

CONFERENCE REPORT

World Conference Cornelia de Lange Syndrome.

Buenos Aires, Argentina. From 14 to 16 November 2013.

Reviewed by Eline van Rooij-Cooymans

The 7th World CdLS Conference took place in Buenos Aires, Argentina, from 14 to 16 November 2013. Cornelia de Lange Syndrome (CdLS) is a rare genetic disorder. One of the possible common features of a child with this syndrome is one or more sensory limitation. Some of them have deafblindness.

Marleen Janssen, Professor of Deafblindness at the University of Groningen and Eline van Rooij, educational psychologist at the Kentalis Rafael school, a school for children with deafblindness in the Netherlands, were invited by the conference organization to present the 'High Quality Communication' research project, a project in which the University and Kentalis Rafael have worked closely. Marleen presented the project's theoretical side and Eline demonstrated a practical example of a child with CdLS who attends the Kentalis Rafael school. The central theme of the project, quality interaction and communication among students with deafblindness, was presented.

What made this conference very special was the fact that it was organized by and for families and focused on this syndrome to provide education and support to families of people with CdLS. The families attended a high quality scientific symposium with their children, which was composed of international medical-scientific CdLS experts from all over the world, who come together every two years to present and discuss the latest research and to share information on medical and clinical treatments.

Extensive medical-scientific information about CdLS was presented. Our presentation concerned a preventive intervention programme focused on communication, supported by video. This was quite new in the CdLS field, especially as we adopted intersubjectivity theory from a developmental psychological perspective and not the more common linguistic perspective.

At the end of every day, participants had private consultations with the experts, they attended workshops on legal concerns, educational issues and medical/behaviour challenges, and had opportunities to meet other families facing similar challenges.

The very active CdLS World Foundation also introduced their website's WIKI 'Ask the

Expert' service at the conference, to allow users to email their questions to members of the Clinical Advisory Board, the Professional Development Committee and the Education Advisory Group. We at the Kentalis Deafblind Centre of Excellence and the University of Groningen will contribute to this service with our expertise on communication and education for children with CdLs.

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