



# ACC Adult Congenital and Pediatric Cardiology

## QUARTERLY NEWSLETTER

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### Support the Legacy of a Pioneer

The ACPC Section is pleased to announce Charles E. Mullins, M.D., F.A.C.C. will deliver the first McNamara Lecture in conjunction with Congenital Cardiology Solutions, at ACC.10 in Atlanta March 14-16. The McNamara Lecture was established to honor Dan Goodrich McNamara, M.D., M.A.C.C. Dr. McNamara is internationally recognized as a pioneer in the congenital heart disease field. [Information about the McNamara Lecture and corresponding endowment is available.](#)

### ACPC Section reaches out to General Cardiologists

Adult patients often enter care for their congenital heart condition through the primary cardiology setting, or live in a region with limited access to specialized congenital care. In response, the Adult Congenital Heart Disease WG has added a general adult cardiologist to the WG to help the Section to provide appropriate guidance for cardiologists caring for ACHD patients. Please contact the [acpsection@acc.org](mailto:acpsection@acc.org) with comments or questions.

Additionally, the WG Chair, Dr. Gary Webb, and Dr. Elyse Foster, have established a semi-annual electronic newsletter on ACHD activities. The newsletter will be available on the [ACPC Section website](#).

### Voice Support for the Congenital Heart Futures Act

Nearly 200 ACPC members, patients and family members made 150 visits to Congressional offices to request for increased funding for research, education and support for a national registry for CHD patients, including presence on National Congenital Heart Lobby Day. Senator Durbin (D-IL) introduced the [Congenital Heart Futures Act](#) in March. Call your Representative and Senators and voice your support!

### Support the ACPC Section objectives

Interested in participating in the ACPC Section? The Section is needs members to support the ongoing and expanding objectives of the congenital heart disease community. Contact [acpsection@acc.org](mailto:acpsection@acc.org) for more information.

### We want your opinion

The ACPC Section is considering expanding its involvement and WG opportunities to include initiatives in advocacy, publications and training. Comments from ACPC colleagues are welcome. [Click here](#) to comment on opportunities you believe would benefit our profession.

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The Adult Congenital and Pediatric Cardiology Section (ACPC) of the American College of Cardiology connects more than 1,200 members who share a professional interest in pediatric cardiology, adult congenital cardiology and congenital heart disease surgery. Members of the ACPC Section speak through a collective voice to advance and advocate priorities that correspond both to the College's mission and the pediatric and congenital cardiology community. Gerard Martin, MD, FACC chairs the ACPC Section. [www.acc.org/acpsection](http://www.acc.org/acpsection)



## ACC lends support to trio of quality improvement projects

All cardiologists aim to do what's best for their patients. But how do you define "best" when there are only limited data to guide the way? That's the dilemma facing pediatric cardiologists and those who treat adults with congenital heart disease (CHD).

"Most recommendations for care in congenital heart disease are based on expert consensus," said Gerard R. Martin, MD, co-director of the Children's National Heart Institute and senior vice president for Children's National Medical Center in Washington, DC. "There is such tremendous variety of structural defects in congenital heart disease that it has been difficult to develop large datasets to show whether one treatment is better than another."

That may soon change, as a trio of quality improvement projects led by the Adult Congenital and Pediatric Cardiology (ACPC) Section and Council and supported by the ACC either begin data collection or put the final touches on tools that will enable cardiologists, surgeons, nurses and other clinicians to define and measure high-quality care in CHD.

### IMPACT Registry

One such project is the [IMPACT Registry](#), a national clinical data registry that will enroll pediatric and adult patients who undergo cardiac catheterization. The IMPACT Registry—short for Improving Pediatric and Adult Congenital Treatment—is being developed under the auspices of the National Cardiovascular Data Registry (NCDR).

A six-month pilot is set to launch in August and will involve about a dozen hospitals across the country. The registry will collect a variety of data elements, including specific data on isolated defects such as atrial septal defect, coarctation of the aorta, valvar aortic stenosis, patent ductus arteriosus and valvar pulmonary stenosis. Definitions and data elements correspond with those used by the Society of Thoracic Surgeons in its surgical data registry as much as possible.

Initially, the IMPACT Registry will focus on episodes of care, but developers hope it will ultimately become a longitudinal database. "With this registry, we will have data fields that allow us to link with the surgeons," said Dr. Martin, who also chairs the NCDR IMPACT steering committee and is the ACPC section co-chair. "Hopefully, we'll be able to not simply improve care around a surgery or a catheterization, but actually over the lifetime of the individual."

Full launch of the IMPACT Registry is slated for the first quarter of 2010. Participation will be open to all pediatric centers, as well as "hybrid" institutions treating both pediatric and adult patients with CHD.

### Quality Metrics

The Quality Metrics Working Group is tackling quality improvement with a broad brush. More than 80 members have divided into teams to define quality measures in eight areas: heart failure/transplantation, imaging, adult CHD, general pediatric cardiology, electrophysiology, cardiac intervention, critical care and nursing. The focus is on determining not only what constitutes a valid indicator of quality, but also how to accurately measure it.

"The challenge is getting the measures honed down so they really make sense in the end," said Kathy Jenkins, M.D., M.P.H., senior vice president, chief safety and quality officer, and a senior associate in cardiology at Children's Hospital Boston. "What is the population? What's in the numerator? What's in the denominator? How will you display that measure? Does it need to be risk-adjusted? If so, what methodology should be used? That's the hard part."

The ultimate goal is to create a scorecard that medical centers can use to judge their own quality of care. Examples of quality metrics under development include sedation-related practices and complications, use of CT and MRI after surgery for coarctation of the aorta, and catheter-associated bloodstream infections.

These and other measures are in the vetting process now. The ACC has developed a web portal where participants can post preliminary measures and get feedback from other members of the working group, as well as updates on quality improvement in general. The next steps will be reviewed by the ACPC Section and Council and by the ACC Task Force on Performance Measures. Dr. Jenkins expects that several of the quality metrics will be approved by the Fall.

"I'm very excited about this," she said. "The best quality measures are coming from within the pediatric subspecialty areas, and I think we're really going to jump ahead of the game. We're creating a process that is very forward looking."

### JCCHD

The ACC is also lending support to a project by the [Joint Council on Congenital Heart Disease \(JCCHD\) National Quality Improvement Collaborative](#) that is attempting to rapidly identify and spread best practices in dynamic way. The project's goal is to improve the survival and quality of life of infants with hypoplastic left heart syndrome during the high-risk "interstage" between the first two surgeries needed to correct this severe heart defect.

"These are the most complex patients with congenital heart disease," said Robert H. Beekman III, M.D., a professor of pediatric cardiology at Cincinnati Children's Hospital Medical Center. "They have the highest morbidity and the highest mortality of any kids we treat, so there's huge room for improvement."

The project is focusing on improving three key drivers of quality: care transitions, interstage nutrition, and at-home monitoring by parents. Six pilot centers are participating in a web-based registry that was launched in April. It will track survival, growth, weight gain, number of days in the hospital, adverse events and other indicators.

Unlike a clinical study, the JCCHD project is attempting to improve performance in near real-time. "Quality improvement science is a way to study outcomes and spread best practices in a dynamic system," Dr. Beekman said. "You introduce an improvement, and if you like the effect, you keep it. If you don't like it, you try something else, but you just keep moving. It's very different from a controlled randomized clinical trial."

For example, Cincinnati Children's will schedule a nutritionist to see each baby at each clinic visit. If this has a positive impact on nutritional status, the practice will be shared throughout the collaborative.

So far 24 other centers have submitted applications to join the collaborative, once the pilot project is complete, increasing the total number of participating centers to 40. Clinical teams from these centers will come together in September for the first face-to-face Learning Session, with both formal sessions and break-outs that enable clinical teams to learn from each other by sharing successful clinical practices.

In all of its quality initiatives, the ACPC Section benefits from the expertise in quality improvement that already exists within the College. Dr. Martin said. He invites new members to join the Section, and welcomes all members to participate in quality improvement activities. For more information, please send an e-mail to Stephanie Mitchell at [acpsection@acc.org](mailto:acpsection@acc.org).

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