



July 22, 2026

Public Comment on the IACC 2026–2028 Strategic Plan Working Draft

On behalf of ASPIRE (Alliance to Solve PANS & Immune-Related Encephalopathies), thank you for the opportunity to comment on the 2026–2028 IACC Strategic Plan Working Draft.

We commend the Committee for creating an ambitious framework that recognizes the biological heterogeneity of autism and avoids a one-size-fits-all approach. We are particularly encouraged by the focus on precision medicine, biologically defined subgroups, coordinated translational research, and the proposed National Neurodevelopmental Regression Initiative. We also appreciate the Strategic Plan's focus on addressing the needs of individuals across the lifespan, including the transition to and continuation of adult care. Collectively, these initiatives have the potential to significantly advance autism research and improve evaluation and treatment for individuals with complex clinical presentations.

Among the Strategic Plan's strengths, we believe the National Neurodevelopmental Regression Initiative offers a significant opportunity. While regression has long been recognized clinically, efforts to understand its underlying biology have been fragmented. By proposing standardized phenotyping, longitudinal cohorts, biomarker discovery, and integrated clinical evaluation, the Committee shifts the focus from describing regression to understanding the biological mechanisms that precede, accompany, and follow it. This framework can help identify clinically meaningful subgroups, improve diagnostic evaluation, and inform more targeted interventions.

As this initiative develops, we encourage the Committee to ensure that regression evaluation includes a structured diagnostic framework for medically treatable causes of acute change from baseline, including abrupt neuropsychiatric deterioration. The Strategic Plan appropriately emphasizes identifying treatable contributors to changes in health and functioning. We recommend the regression initiative explicitly state that sudden or dramatic changes in behavior, cognition, adaptive functioning, eating, continence, sleep, or emotional regulation should prompt comprehensive medical evaluation when clinically indicated, rather than being presumed to reflect autism progression alone.



A standardized evaluation framework will strengthen both research and clinical care. Consistent approaches to evaluating regression will improve cohort selection, facilitate study comparisons, enhance biomarker discovery, and reduce the risk of overlooking treatable medical conditions. The Initiative's value will depend not only on how well regression is characterized, but also on how effectively it identifies underlying biological mechanisms and medically treatable contributors to acute change from baseline.

ASPIRE also encourages the Committee to align the National Neurodevelopmental Regression Initiative with the proposed Acute Neuroimmune Destabilization Evaluation Pathway. These initiatives address overlapping clinical populations and related scientific questions. Integrating them will strengthen both efforts by emphasizing the evaluation of treatable neuroimmune disorders, including PANS/PANDAS where clinically applicable, within a comprehensive diagnostic framework for individuals experiencing abrupt regression or other acute changes from baseline, including neuropsychiatric deterioration, while maintaining the broader precision medicine approach of the Strategic Plan.

We strongly support the Strategic Plan's commitment to investigating biologically defined subgroups and the interactions among immune, infectious, metabolic, gastrointestinal, genetic, and other biological mechanisms. Historically, these systems have often been studied independently, despite increasing recognition of their interactions in influencing clinical presentation and treatment response. Continued investment in integrated, multidisciplinary research can improve patient stratification, accelerate biomarker discovery, and guide the development of more individualized diagnostic and therapeutic approaches.

The Working Draft represents an important step forward in federal autism planning. Instead of seeking a single explanation for autism, it embraces biological complexity and prioritizes understanding the mechanisms underlying diverse clinical presentations. We believe the National Neurodevelopmental Regression Initiative could become one of the Strategic Plan's most impactful contributions. Ensuring that its evaluation framework explicitly includes medically treatable causes of acute change from baseline, including abrupt neuropsychiatric deterioration and acute neuroimmune disorders such as PANS/PANDAS when clinically appropriate, will help the Initiative achieve its full scientific and clinical potential.



Thank you for your thoughtful consideration of these comments and for your continued commitment to advancing autism research and improving the lives of autistic individuals and their families.

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