



EUROPEAN COMMISSION

Stella Kyriakides
Member of the Commission

Greeting - Symposium about Syngap1 and Related Disorders

I was deeply touched when I heard about the story of little Leon who in many ways is the reason why you are having this symposium today. As a clinical psychologist working with children and families faced with many different challenges I know the many difficulties faced especially in the area of rare diseases.

And it is Leon who brought us all together today.

I would like to extend my warmest greetings to all attendees, speakers and organisers of the Syngap1 Symposium.

COVID-19 has increased the physical distance between us. But cooperation, sharing ideas and exchanging knowledge are fundamental to what allows us to progress together, as humanity.

I am, therefore, delighted to hear that the previously postponed gathering can now take place in a digital format.

I understand that there are only a few hundred patients worldwide that are diagnosed with a neurodevelopmental disorder due to a mutation in the Syngap1 gene. Each and every one of them is special and important. Behind every number is a person: a child, a son, a daughter, a friend, a father, a mother. Each person is precious, is unique, and deserves a full and happy life.

Rare disease patients often face more challenges than other patients in finding the right specialist to explain to them what it is that they are suffering from – let alone finding someone that can cure or treat the disease.

It is because of this that we established the European Reference Networks at EU level. These are virtual but highly effective networks across Europe. They tackle complex or rare diseases and conditions that require highly specialised treatment and concentrated knowledge and resources. Cases can be discussed by a virtual advisory board of medical specialists across different countries and disciplines. This way it is the medical knowledge and expertise that travel, rather than the patients.

The search for the right specialist – and, more importantly, the right answers – together with the protracted uncertainty can sometimes be just as exhausting as the disease itself, if not more so.

That is why I am glad that you have all gathered here today to put your minds together. Only through cooperation and sharing our expertise can we eventually help children like Leon.

When I think of the lonely scientist in a lab somewhere working on a new treatment or of Leon's family that has launched this wonderful initiative, I am reminded of the quote by Margaret Mead:

"Never doubt that a small group of thoughtful, committed, citizens can change the world. Indeed, it is the only thing that ever has."

For Leon and his family, and for all participants of this symposium, I wish you as many of those little moments of happiness and sunshine as possible. Because it is those moments that keep us going.

Yours Sincerely,

A handwritten signature in blue ink that reads "S. Kyriakides". The signature is written in a cursive, flowing style.

Stella Kyriakides