FROM THE SOCIETY

Adults with Complex Conditions Originating in Childhood Task Force Ends Year with a Bang

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In October of last year, we were thrilled to announce here in SGIM Forum that the SGIM Council had approved the formation of the Adults with Complex Conditions Originating in Childhood Task Force. The task force’s mission was: 1) to provide education within SGIM on the issues facing young adults with complex and disabling conditions originating in childhood and the general internists who care for them and 2) to be SGIM’s representatives in ongoing national efforts to advocate for and determine models of care for this patient population through partnership with other organizations. The task force came together shortly after the announcement of its formation and immediately went to work. In just a short time, the task force has accomplished a great deal. We capped off our first year as a task force with a strong presence at the annual meeting in San Diego.

The task force’s goal for this year’s annual meeting was to offer educational sessions to the membership related to caring for adults with disabilities and chronic conditions. We were fortunate to be able to offer two such sessions. A group led by task force member Mariecel Pilapil presented a workshop, titled “Preventive Screening in Young Adults with Special Health Care Needs: A Primary Care Perspective,” and Jennifer LeComte, the co-chair of the task force, led a group in presenting a Special Symposium, titled “Caring for Adults with Complex Conditions Originating in Childhood: Building Bridges to Ensure High Quality Longitudinal Care.” Both sessions were well attended and very well received.

The highlight of our efforts in San Diego was that we were able to invite Mariah Kilbourne, Miss Wheelchair America 2013, to speak as part of the special symposium through financial support received from Kaiser Permanente. Ms. Kilbourne was invited to bring a perspective to the session that is not commonly offered—the patient’s perspective. As a young adult with disabilities, she was able to share her stories transitioning from pediatric to adult health care systems, her experiences with different health care providers, her efforts to attend school and join the workforce, and her values and needs in working with internal medicine and adult specialty providers. Her participation in the symposium was both moving and motivating. As hoped, she was able to inform the audience as to what young adults with complex health conditions and needs really want from us. The rest of the symposium panel then followed her talk with practical information and suggestions on how we can all meet this challenge, capping off a successful session.

The task force has been busy beyond its offerings at the annual meeting. In January 2014, the task force co-hosted a roundtable with Kaiser Permanente and Physician Parent Caregivers in Washington, DC, titled “Quality Health Care for Young Adults with Chronic Conditions & Disabilities.” This two-day meeting brought together a diverse group of policy, medical, and advocacy stakeholders. The roundtable was intended to be the first in a series of efforts to involve multiple stakeholders and participants in the effort to move forward an agenda that benefits young adults with chronic and complex conditions. Over the last nine months we have made connections with a number of other organizations with similar goals and have been invited to collaborate on projects with those groups. Most recently we were invited to have a role on the advisory council for a grant being submitted to the Health Resources and Services Administration by members of the Health Care Transition Research Consortium to create a research network focused on the care of adults with autism spectrum disorders. We have also developed a needs assessment survey that we have distributed to SGIM members on GIM Connect and E-News to learn how we can best serve SGIM in the future. These efforts along with the sessions at the annual meeting completed an exciting first year.

Moving forward, the Adults with Complex Conditions Originating in Childhood Task Force hopes to maintain its momentum as we enter our second year of existence. We have set aggressive goals for the upcoming year, including building on our past successes and hopefully expanding on them as well. We would love to add more of a focus on research to our educational and advocacy efforts. Hopefully when the 2015 annual meeting in Toronto comes around, we will have had another big year with more successes, and we will have an even larger presence at the annual meeting with more exciting offerings such as we had in San Diego for everyone to enjoy and learn from.