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

Here are the details of some of the ongoing studies at CARE-ADD

1. **Genetic exploration of children with ASD and their parents**: It is important to understand the function of genes and the molecular pathways that can impact bodily processes and brain functions leading to clinical features of autism. The identification of genetic markers can help bridge the knowledge gaps and provide useful information and aid early diagnosis of ASD in infants. Early detection is the key to helping any child with autism or related developmental disorders in order to reach their potential.

High risk groups like children with siblings diagnosed with autism, children born with obstetric risk faction and eventful birth with postnatal complications should be monitored by physicians and families.

Recruitment Requirements: For the genetic study, CARE-ADD seeks blood samples from children and families. Stringent blood draw protocols are followed for the same. The use of anaesthetic cream makes the procedure as near painless as possible.

2. **Autism, autistic traits and other broad development outcomes in a cohort of children with well characterized placenta and birth data from SJMCH**: The principal aim of this study is to associate placental histopathology and placental biomarkers with developmental outcomes by systematic screening and follow up of the children delivered at St. John's Medical College Hospital.

We are not inviting participants - as this study is a follow up study of those already recruited for another study in the pathology department

3. **Play Behaviour in Autism:** Using play as an early diagnostic screening tool enables clinicians, parents and caregivers the opportunity to evaluate dyadic social interactions and overall play behaviour that may indicate risk for autism. CARE-ADD is exploring play behaviours with a goal to design computational predictive models for screening and diagnosis of autism in infants and toddlers.

Recruitment requirements: CARE-ADD seeks participants aged 12-42 months for the Play Behaviours study. Children with ASD and typical children will be recruited.

4. **Proof of Concept Study to test the BubbleMind - soothing app for children with ASD**

BubbleMind is a mobile & tablet-based application which incorporates all sensory features (audio, visual and touch). This is a completely novel study with possible benefits to the society to act as an easy access immediate intervention for children, with minimal support from caregiver/parents/teachers.

Recruitment requirements: Children of ages 4-7 years with ASD are invited to participate in this study. The participant is required to continue using the app for a period of 3 months at home. A follow-up assessment will be done after a period of 3 months.

5. **Modifying and Validating the ScreenPlay app, a tool for screening children for autism in child**

The current study intends to explore the validity of an app-based screening tool, ScreenPlay, from Kidaura Innovations. This tool is based on motor coordination aspects that are being increasingly recognized in the area of Autism. We intend supporting the further finetuning of this tool to become capable of discriminating autism from normal children and children with other developmental disorders and confirm its validity in the said groups.

Recruitment Requirements: Children between ages 3 and 6 are invited to participate in the study. Children with ASD, developmental disorders other than ASD and typically developing children will be recruited for the study.

6. **Obstetric factors and Autism: A multi-centre exploratory case-control study:**

In children and adolescents with Autism Spectrum Disorders (ASD) it is yet to be clearly determined if complications during pregnancy can contribute a primary risk for development of ASD or affect the genes of the child during pregnancy. We wish to obtain a profile of these pregnancy related events and/or complications from four centres in the country.

Recruitment Requirements - April 2021 to July 2021. Children with ASD and typically developing controls will be recruited. Families will be asked to share the pregnancy and birth details of their child along with reviewing records related to the same.

7. **Exploring the ongoing impact of coronavirus pandemic on families who have individuals with autism:**

Recruitment for this study is closed

8. Autism in children with Cerebral Palsy (CP)

Early identification of autism features in children with CP has probably not been explored in young children in India and internationally. Determining methods of early identification can change the model of early intervention in this group of children with CP. This study will determine challenges of diagnosing ASD in children with CP and those with sensory motor deficits using qualitative methods. In this study, we intend to identify motor deficits in infants who screen positive for ASD (SP- ASD) and determine neurobiological underpinnings of the same using EEG and MRI based connectivity analyses.

The study has two phases. Phase 1 - Clinical assessments and evaluation, Phase 2: EEG and MRI investigations will be done twice across the year to explore the neural correlates of emerging symptoms.

Recruitment Requirements - March 2021 to November 2022

Children at risk for CP and/or ASD with age between 12 to 24 months are invited to participate in the study. Detailed physical, medical and neurological assessment will be done. EEG and MRI investigations will be done in natural sleep. Children will have to undergo a follow - up assessment, EEG and MRI 1 year after the first investigation.

9. **Teenage and Young Adults Programme:** There are very few assessments that give a comprehensive picture of the life of the adult individual with ASD tapping into all their characteristics, skills and needs which includes communication and interpersonal skills, educational level, decision making and problem solving, flexibility and ability to prioritize, mental health or behavioural challenges, ability to ask for help, motivation, interests, and other skills. The existing literature, though scarce, indicates the lack of adequate services to help teenagers and young adults with ASD. This lack of services leads to these individuals not receiving help after their school life. This further escalates to problems like lack of employment, social life, and ability to lead an independent life.

We at CARE-ADD intend to do a comprehensive assessment for individuals in this age-group and attempt addressing their needs as part of this operational research study. This study will be done in two phases. Phase 1 will involve in depth clinical assessments at the CARE-ADD centre (or online). Phase 2 will involve the use of Structured instruments and proformas to conduct assessments of the teenager and young adults with ASD in clinical as well as home-based contexts and community settings such as restaurants, transport terminals, parks and so on.

Through these assessments, parent interviews and subsequent interviews of experts in the field, we intend to further develop a model of assessments and basic interventions for young adults with autism.

Recruitment Requirements: Adolescents and young adults (over 14 years of age) diagnosed with ASD.

10. Parent Mediated Intervention in Autism – A preliminary study of parental needs, challenges and methods: Intervention in autism is a long-term process which requires 24-hour involvement to be effective. It is now recognized that active parent involvement leads to

optimum outcome. We at CARE-ADD have undertaken a study to understand the status of parent mediated interventions in India. This is a qualitative study involving interviews of professionals from centres across India. We have finished this first phase and now are looking to recruit parents who have undergone parent mediated interventions.

Recruitment Requirements: Parents of children with ASD between the ages of 6 to 20 years.