



# 2017 International Meeting Notes

Dear International Families,

One of the great many experiences we shared during the Conference at Redondo Beach was an informal meeting with our families coming from overseas. Having an opportunity to get together and hear from everyone is always a good indicator of what is important to share and where we can improve our communication!

In our meeting we had families attending from the following countries: Italy, Switzerland, Canada, China, France, Brazil, Russia, Austria, Poland, Australia, Spain and the USA. Our family members touched upon key topics:

1. Sending out Information Packages for newly diagnosed families: It is important that we keep the communication flow to new families with relevant information. For example, The first 100 Days, also information about local resources (schools, doctors).
2. Increased frequency of updates on scientific and research projects. ,as they occur or on a quarterly basis via the Mirror Newsletter.
3. Fact Sheet/Form Letter about Dup15q disorder addressed to medical professionals and intended to help support a diagnosis, available on Dup15q website for those families that need it
4. Increased awareness in China and other Far East countries: Need to provide means to make Dup15q information available through means other than Google search engine so that families may access information about the disorder.

For every one that attended the meeting: We are very grateful to have the chance to meet every one of you in person and hear all your questions and concerns! On behalf of the Dup15q Alliance Board, I want to first express our gratitude for your feedback but also I want to reiterate our pledge to support your efforts to advocate for your child(ren) and increase awareness in the educational, medical and research areas in your home countries!

Feel free to send me a personal message with your questions and concerns! My email address is [gomezfv@optonline.net](mailto:gomezfv@optonline.net).