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## Dutch Family Participates in Medical Center Grand Rounds

The University Medical Center/WKZ Utrecht, Netherlands, recently conducted a virtual grand rounds and invited Jan Jongerius and Chantal Dupree to participate and provide a presentation. There were about 50 participants, including pediatricians, medical assistants in training, and medical students. Jan and Chantal, residents of Utrecht, are IWSA volunteers, and parents of seven-year-old Maelynn, and her older sister and brother. Maelynn's nephrologist, Dr M. Lilien, invited Jan and Chantal to speak about the role of the IWSA, the parent/patient organization supporting individuals with WAGR syndrome.



Presentations by several disciplines were included in the grand rounds, including nephrology, clinical genetics, and pediatrics. Information related to the clinical picture and genetics of WAGR syndrome were presented by Dr Marjolijn Jongmans, clinical geneticist. Jan's presentation highlighted the role of the patient organization representing individuals with WAGR syndrome and their families.

"Time was limited and we were asked to address a number of topics," explains Jan. These topics included:

- How do parents with a child with WAGR syndrome find other parents and the IWSA?
- What does the organization look like and what kinds of activities does it organize?
- How can the organization contribute to improving care for patients?
- What and how can parents and medical providers learn from each other?

IWSA representatives helped Jan create a powerpoint presentation. He also shared the IWSA website, which received high marks from the organizing physician, who said, "The website is fantastic and beautiful" and suggested that the medical students look at it for the right information.

Jan was also asked to share his family's personal story. "After diagnosis of WAGR syndrome," he explained. "We were very lucky to receive appropriate medical support and we were also connected with another family of a child with WAGR syndrome being treated at UMC in Utrecht." Jan's presentation included a slide highlighting Maelynn's challenges and accomplishments. "Maelynn," Jan shared, "is a brave girl with a very strong personality...she winds everyone around her finger with her endearing and uninhibited behavior!" He detailed some of her challenges, which currently include auditing processing issues, cognitive impairment, fine and gross motor delays, sleeping problems, and emerging behavioral problems. Despite her many challenges, Jan says that Maelynn has not had Wilms tumor and is

progressing very well at her own pace in school.



"The IWSA is our guiding light in the path of WAGR syndrome to this day," explains Jan. "They provide all available and substantiated information and are the largest network of fellow sufferers and experts worldwide. We serve the IWSA with the aim of helping other parents when they are confronted with the diagnosis of WAGR syndrome."

Jan and Chantal have actively volunteered for the IWSA since 2015 by providing support and information to families and the medical community in the Netherlands and throughout the world. Their work has included translating information from English to Dutch, welcoming new families in Europe, and fundraising for the IWSA.

Thank you Jan and Chantal for helping to raise awareness of WAGR syndrome and for sharing your personal story!