PRESS RELEASE

May 10, 2021

Saniona Launches New Video Series to Highlight the Impact of Prader-Willi Syndrome and Hypothalamic Obesity on Patients and Caregivers

Saniona (OMX: SANION), a clinical stage biopharmaceutical company focused on rare diseases, today announced its "Saniona's Community Voices" video series, which will feature the voices of people living with rare diseases, their caregivers and their medical professionals. The series will launch during the month of May, which is both Prader-Willi syndrome (PWS) and Brain Tumor Awareness Month and will begin by spotlighting the impact of these conditions on patients and their families.

"Our work to discover, develop, and deliver innovative treatments begins with listening to and learning from people living with the rare diseases we aim to treat," said Rami Levin, President and Chief Executive Officer, Saniona. "These stories from the Prader-Willi syndrome and hypothalamic obesity communities will serve as powerful reminders that we need to move faster, work harder, and push the limits of what we thought was possible. Not just during the month of May, but every day, as patients are waiting for treatments and are counting on us."

HO and PWS are rare diseases characterized by excessive weight gain and hyperphagia, an uncontrollable hunger. There are no treatments for HO, and there are no treatments for the hyperphagia associated with PWS.

The video series will feature interviews with caregivers and leading physicians in the PWS and HO fields, including:

- **Lynn Garrick, RN, BSN,** the mother of a 13-year-old son living with PWS. She is also a regional program director for 13 PWS group homes, the medical and research coordinator for PWS-USA, and a member of the board of directors for the Minnesota PWS Association.
- **Tony Holland, MD, CBE,** Emeritus Professor of Psychiatry at the University of Cambridge. He is a pioneer in PWS research, investigating the relationship between PWS and overeating, and a passionate advocate for the PWS community.
- **Marci Serota, RDN,** the mother of a 14-year-old son living with HO. She is also a Registered Dietitian Nutritionist who focuses on childhood obesity and HO. Marci brings her personal experience into her work to help others dealing with this extremely difficult condition. She is the author of *Hungry for Solutions: A Mother's Quest to Defeat Hypothalamic and Childhood Obesity*, which discusses her family's experience with HO and provides nutritional guidance to those who struggle with it.
- **Ulla Feldt-Rasmussen, MD,** Chief of Medical Endocrinology at the National University Hospital in Copenhagen, a Professor at the University of Copenhagen. She is a leading authority on HO and a member of Saniona's Scientific Board.

"Saniona's Community Voices" videos will be posted throughout the month of May on the Saniona YouTube channel: bit.ly/SanionaYouTube.

For more information, please contact

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About Saniona

Saniona is a biopharmaceutical company focused on discovering, developing, and delivering innovative treatments for rare disease patients around the world. The company's lead product candidate, Tesomet, is in mid-stage clinical trials for hypothalamic obesity and Prader-Willi syndrome, severe rare disorders characterized by uncontrollable hunger and intractable weight gain. Saniona's robust drug discovery engine has generated a library now consisting of more than 20,000 proprietary modulators of ion channels, a significantly untapped drug class that is scientifically validated. Lead candidate SAN711 is entering Phase 1 for rare neuropathic disorders, with SAN903 for rare inflammatory and fibrotic disorders advancing through preclinical development. Led by an experienced scientific and operational team, Saniona has an established research organization in Copenhagen, Denmark and is building its corporate office in the Boston, Massachusetts area, U.S. The company's shares are listed on Nasdaq Stockholm Small Cap (OMX: SANION). Read more at www.saniona.com.

About Prader-Willi Syndrome (PWS)

Prader-Willi syndrome (PWS) is recognized as the most common genetic cause of life-threatening obesity, with an estimated number of patients between 11,000 and 34,000 in the U.S. and between 17,000 and 50,000 in Europe. The disease results from a deletion or loss of function of a cluster of genes on chromosome 15, which leads to dysfunctional signaling in the brain's appetite/satiety center (hypothalamus). Many of those affected with PWS suffer from insatiable appetite (hyperphagia); abnormal growth and body composition; low muscle tone (hypotonia); and social, emotional, or cognitive deficits. Hyperphagia is reported by caregivers to be among the most worrisome aspects of PWS, as this insatiable hunger persists no matter how much the patients eat and often requires caregivers to install locks on refrigerators and cabinets where food is stored. Many of those affected with PWS become morbidly obese and suffer shortened life expectancy and significant mortality. Common causes of mortality in PWS include respiratory disease, cardiac disease, infection, choking, gastric rupture, and pulmonary embolism. There are no medications approved specifically for the hyperphagia associated with PWS, and there is no cure for this disease. Treatment depends on symptoms and often includes hormone replacement. If obesity is avoided and complications are well managed, life expectancy for individuals with PWS is normal or near normal, and most individuals can lead healthy lives.

About Hypothalamic Obesity (HO)

Hypothalamic obesity (HO) is a rare disorder caused by injury to the hypothalamus, most commonly sustained during surgery to remove a rare, noncancerous tumor called a craniopharyngioma (CP). HO is characterized by rapid, excessive and intractable weight gain that persists despite limited food intake. Patients may have hyperphagia, an uncontrollable hunger, and may display abnormal food seeking behaviors such as stealing food. Additional symptoms may include memory impairment, attention deficit, excessive daytime sleepiness and lethargy, issues with impulse control, depression, and suicide. HO patients are also at increased risk of developing obesity-related comorbid conditions such as type 2 diabetes, non-alcoholic fatty liver disease, hypertension, stroke, and congestive heart failure. Ultimately CP survivors with hypothalamic injury report at least three times higher 20-year mortality than CP survivors without hypothalamic injury. There are no medications approved specifically for HO, and there is no cure for this disease. Many HO patients are treated with approaches used for general obesity such as surgery, medication and lifestyle counseling, but these are often ineffective. The prevalence of HO is estimated to be between 10,000 and 25,000 in the U.S. and between 16,000 and 40,000 in Europe. It occurs most often in children and older adults, creating a burden for both patients and families.