Maximizing Biospecimen Collection for Childhood Disorders

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| **Project Name:** Maximizing Biospecimen Collection for Childhood Disorders |
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| **Principal Investigator institution**:  Kaiser Permanente Northern California, Oakland, CA |
| **Funder** NIMH |
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| **Abstract:** Autism Spectrum Disorder (ASD) and Bipolar Disorder (BD) are the two most common severe mental disorders affecting children and adolescents.  Few evidence-based treatments exist for either condition.  Furthermore, response to treatment varies widely between individuals – and no evidence exists to match individual children with specific treatments.  Research to address these gaps – both to develop new treatments and to more effectively match individuals with treatments – will isolating on identifying biomarkers or endophenotypes that can accurately identify more homogeneous subgroups of patients and genetically related family members.  This next generation of research will require collecting biospecimens from large and representative samples of families affected by childhood mental disorders and linking those specimens to comprehensive and longitudinal health records.  The main aim of this pilot is to identify the best ways to maximize biospecimen collection from children with mental health conditions.  We plan to meet this goal by leveraging and extending our work during the first cycle of MHRN funding on the feasibility of biospecimen collection from families of children with Autism Spectrum Disorder (ASD).  We will use a mixed methods approach to develop low-cost, tailored recruitment and consenting processes that specifically address concerns about participating in studies using biospecimens from children with mental health conditions and that are appropriate to large and diverse populations. |
| **Grant Number:**  U19MH092201 |
| **Participating Sites:**   * Kaiser Permanente Northern California, Oakland, CA (Lead Site) * Kaiser Permanente Georgia, Atlanta, GA * Kaiser Permanente Northwest, Portland, OR |
| **Investigators:**  Lisa Croen, PhD Ashli Owen-Smith, PhD Frances Lynch, PhD |
| **Major Goals:**  **Specific Aim 1:** Using data from a feasibility study of biospecimen collection conducted during the first cycle of MHRN funding and health system electronic medical record (EMR) data, we will examine the demographic and clinical characteristics of children and their families predicting successful recruitment of families to participate in biospecimen collection.  **Specific Aim 2:** Explore knowledge, attitudes and beliefs about biobanking and perceived facilitators and barriers to biobank participation among parents of children with mental health conditions from diverse backgrounds using ethnographic/qualitative methods (interviews, focus groups).  **Specific Aim 3:** a) Develop tailored methods for recruiting and consenting children/adolescents with mental health conditions and their families into a biospecimen bank for future research  b) Develop a strategy for pilot testing those methods across different pediatric mental health conditions.  Focus on low cost methods appropriate for large and diverse populations |
| **Description of study sample:**  Fifteen families who participated in the MHRN1 study at each of the three study sites, for a total of 45 ASD interviews and 15 families who have a child with a bipolar disorder diagnosis at KPNC, for a grand total of 60 families. |
| **Current Status:**  Aim 1: Data analysis in progress.  Aim 2: Coding of all interviews was completed at all sites.  Data analysis is in progress.  We expect to have a manuscript submitted for publication by year’s end. |
| **Study Registration:**   * 15 ASD families have been recruited at KPGA * 15 ASD families have been recruited at KPNW * 30 families (15 ASD and 15 Bipolar) families have been recruited at KPNC. |
| **Publications:**  Manuscript in progress for Aim 2. |
| **Resources:**  N/A |
| **Lessons Learned:** N/A |
| **What’s next?**   * Finalize data analyses and manuscripts. |
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