

Research at CARE-ADD

In our effort to learn more about Autism and related developmental disorders as well as develop useful strategies for the future, CARE-ADD invites families to participate in our clinical research. Participation in research-based evaluation involves no cost to families. Their participation is not connected with the services they receive at this centre. Formal Informed Consent process as mandated by our Institutional Ethics Committee will be followed.

It is pertinent to point out here that many neurological conditions that were deemed untreatable (such as Lysosomal Storage disorders, Duchenne Muscular Dystrophy, Spinal Muscular Atrophy, etc.) are now having newer therapeutic options based on careful research in large number of subjects and their families. We strongly believe that having data (behavioural and cognitive, blood based including genetics, electro/neurophysiological measures such as EEG and MRI) from a large number of children/adults with autism and their families and collaborating with professionals from a variety of backgrounds would help us understand autism better and lead to development of treatment protocols in the future. Such developments are likely to benefit the wider autism community in the years to come. Data sets from other countries may vary significantly from that obtained from families in India and it is imperative to eventually draw conclusions from our own data.

The centre is currently recruiting families for the following studies:

1. Understanding Play Behaviours in Autism: We wish to evaluate dyadic (interactions of child with another person - such as Parent / Carer / Nurse, etc.) social interactions and overall play behaviours in infants and toddlers as potential indicators of risk for autism. Specifically, we are exploring play behaviours with the goal of designing computational models for screening and diagnosis of autism in infants and toddlers. We will be enrolling children between the age of 9 and 48 months for this study. Early detection is the key to helping any child with autism or related developmental disorders to realise her/his full potential.

2. Genetic Study: It is believed today that key differences in the genetic make-up that lead to changes in the way the brain develops, underly most of the challenges that present as autism. Risk factors for ASDs can be found across the full spectrum of genetic variation. These genetic clues are the first step in gaining insight into the biological underpinnings of ASDs.

A central goal of genetic research in ASDs is to nominate molecular pathways for further interrogation and thus to link biological mechanisms with behaviour. On the basis of experience in other fields of medicine, the resulting knowledge should enable the discovery of new treatments. The identification of genetic markers can also help bridge knowledge gaps and provide useful information that can aid early diagnosis of ASD in infants. Epigenetics refer to changes to the way genes express proteins, without changes in their structure. Environmental factors can induce biological changes by impacting genes in the developing foetus. We plan to map the complete genetic and epigenetic changes in ASD in order to obtain a more complete picture of the genetic architecture. This could lead to productive stratification of epidemiologic studies and clinical trials. We also plan to build a biobank of clinical samples from patients and families. This will lead to continued aggregation of samples for consortium studies. Such an approach to genomics will greatly improve the understanding of ASD biology in the coming years and may contribute significantly to much needed new treatments. The children can be in any age range. We will need to ascertain a few specific clinical details too. Stringent blood draw protocols complying with GLP practices have been developed for the same. The use of anaesthetic cream makes the procedure as near painless as possible from small children.

3. A study on Autism, Autistic Traits and other Neurodevelopmental Outcomes in Children:

Placentae have been obtained between 2013 and 2018 from mothers delivering at St. John's and a follow up to evaluate child outcomes (2-6 years old in 2020) from these deliveries will be initiated through field visits shortly. Families will be contacted based on details available in our records and then recruited for providing details on the children. This study will help us understand if a variety of intra-uterine factors that lead to changes in placenta can impact the genetic make-up of the foetus, apart from directly affecting brain development.

4. Other studies in the pipeline: High risk groups such as children with siblings diagnosed with autism, children born with obstetric risk factors and eventful birth with/without post natal complications would be monitored by us through clinical, behavioural and cognitive assessments besides EEG and MRI scanning. Other studies such as follow up of high-risk children and others, a study exploring the role of placental anomalies in child development through a prospective birth cohort and another study evaluating autism in the presence of cerebral palsy, etc. are being put together. We will update this page along with clear informed

consent protocols and detailed FAQs for studies as and when we are ready. The earliest update may be June 2020. Most important of all, even as we seek support and understanding from families for all our research endeavours, we wish to learn from them on the research priorities and also understand emerging data. These would be a key component of periodic family meetings that have been envisaged since December 2019.

If you would like to participate in our research studies please contact us at 080-22065644 or mail to info.careadd@stjohns.in