

Join the FANN club: Results from an interdisciplinary network for professionals on ASD in females

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Background

The diagnosis for ASD seems largely based on the male phenotype. Consequently, ASD is diagnosed more frequently in males than in females (4.5:1; CDC, 2012). **Women are often misdiagnosed or diagnosed much later in life** (Shattuck et al., 2009).

The **different manifestation of ASD in females** is not reflected in the current diagnostic DSM-criteria (van Wijngaarden et al., 2014). Despite the fact that the DSM-5 states that “girls without accompanying intellectual impairments or language delays may go unrecognized, perhaps because of subtler manifestation of social and communication difficulties”, it lacks concrete criteria to diagnose these females with ASD. Our project groups will develop and implement scientifically based knowledge to fill in this gap regarding women with ASD.

In order to do so, **the FANN was initiated in March 2017**. The FANN is a Dutch interdisciplinary network for professionals (psychologists, psychiatrists, researchers, etc.) who are committed to improve the diagnostic and treatment of females of all ages with autism. The members of FANN are all experts in the field of autism in girls and/or women. Also experienced experts (women with ASD) participate in this network.

Objectives

The objectives of FANN are to encourage knowledge exchange, to promote collaboration in scientific research, and to prompt implementation of scientific knowledge in clinical practice.

Methods

The **FANN core group** consist of 55 registered members, from all parts of the Netherlands. Within de FANN core group, several project groups have been set up to focus on specific areas.

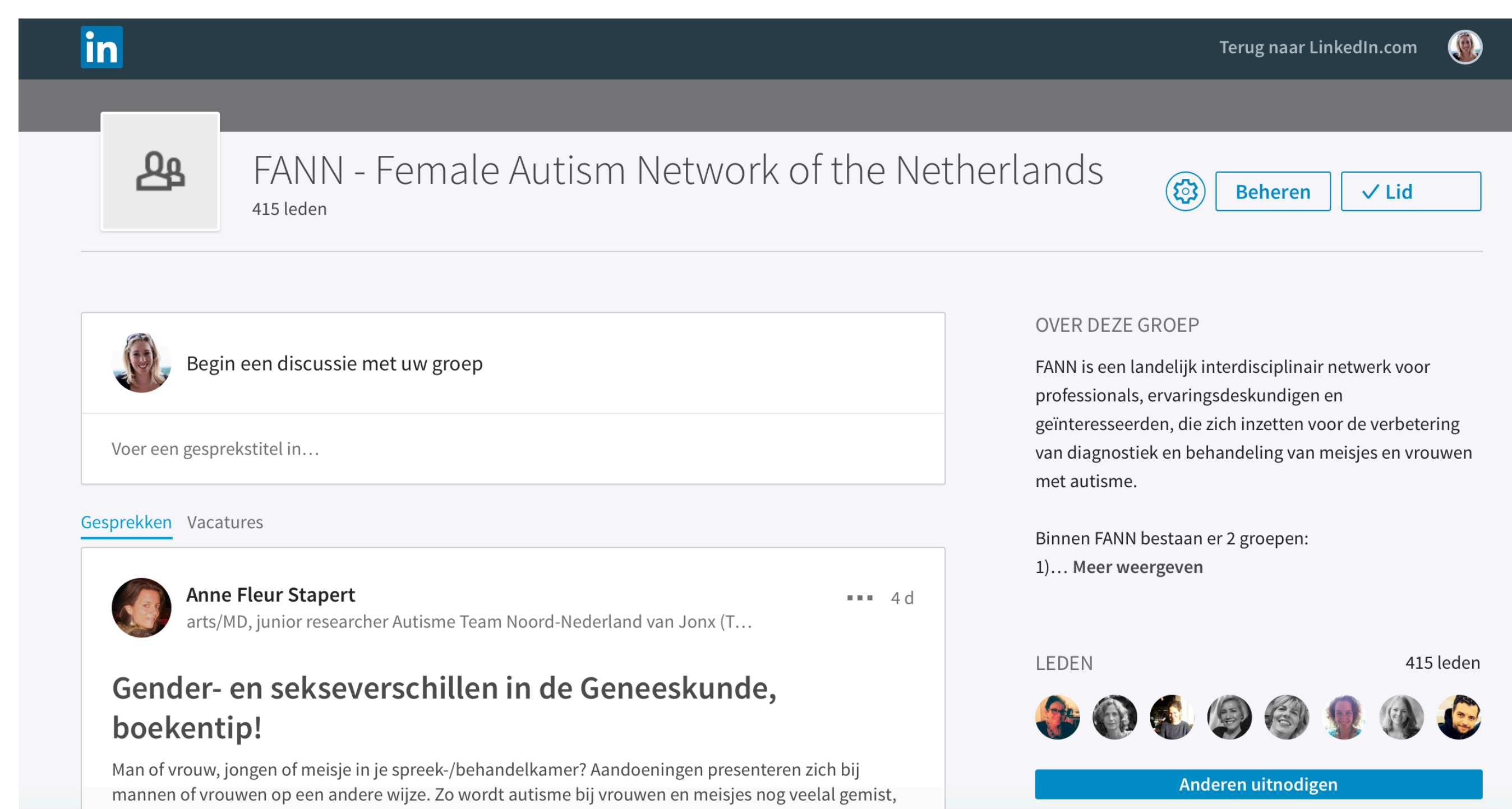
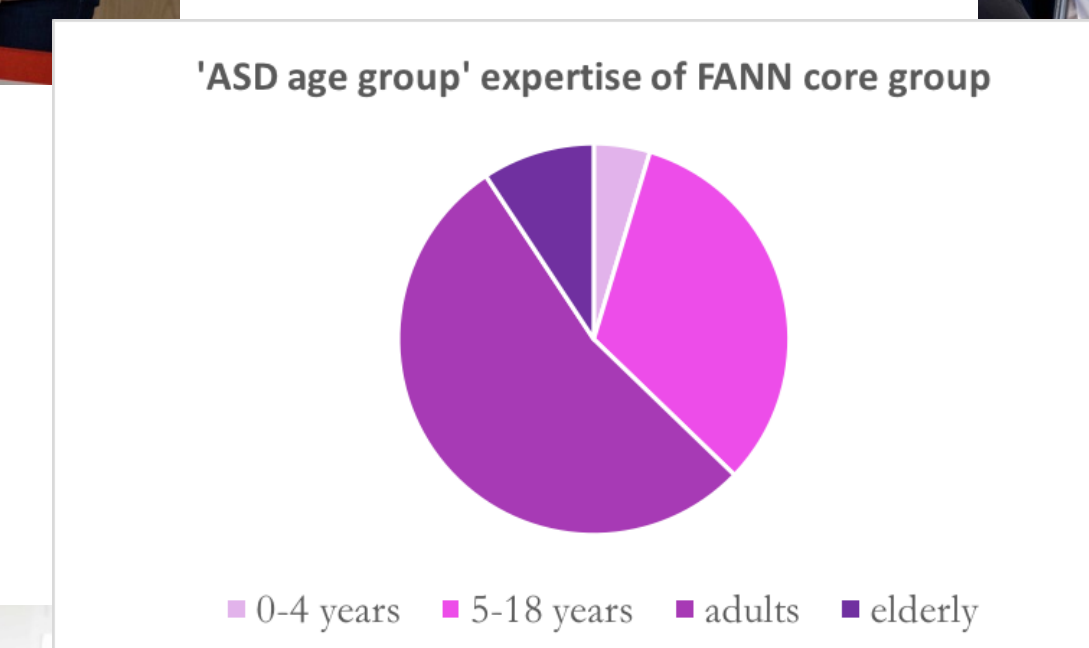
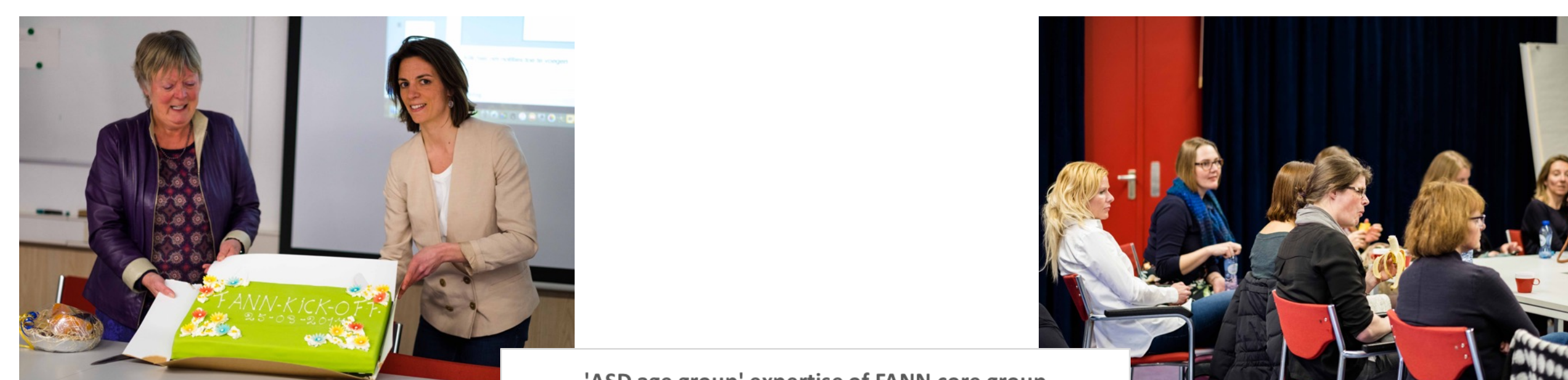


Kick-off meeting 2017-03-25, with Judith Gould



Meeting 2018-03-10, with Meng-Chuan Lai

Knowledge exchange is done through the **FANN LinkedIn group** - now already consisting of 415 members - and the recently launched FANN website.



Results

The **FANN core group** met three times over one year. International guest speakers were dr. Judith Gould (UK) and dr. Meng-Chuan Lai (University of Toronto).

Based on an **online questionnaire**, the **FANN core group** indicates that the following subjects are important: being a knowledge network, providing a (digital) platform, unraveling woman-specific ASD diagnostic features, ameliorating the recognition of ASD in women (including case identification), improving quality of care for women with ASD (preventing misdiagnoses, promoting better and faster diagnosis, developing effective therapy), fostering de-stigmatization, focusing on acceptance of women with ASD in society, and promoting scientific research.

For now, **six Project groups** were formed, namely on: 1) Diagnostics, 2) Treatment, 3) Co-morbidity, 4) Gender identity and sexuality, 5) Pregnancy and parenthood, and 6) Knowledge transfer.

The passed year, the **FANN LinkedIn group** shared the following information on ASD in females: conferences to attend (20%), publications to read (18%), blogs, vlogs and websites to visit (16%), advised therapist with an eye for ASD in females (16%, with also requests from abroad), media attention (10%), request for specific information (6%), opinions (6%), research findings (4%) and miscellaneous (5%).

On the **FANN website** - www.femaleautismnetwork.jimdo.com - a section on information about ASD in girls/women is recently launched to provide the general public with knowledge.

Conclusions

The FANN exists since March 2017, but already inspired many people. There is a great need for such a network, which provides a unique angle on females with ASD. We are most certainly open to international collaboration with similar initiatives.

References

- Shattuck, P. T., Durkin, M., Maenner, M., Newschaffer, C., Mandell, D. S., Wiggins, L., ... & Baio, J. (2009). Timing of identification among children with an autism spectrum disorder: findings from a population-based surveillance study. *Journal of the American Academy of Child & Adolescent Psychiatry*, 48(5), 474-483.
- Van Wijngaarden-Cremers, P. J., van Eeten, E., Groen, W. B., Van Deurzen, P. A., Oosterling, I. J., & Van der Gaag, R. J. (2014). Gender and age differences in the core triad of impairments in autism spectrum disorders: a systematic review and meta-analysis. *Journal of Autism and Developmental Disorders*, 44(3), 627-635.



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