

March 26, 2020



Dear World Duchenne Organization,

In light of the current COVID-19 outbreak, patient safety and well-being remains our highest priority in all ongoing studies. Santhera is closely monitoring the impact of COVID-19 on its operations to continue meeting the needs of the patients and securing an uninterrupted supply of medication to both clinical study participants and patients enrolled in expanded access programs.

In this context, Santhera, in collaboration with Health Authorities, Investigators, and its Clinical Research Organization partner, are working diligently to ensure the safety of, and the continued supply of study medication to, the DMD patients participating in SIDEROS and SIDEROS-Extension.

On March 19th, in line with guidance provided by Health Authorities, investigators and site staff were provided instructions with recommended, immediate measures in case patients are not able to come to the study sites for a prolonged period. These recommended measures could include phone or video visits to ensure patient safety; visits to local laboratories; and direct delivery of study medication to the patients' home. For the direct-to-patient delivery of study medication, Santhera has implemented measures to ensure that the identity of all study participants is protected. Also, as part of the SIDEROS clinical study protocol, participants perform respiratory measurements, using a hand held device, at home on a weekly basis, and the patients should continue doing so throughout the COVID-19 pandemic.

Participants in our clinical studies who have questions about their participation during the COVID-19 situation, should reach out directly to the study team at their site. As this is a global study, we acknowledge that conditions will vary based on country and city and that decision-making is best left to the family and their physician.

We would like to express our deep appreciation to the study participants for their dedication to SIDEROS and SIDEROS-Extension during what we recognize as a particularly stressful time for many families across the world. We all are facing exceptional and challenging times with this changing and evolving Covid-19 landscape and together we will overcome this outbreak.

Sincerely,

Vanessa dos Reis Ferreira
Head Patient Advocacy Europe

Kristina Sjöblom Nygren
Head Development and CMO