Santhera launches “Take a Breath DMD” respiratory awareness campaign

The “Take a Breath DMD” campaign will underscore the importance of respiratory care for people living with DMD. The mission of this educational campaign is to help people living with DMD and their families receive information to help manage respiratory complications, including information about breathing, coughing, and pulmonary care.

On the new educational website, TakeABreathDMD.com, patients and families residing in the U.S. can find practical, in-depth information in one centralized location. Visitors to the site can also sign up to receive additional interactive tools and resources in the future, as well as stay informed about new advances.

Updated Guidelines to Evaluate Breathing:
The updated guidelines were funded and coordinated by the Centers for Disease Control and Prevention and recently published in Lancet Neurology

- Test pulmonary function at least once while ambulatory and every year after loss of ambulation
- Daily lung volume recruitment when Forced Vital Capacity (FVC) is less than 60% predicted
- Discuss with your doctor cough assist when cough peak flow is less than 270 liters per minute, FVC is less than 50% predicted, or MEP is less than 60 cm H20+
- Discuss with your doctor nighttime ventilation when there are signs or symptoms of sleep hypoventilation or abnormal sleep study, when FVC drops below 50% predicted, MIP <60cm H20 or awake baseline SpO2 95% or pCO2 >45mm Hg

The updated care standards state that men with Duchenne should be using most or all of these interventions by ages of 18-22

For more information about the updated Duchenne care guidelines: http://www.parentprojectmd.org/site/PageServer?pagename=Care_guidelines

Santhera in the Community

Several organizations hold educational events for families and people with DMD, and we look forward to seeing you there. At these events, we will provide additional information and answer questions about the SIDEROS clinical trial and the importance of preserving respiratory muscle function in Duchenne.

Please join us at the following events:

- Richmond – Mar 24: Jett Foundation
- Grand Rapids – Mar 24: PPMD
- Iowa City – April 7: CureDuchenne
- Denver – April 21: CureDuchenne
- Charlotte – April 21: Jett Foundation
- Minneapolis – April 28: PPMD
SIDEROS Trial
Sites Enrolling:

University of Alabama, Birmingham, Dr. Troxler
Arkansas Children’s Hospital
Little Rock, Dr. Stefans
Banner-University Medical Center,
Tucson, Dr. Daines
Phoenix Children’s Hospital, Dr. Woodward
Loma Linda University Children’s Hospital,
San Bernardino, Dr. Michelson
UC Davis
Sacramento, Dr. McDonald
UCLA
Los Angeles, Dr. Shieh
Children’s Hospital of Los Angeles,
Dr. Ramos-Platt
Shriners Hospital for Children
Tampa, Dr. Couloris
Center for Integrative Rare Disease Research, Atlanta, Dr. Phan
University of Iowa
Iowa City, Dr. Mathews
University of Kansas
Kansas City, Dr. Statland
Johns Hopkins University
Baltimore, Dr. Crawford
Boston Children’s Hospital, Dr. Darras
Gillette Children’s Specialty Healthcare,
St Paul, Dr. Smith
Carolinas HealthCare System
Charlotte, Dr. Brooks
Cincinnati Children’s Hospital
Dr. Tian
MetroHealth Medical Center
Cleveland, Dr. Prochoroff
Children’s Hospital of Philadelphia
Dr. Mayer
Wesley Neurology Clinic
Memphis, Dr. Bertorini
Cook Children’s Medical Center
Ft. Worth, Dr. Marks
University of Utah
Salt Lake City, Dr. Butterfield

SIDEROS TRIAL CURRENTLY ENROLLING

Study of whether idebenone is safe and effective at delaying the loss of respiratory function

The SIDEROS clinical trial is currently recruiting boys with DMD ages 10 and older at more than 20 trial sites in the U.S. The study will compare the efficacy of idebenone to placebo in boys and men currently on steroids. Idebenone is an investigational drug in Phase 3 development for patients with DMD who have a decline in respiratory function.

To be eligible for the trial, boys must be: 10 or older; immunized against the flu and pneumonia; have an FVC of between 35-80% predicted; and be on steroids for at least 12 months with no dose adjustments in the past 6 months (can switch between prednisone and deflazacort if it is a weight equivalent dose).

To learn more about the trial, please visit:
www.clinicaltrials.gov NCT02814019
or http://www.siderosdmd.com/ or contact sideros@santhera.com

Lung function is important. So is feeling supported. Visit our site for helpful information about respiratory health and to stay informed about the latest news in DMD.

TakeabreathDMD.com

If you have questions for Santhera, please contact: patient.advocacy@santhera.com

For questions about the SIDEROS clinical trial, please contact: SIDEROS@santhera.com