

Parma, 19<sup>th</sup> may 2026

*Dear President Metsola,*

*Dear Commissioner Várhelyi,*

*Dear Hon. Salvatore De Meo,*

On behalf of the families and children represented by Associazione Genitori PANS PANDAS BGE ODV, we would like to express our deepest gratitude for your presence, your words and your attention during the international conference:

“PANS & PANDAS: A Bridge Between Science, Healthcare and European Policies”

held at the European Parliament on 13 May 2026.

For many families across Europe, this event represented a historic moment. **For the first time, children affected by PANS/PANDAS entered the heart of the European institutions not as invisible cases, but as children deserving recognition, dignity, care and future.**

The strong institutional message that emerged during the conference — that Europe can and must do more for rare and poorly recognized diseases — gave hope to thousands of families who have often felt abandoned and unheard.

Today, however, we kindly ask that this important institutional moment does not remain only symbolic, but becomes the beginning of a concrete European action.

In particular, we respectfully renew the priorities discussed during the conference:

- the creation of a European fund dedicated to research on PANS/PANDAS;
- the identification and the recognition of specialized European centers for diagnosis, treatment and multidisciplinary care;
- the establishment of a European registry to collect epidemiological and clinical data and support scientific cooperation among Member States;
- the promotion of shared European clinical pathways and professional training programs;
- the establishment of a European working group aimed at developing shared guidance frameworks for the recognition, diagnosis and multidisciplinary management of PANS/PANDAS syndromes, with the awareness that each Member State may subsequently decide independently whether or not to adopt them within its own national healthcare system, but recognizing that such an initiative would nevertheless represent a European signal of enormous scientific, healthcare and human value;
- stronger collaboration between institutions, researchers, healthcare systems and patient associations.



To further pursue the abovementioned objectives, the Parents' Association PANS PANDAS BGE remains fully available to all Institutions of the European Union and reaffirms its commitment to providing active, constructive, and ongoing cooperation.

**Research is essential, but children and families cannot wait years to be recognized and treated appropriately.**

Behind every clinical record there is a real child, a real family and a daily battle for dignity, education, healthcare and life.

We truly hope that the bridge built at the European Parliament on 13 May will become a lasting European network of cooperation and action.

Thank you again for listening to the voices of our children.

With gratitude and hope,

*President*  
Fabridi Lalli

*Head of Institutional Relations*  
Vincenzo Casaregola