Many at local ALS Support Groups

- PT/OT- Transfers and Safety

- Dietary- Nutrition

– Dr Barkhaus

› MCW

- Dept of Physical Medicine and Rehabilitation

 - › Clinical Neurophysiology of ALS

- Palliative Care Program

 - › Palliative Care in ALS



ALS Clinical Trials

- › **Mitsubishi Tanabe Pharma Development America, Inc:** MT-1186-A01: A Phase 3, Multi-center, Open-label, Safety Study of Oral Edaravone Administered over 48 Weeks in Subjects with Amyotrophic Lateral Sclerosis (ALS)
 - This project is being done to evaluate the long-term safety and tolerability of oral edaravone in participants with Amyotrophic Lateral Sclerosis (ALS) over 48 weeks.



ALS Clinical Trials

- › **Mitsubishi Tanabe Pharma Development America, Inc:** Radicava ®/Edaravone Findings in Biomarkers From ALS (REFINE)
 - This study hopes to find biomarkers to show why IV Edaravone could slow ALS symptom progression



ALS Clinical Trials

- › **Healey Center for ALS at Mass General:**
HEALEY ALS Platform Trial
 - This study is to evaluate the efficacy of multiple investigational products as compared to placebo on ALS disease progression.

A photograph of three glass bottles on a light blue surface. On the left is a large, dark brown glass bottle with a rounded body and a narrow neck. In the center is a tall, slender, light green glass bottle. On the right is a small, square-shaped blue glass bottle with a yellow label and a white cap. The background is a solid light blue.

ALS Clinical Trials

- › Couple of additional oral edaravone (Radicava) studies that hopefully will be approved by the time you hear this



ALS Clinical Research

› Local

– Student projects

› Samira Samant

– Chart review project

› Gloria Lin

– Clinical Genetics

› DNA Collection- Systematic analysis of molecular pathways implicated in amyotrophic lateral sclerosis



ALS Clinical Research

- › Youth Care- Melinda Kavanaugh, PhD
 - Skill, confidence and support: conceptual elements of a child/youth caregiver training program in amyotrophic lateral sclerosis - the YCare protocol.

Kavanaugh MS, Cho Y, Fee D, Barkhaus PE.

Neurodegenerative Disease Management, 2020 Aug

- US data on children and youth caregivers in amyotrophic lateral sclerosis.

Kavanaugh MS, Cho CC, Howard M, Fee D, Barkhaus PE.

Neurology, 2020 Apr