PS2-47:

Complementary and Alternative Medicine Use Among Children with Autism Spectrum Disorders: Findings from the Mental Health Research Network Autism Registry Web Survey

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Background/Aims: Approximately 1 in 88 children in the U.S. are diagnosed with Autism Spectrum Disorder (ASD). Unfortunately, there is no identified etiology or definitive cure for ASD. Therefore, it is not surprising that many parents turn to complementary and alternative medicine (CAM) therapies for their affected children. Prior studies have suggested that CAM use is common in this population; however, these studies have been limited by small samples and an inability to assess response rates. The purpose of this analysis is to examine the prevalence and correlates of CAM use among a group of geographically- and racially/ethnically-diverse children with ASD who are enrolled in the Mental Health Research Network (MHRN) Autism Registry. **Methods:** A web-based survey of parents of children with ASD was implemented at 4 MHRN Autism Registry sites in order to obtain information not available in health plan databases including parents' use of CAM. Parents were asked to report what CAM therapies they have ever used/used within the past 3 months, what they have paid for these therapies and the degree to which they perceived them as harmful or helpful. The domains of CAM therapies on the survey included natural products (e.g., vitamins), mind-body medicine (e.g., acupuncture) and manipulative/body-based practices (e.g., chiropractic). **Results:** To date, approximately 8800 recruitment letters have been mailed and 800 surveys have been completed. Findings related to the prevalence of CAM use among this population, in addition to the correlates of CAM use (including socio-demographics, age at diagnosis, severity of ASD, medical co-morbidities, health care utilization and parental satisfaction with care) will be presented. **Conclusions:** We were able to successfully implement a web-based survey of parents of children with ASD across 4 MHRN sites. With 800 completed surveys (recruitment will continue through November 2012 and thus this number is expected to increase), this is the largest known population-based survey on CAM use in a population with ASD to date. Prior studies indicate that CAM use among this population is common; therefore, it is critical that providers understand this phenomenon so they can help families make well-informed health care decisions and prevent possible CAM-drug interactions.

Keywords: Autism; Complementary and Alternative Medicine; Survey Research

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HMORN Administrative and Technical

B1-1:

Get to Know the HMORN and Its Key Tools and Processes

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Background/Aims: This session will provide investigators, project teams, and organizational administrators with a basic understanding of the HMO Research Network's (HMORN) structure and organization, as well as several key processes the HMORN has developed to streamline collaboration across sites. Those new to the Network, to multi-center research, or just needing a refresher will benefit from an overview of HMORN governance, the Virtual Data Warehouse (VDW), multi-site grant writing tools and resources, and the IRB ceding process. **Methods:** HMORN staff will provide a high-level orientation of governance structures, communication tools and mechanisms, the Collaboration Toolkit, HMORN consortia, and scientific interest groups. A member of the Network's Grant Development Resources Workgroup will provide a review of the many tools and resources available to grant writers,

along with information about how to access them. The Virtual Data Warehouse (VDW) and the query-tool HMORNnet will be presented by the VDW Operations Committee, along with information about tools and resources for investigators and programmers to make the most of these resources. Finally, the IRB Workgroup lead will present an overview of the HMORN's successful IRB ceding process in order to provide teams with the information needed to determine if the ceding process is right for their project, and if so, how to use it. **Results:** Session attendees will be given the opportunity to ask questions of the panel of presenters during an open discussion period at the end of the session. **Conclusions:** The HMORN is a dynamic organization. New staff attend the annual conference each year, and the HMORN is constantly improving upon and expanding its resources. This orientation session will serve as an excellent way for attendees to directly connect with those most able to help them understand the Network and make the most of its resources and processes.

Keywords: Orientation; Operations; Resources

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B1-2:

The New Federal Conflict of Interest (COI) Regulations - One Step Forward?

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Background/Aims: All research institutions receiving federal funds must comply with new regulations regarding investigator COI. The adoption and implementation of these regulations has proven to be a challenge for many institutions and individual investigators. The purpose of this presentation is to explore what the new regulations actually mean, and to discuss best practices regarding their operationalization. **Methods:** We will look at how each HMORN member has implemented the regulations, the institutional policy created as a result, and the resulting practices put in place to meet regulatory requirements. Policies that go beyond the federal requirements will also be discussed. **Results:** We will compare strategies among HMORN members in an attempt to elicit successful practices that may be adaptable throughout the Network. **Conclusions:** The federal regulatory burden seems to be constantly increasing, in some cases with good reason. Meeting the burden with a minimum of disruption and cost should be the goal of any successful research program.

Keywords: Conflict of Interest; Federal Regulations; Funding

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B1-3:

Member Engagement in Patient-Centered Research

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Background/Aims: Meaningful patient-centered research requires the engagement of patients at multiple stages of the research process. The process and degree of patient engagement may differ depending on study design, methodology, and research question. However, there are few tools and guidelines on how to engage end-users in the research process. The goal of this project was to develop operational infrastructure, processes, and research designs and methods that facilitate the systematic engagement of members from the Kaiser Permanente Colorado (KPCO) region throughout the entire life cycle of research. **Methods:** With input from investigators, staff, operational stakeholders, and the human subject protection team, we identified relevant resources and developed a toolkit on member engagement. The process included: 1) Focused literature review on processes of stakeholder engagement in research; 2) Inventory of research projects with components of patient engagement; 3) Stakeholder interviews to identify existing operational processes and tools for member engagement within and outside of KPCO. These informed the development of a comprehensive toolkit. **Results:** The toolkit includes an annotated bibliography of the stakeholder engagement literature, a guide to the identification and initial engagement of members, principles for engagement of members in research, guidelines for human subject considerations for member engagement, and a set of research case examples. The toolkit was tested for usability and