

SOCIETY OF PEDIATRIC PSYCHOLOGY CRANIOFACIAL SIG

Division 54, Society of Pediatric Psychology

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Notes from the Co-Chairs

It has been another wonderful year! Amy Conrad, one of the SIG's first two co-chairs, has completed her term and we welcome Canice Crerand in her place. Our committees have been working on presentations and short courses to spread our goals/mission. ACPA brought the third annual Mental Health Forum and fourth annual SIG meeting, where we were joined by other mental health professionals working with families impacted by a craniofacial diagnosis. As the important role that Mental Health plays in craniofacial care is becoming more widely recognized, goals for the future include increased communication, collaboration and education.

Committee Updates [Celia Heppner]

At the time of this newsletter, there are 45 official members of the Craniofacial SIG. This year, members of our Outreach and Evidence-Based Practice Committees focused on continued recruitment and increasing methods of communication and accessibility, as well as development of Fact Sheets with information on common psychosocial and educational concerns that can be distributed to educate community providers about these population-specific issues.

Craniofacial PAT Update [Canice Crerand]

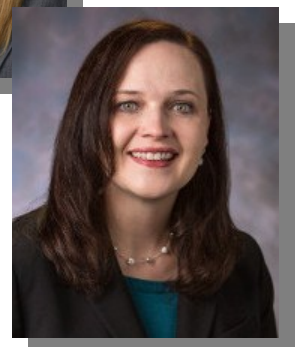
The Americleft Psychosocial Outcomes Committee developed a craniofacial version of the Psychosocial Assessment Tool (PAT; Pai, A.L., Patino-Fernandez, A.M., McSherry, M., Beele, D., Alderfer, M.A., Reilly, A.T., Hwang, W-T., & Kazak, A.E. (2008). The psychosocial assessment tool (PAT2.0): Psychometric properties of a screener for psychosocial distress in families of children newly-diagnosed with cancer. *Journal of Pediatric Psychology*, 33, 50-62.) in 2014. The PAT is a brief, parent-report screener of family psychosocial risk related to child problems, family problems, family social support, family structure and resources, sibling problems, and family beliefs. Dr. Canice Crerand at Nationwide Children's Hospital was recently awarded a grant from the Cleft Palate Foundation to evaluate the psychometric properties of the PAT-Craniofacial Version. The PAT-Craniofacial Version includes assessment of craniofacial-specific risk factors such as speech and appearance concerns, social stigmatization, and developmental and physical problems, and is intended to help clinicians differentiate families who may require additional resources and support in managing their child's condition from those who are at low risk of experiencing problems. This screener has a 6th grade reading level and primarily requires yes/no responses. It takes about 10-15 minutes to complete. This measure is free but a user agreement is required for both clinical and research purposes. Please contact Stephen Didonato at stephen.didonato@nemours.org if you would like more information about the PAT Craniofacial Version.

Upcoming Projects [Celia Heppner]

We are in the process of finalizing the CL/P fact sheet for mental health providers in the community. Our next step will be to develop a fact sheet for community providers on complex craniofacial conditions. During the Mental Health Forum at ACPA, we also discussed the option of developing additional fact sheets in the future geared towards pediatricians, obstetricians, and community dentists to provide information on relevant psychosocial issues for the craniofacial population. Please contact Celia Heppner at celia.heppner@childrens.com if you are interested in collaborating on this project.

Goals/Mission:

The SIG seeks to improve understanding and treatment of behavioral, emotional, academic, medical, and familial issues that patients experience through evidence-based practice.



SIG Structure:

Co-Chairs:

- Celia Heppner, PsyD
- Canice Crerand, PhD

Student Representative:

- Lillian Hamill, BS

Committees:

- Outreach/Recruitment Committee
- Evidence Based Practices Committee

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AmeriCleft Updates [Canice Crerand]

The AmeriCleft initiative seeks to increase standardized measurement of treatment outcomes to allow for comparisons across institutions. The Psychosocial group (composed of social workers and psychologists) met initially in 2013 and over the course of 1 ½ years, has developed a protocol designed to evaluate the family dynamics, psychosocial functioning, and quality of life of patients. Over the past year, the committee has finalized the assessment battery and drafted an IRB protocol with the goal of collecting data at six sites (Nationwide Children's Hospital, Columbus, OH; Shriners' Hospital, Chicago, IL; The Hospital for Sick Children, Toronto, Ontario, Canada; University of Iowa Children's Hospital, Iowa City, IA; Lancaster Cleft Palate Clinic, Lancaster, PA; and Children's Medical Center, Dallas, TX). The battery will be administered to patients between the ages of 8-10 years old along with their parents. Other sites interested in participating can contact the Americleft Psychosocial Committee Chair, Dr. Kathy Kapp-Simon, at kapp.simon@gmail.com

Student Spotlight [Glynnis McDonnell]

"I have had an interest in the psychosocial development of children, adolescents, and young adults with medical conditions since I began working toward my master's degree in Clinical Psychology at Teachers College, Columbia University in 2011. Currently, I am a member of a lab at St. John's University that conducts research relating to the psychosocial development of children and adolescents with craniofacial conditions. I am assisting with several projects about social competence and self-esteem in this population, as well as the role of parents in scaffolding the social interactions of children with craniofacial conditions. Through this research, I have learned about the social challenges faced by children with craniofacial conditions and the strategies they and their parents utilize to cope with these challenges. I hope to build upon this experience to identify strategies to support the social development of children, adolescents, and young adults with chronic illnesses."



Glynnis McDonnell is a rising second-year Ph.D. student in the Clinical Psychology program at St. John's University.

Announcements

Member Publications

Craddock, M.M., Gray, K.E., **Kapp-Simon, K.A.**, Collett, B.R., Buono, L.A., & Speltz, M.L. (in press). Sex differences in the neurodevelopment of school-aged children with and without single-suture craniosynostosis. *Child's Nervous System*.

Crerand, C.E., Rosenberg, J., **Magee, L.**, Stein, M., Genderson-Wilson, M., & Broder, H. (2014 Epub). Parent-reported family functioning among children with cleft lip/palate. *The Cleft Palate-Craniofacial Journal*.

Gray, K.E., **Kapp-Simon, K.A.**, Starr, J.R., Collett, B.R., Wallace, E.R., & Speltz, M.L. (2015). Predicting developmental delay in a longitudinal cohort of preschool children with single-suture craniosynostosis: Is neurobehavioral assessment important? *Dev Med Child Neurol*, 57(5). 456-462.

Gray, K.E., **Kapp-Simon, K.A.**, Starr, J.R., Collett, B.R., & Speltz, M.L. (2015). Longitudinal analysis of parenting stress in mothers and fathers of infants with and without single-suture craniosynostosis. *Cleft Palate-Craniofacial Journal*, 52(1), 3-11.

Johns, A.L., Lucash, R.E., Im, D.D., & Lewin, S.L. (2014). Pre and post-operative psychological functioning in younger and older children with microtia. *Journal of Plastic, Reconstructive & Aesthetic Surgery*, 68(4), 492-497.

Kapp-Simon, K.A., Edwards, T., Ruta, C., Crilly Bellucci, C., Topolski, T.D., Rumsey, N.J., & Patrick, D.L. (in press). Shared surgical decision-making and youth resilience: Correlates of satisfaction with clinical outcomes. *Journal of Craniofacial Surgery*.

Member Grants

Amy Conrad, PI— "Training in Neuroimaging of Cognitive Development in Craniofacial Diagnoses," K23 Award, 2014-2019.

Alexis Johns—Donation to help fund Division of Plastic and Maxillofacial Surgery and Craniofacial and Cleft Center support groups., Emi-Jay, Inc., 2014-2019.

Alexis Johns—Donation to help fund Division of Plastic and Maxillofacial Surgery and Craniofacial and Cleft Center support groups, Meta and George Rosenberg Foundation, 2014.

Co-Chair Transition

As Celia Heppner's term as co-chair will end in December 2015, SIG co-chair elections will take place this fall to fill the spot she will be vacating. Please consider running for co-chair or nominating a colleague!

We're online:

www.apadivisions.org/division-54/sigs/craniofacial/index.aspx

Contact us to join our SIG:

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