The Ted Lindsay Foundation Research Report 2020

I am ever grateful to the Ted Lindsay Family and The Ted Lindsay Foundation for their continued support of our research program. This has been a challenging year for so many. The coronavirus pandemic has impacted the autism community in unprecedented ways. In March, our entire nation was ordered to stay home: schools were closed, the specialized care and support needed by children and adults with autism was inaccessible, and clinical research studies were put on hold. While a lockdown is challenging under any circumstances, this was an experience that was particularly difficult for the autism community. As families tried to cope with the sudden loss of professional support precipitated by the lockdown, The Johnson Center, along with many other specialized centers were quickly learning how to move their services on-line to provide resources, counseling, instructional aids, and overall support to families confined to their homes.

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder characterized by challenges in social interaction and communication, and restricted and repetitive patterns of behavior. Current estimates suggest that ASD affects approximately 1 in 54 children in the U.S., which represents about a 17% increase in prevalence annually. Understanding the causes of this disorder, and how to implement the very best treatments and interventions, remains an important goal for clinicians and researchers. Many families struggle to get a diagnosis for their child due to poor access to assessment providers, the cost and financing of assessments, and for some parents, a perceived stigma of having a child with special needs. One thing is clear though, the earlier a diagnosis is made – the earlier interventions can begin.

Over the past 18 months, our research team has been tackling the issue of how early can autism can be detected. To try to answer this question, we have been working on identifying blood biomarkers for ASD. A blood biomarker is a substance that can be reliably measured (a gene, protein, metabolite etc.) that is associated with a specific disease or condition, in this case, ASD. While some diseases already have reliable blood biomarkers, there are no reliable blood biomarkers for ASD currently available.

With grant support from the Ted Lindsay Foundation, we have recently completed our largest proteomics study to date, screening over 1300 potential biomarkers in 200 children with and without ASD. From this study, we have identified a panel of 9 proteins that were not only found to be associated with ASD, but levels also correlated with ASD severity, as measured by standardized diagnostic assessments. This panel of 9 ASD biomarkers was able to accurately diagnose ASD in 86% of cases.

This study is among several recent and ongoing efforts to improve early diagnosis of ASD by shifting the focus to biological measurements instead of behavioral symptoms. Since ASD is a very heterogeneous disorder, identifying potential biomarkers for even a subgroup of children with ASD, would be very helpful for early diagnosis, as well as for the development of therapeutic interventions. This approach would provide an additional tool to ascertain ASD risk, potentially in very young children, before behavioral testing would be feasible. As our knowledge of these risk factors grows, so do the opportunities for promoting healthy pregnancies and better outcomes for children at high risk for ASD.

When we are able to safely resume our biomarker research, we will continue the *validation* phase of this work, which includes screening additional blood samples from additional groups of children, with and without ASD, for the identified panel of 9 protein biomarkers to confirm that these markers are indeed specific to autism. This approach will not only provide important insight into the molecular mechanisms involved in the etiology of ASD, but also allow us potentially develop targeted treatments for the core symptoms – an exciting prospect.

In the interim, we continue to look for ways to support families during this unprecedented time. During the lockdown, many parents of children with ASD lost most or all of their institutional, educational and therapeutic support, leaving them to independently manage the daily issues related to their child's diagnosis. Restrictions on usual activities and changes in routines have greatly impacted many children with autism leading to an escalation in challenging behaviors and anxiety, an increase in the use of psychotropic medications, and in many cases, long-term consequences for the mental health of the parents and caregivers. In August we announced the start of an online, questionnaire-based study to examine the psychosocial and behavioral impact of COVID-19 on children with ASD and their families. The data obtained from this study will be used to inform educational, behavioral, and mental health professionals to determine how to better support families with a child with ASD during this extremely challenging time. It is clear that collaborations with clinicians, researchers and people with ASD and their families will help us develop ways to improve the everyday lives of impacted families.

I would like to extend our sincerest thanks to the Ted Lindsay Foundation for their continued support of our research. While Mr. Lindsay is no longer with us, his past words of encouragement, and drive for getting things done, will continue to spur our research program so we can make a difference in the lives of families living with autism.

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