

Center for Innovation in Chronic Disease Care

FY13 Annual Report

July 1, 2012 through June 30, 2013

Mission

The mission of the Center for Innovation in Chronic Disease Care is to accelerate improvement in outcomes for children and adolescents with chronic conditions by developing and evaluating new methods of care delivery and by applying innovative approaches to quality improvement and research in chronic disease.

Center Highlights

- The Center has two integrated components --- the Chronic Care Research Group and the Asthma Clinical Innovation Laboratory. The main population of focus is adolescents with chronic disease. At CCHMC as elsewhere, adolescents with chronic disease have worse outcomes than younger patients. This is likely due to a combination of biological behavioral, developmental and health system factors.
- The **Collaborative Research Group** brings together 15 investigators (including faculty and fellows) from eight disciplines (adolescent medicine, cardiology, general pediatrics, general internal medicine, clinical psychology, speech and language pathology, statistics and quantitative analysis, and pastoral care). They represent nine CCHMC divisions (adolescent medicine, behavioral medicine and psychology, cardiology, emergency medicine, general and community pediatrics, pastoral care, patient services, pediatric medicine and rehabilitation, and pulmonary medicine) as well as Family Medicine at the University of Cincinnati. Main areas of focus include interventions to improve adherence and self-management; spirituality and coping among adolescents with chronic illness; quality of life; and transition to adult care.
- Collaborating researchers contributed to 39 peer-reviewed publications in FY13 related to chronic disease care (see publications list) and acted as principle or co-investigators in 38 federal, foundation or locally sponsored investigations (see list of active grants), and 4 grants currently under review (see grants in review).
- **The Asthma Innovation Laboratory** bridges research and health care improvement. It develops and prototypes care delivery innovations; translates existing research resources into practice-friendly tools that can be replicated elsewhere; and uses quality improvement methods to continuously improve the clinical care it provides to 291 adolescents with asthma.

RESEARCH HIGHLIGHTS

Bringing Neighborhood Phenotypes and Geomarkers to the Bedside for Children with Asthma

This three year study, beginning in 2013, is funded by a Proctor Scholar Career Development Award. The Principal Investigator is Andrew Beck, MD, MPH of General and Community Pediatrics. The study looks at neighborhood physical environment (ie density of substandard housing) and whether it predicts hospital readmission and emergency department revisit among hospitalized asthmatics. Data sources for the study include Cincinnati Area Geographic Information Systems (CAGIS), Cincinnati Building Department, US Department of Housing and Urban Development, census.gov, Legal Aid referrals from our clinics, and household surveys. The hypothesis for the study is that area level measure of substandard housing will be associated with risk of asthma

related reutilization, with the primary outcome being either ED revisit or hospital readmission, and that this same metric will be associated with household level reports of household risks.

Development in Adolescence and Adulthood: Links with Health Care Transitions

The long term-goal of this research proposal, being proposed by Sarah Beal, PhD, Adolescent and Transition Medicine, is to develop an independent research career focused on integrating developmental science and the medical setting, specifically as it related to transitions to adulthood and transfers in healthcare. The objective of the proposal is to fill a gap in our current understanding of how health and development intersect to shape the successful young adult transition, while also providing a means for Dr. Beal to establish independence as a researcher. The central hypothesis of the proposal is that effective timing and approach for the transfer in healthcare is dependent on the role changes youth are experiencing. This will be the first study to examine links between healthcare transfer and transitions to adulthood.

Adolescent Controlled Text Messaging to Improve Asthma Medication Adherence in Primary Care

Asthma, the most common chronic condition of childhood, currently affects millions of adolescents. The rates, severity and adverse outcomes for those in poor minority populations are higher. One reason for this is the lack of adherence to medication among these adolescents. Maria Britto, MD, MPH and a team of researchers has developed a novel, developmentally appropriate, adolescent controlled, calendar-to-text messaging intervention suitable for use in primary care to improve adherence by promoting autonomy and control and prompting use of controller medications for these adolescents. Their proposal includes a pilot randomized controlled trial, in four Cincinnati Childrens based primary care clinics, of a texting intervention to increase adherence to preventive asthma medication among this poor minority population.

QUALITY IMPROVEMENT WORK

Population Management

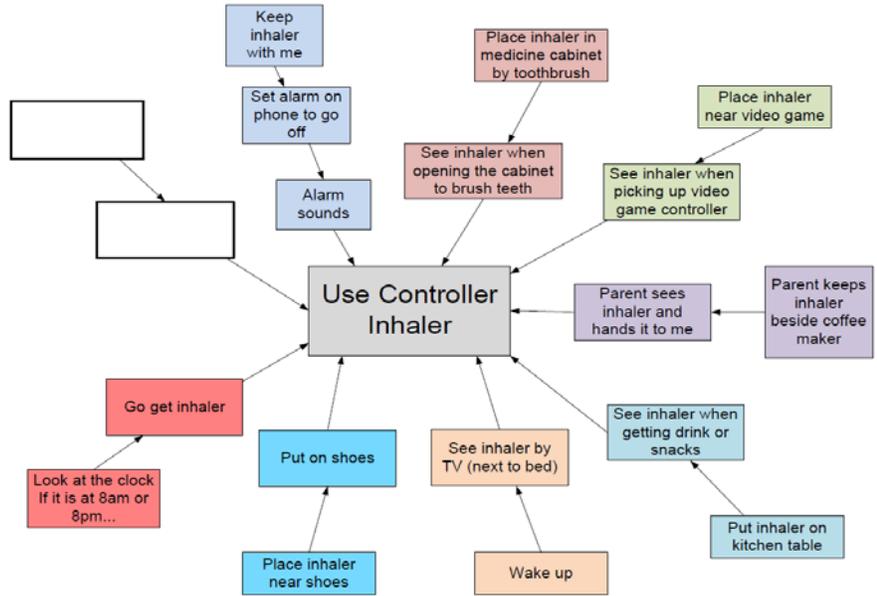
Population management employs proactive steps to manage patient care before, during and after a visit by using a system of coordinated healthcare interventions and communications for populations with conditions in which patient self-care efforts are significant. In FY2013, the lab team concentrated on the identification and reduction of care gaps including immunizations, pulmonary referrals and annual physical examinations. At the end of the year, care gaps were at 17%.

Transition to Adult Care

In FY2013, the lab team developed, tested and implemented the use of a brochure to assist patients preparing for a transition to adult primary care.

Behavior Management

In FY2013, in addition to regular meetings, the team held a retreat and prioritized different issues patients face in trying to maintain well-controlled asthma. Using brainstorming, priority mapping and patient input, the team ultimately chose to develop an intervention to help patients in preparation or action to remember to regularly take their controller medication. The intervention is a diagram that helps patients use everyday occurrences or habits trigger the use of their controller inhaler. In FY2014, the team will continue testing and implementation of the tool and determine whether it improves adherence.



Staff



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Maria Britto, MD, MPH
Adolescent and Transition Medicine, and
Anderson Center
Center Director



Terri Byczkowski, PhD
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Research Group



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Janet Wimberg
 Patient Services
 Lab Team Parent Coordinator

Publications in FY13

1. Anderson JB, Czosek RJ, Knilans TK, Marino BS. The effect of paediatric syncope on health-related quality of life. *Cardiol Young*. Oct 2012;22(5):583-588.
2. Babcock L, Byczkowski T, Wade SL, Ho M, Bazarian JJ. Inability of S100B to predict postconcussion syndrome in children who present to the emergency department with mild traumatic brain injury: a brief report. *Pediatr Emerg Care*. Apr 2013;29(4):458-461.
3. Babcock L, Byczkowski T, Wade SL, Ho M, Mookerjee S, Bazarian JJ. Predicting postconcussion syndrome after mild traumatic brain injury in children and adolescents who present to the emergency department. *JAMA Pediatr*. Feb 2013;167(2):156-161.
4. Beal S, Brewster LP. Femoral and carotid intima media thickness- two different measurements in two different arteries. *J Surg Res*. Aug 24 2012.
5. Beck AF, Klein MD, Kahn RS. Identifying social risk via a clinical social history embedded in the electronic health record. *Clin Pediatr (Phila)*. Oct 2012;51(10):972-977.
6. Beck AF, Simmons JM, Huang B, Kahn RS. Geomedicine: area-based socioeconomic measures for assessing risk of hospital reutilization among children admitted for asthma. *Am J Public Health*. Dec 2012;102(12):2308-2314.
7. Brinkman WB, Hartl Majcher J, Poling LM, et al. Shared decision-making to improve attention-deficit hyperactivity disorder care. *Patient Educ Couns*. May 10 2013.
8. Britto MT, Hesse EA, Kamdar OJ, Munafo JK. Parents' Perceptions of a Patient Portal for Managing Their Child's Chronic Illness. *J Pediatr*. Mar 28 2013.
9. Brown KL, Ichord R, Marino BS, Thiagarajan RR. Outcomes following extracorporeal membrane oxygenation in children with cardiac disease. *Pediatric critical care medicine : a journal of the Society of Critical Care Medicine and the World Federation of Pediatric Intensive and Critical Care Societies*. Jun 2013;14(5 Suppl 1):S73-83.
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11. Byczkowski TL, Munafo JK, Britto MT. Family perceptions of the usability and value of chronic disease web-based patient portals. *Health Informatics Journal*. September 20, 2013 2013.
12. Crockett LJ, Beal SJ. The life course in the making: gender and the development of adolescents' expected timing of adult role transitions. *Dev Psychol*. Nov 2012;48(6):1727-1738.
13. Crosby LE, Parr W, Smith T, Mitchell MJ. The community leaders institute: an innovative program to train community leaders in health research. *Acad Med*. Mar 2013;88(3):335-342.
14. Czosek RJ, Anderson J, Houry PR, Knilans TK, Spar DS, Marino BS. Utility of ambulatory monitoring in patients with congenital heart disease. *Am J Cardiol*. Mar 1 2013;111(5):723-730.
15. Czosek RJ, Bonney WJ, Cassidy A, et al. Impact of cardiac devices on the quality of life in pediatric patients. *Circ Arrhythm Electrophysiol*. Dec 2012;5(6):1064-1072.
16. DeWitt EM, Kimura Y, Beukelman T, et al. Consensus treatment plans for new-onset systemic juvenile idiopathic arthritis. *Arthritis Care Res (Hoboken)*. Jul 2012;64(7):1001-1010.
17. Dewitt EM, Li Y, Curtis JR, et al. Comparative effectiveness of nonbiologic versus biologic disease-modifying antirheumatic drugs for rheumatoid arthritis. *J Rheumatol*. Feb 2013;40(2):127-136.
18. Dorn LD, Beal SJ, Kalkwarf HJ, Pabst S, Noll JG, Susman EJ. Longitudinal impact of substance use and depressive symptoms on bone accrual among girls aged 11-19 years. *J Adolesc Health*. Apr 2013;52(4):393-399.
19. George-Abraham JK, Zimmerman SL, Hinton RB, Marino BS, Witte DP, Hopkin RJ. Tetrasomy 15q25.2-->qter identified with SNP microarray in a patient with multiple anomalies including complex cardiovascular malformation. *Am J Med Genet A*. Aug 2012;158A(8):1971-1976.
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21. Grosseohme DH, Cotton S, McPhail G. Use and sanctification of complementary and alternative medicine by parents of children with cystic fibrosis. *J Health Care Chaplain*. 2013;19(1):22-32.
22. Grosseohme DH, Cotton S, Ragsdale J, Quittner AL, McPhail G, Seid M. "I honestly believe god keeps me healthy so i can take care of my child": parental use of faith related to treatment adherence. *Journal of health care chaplaincy*. 2013;19(2):66-78.
23. Grosseohme DH, Ragsdale JR, Cotton S, et al. Using spirituality after an adult CF diagnosis: cognitive reframing and adherence motivation. *J Health Care Chaplain*. 2012;18(3-4):110-120.
24. Huppert JS, Reed JL, Munafo JK, et al. Improving notification of sexually transmitted infections: a quality improvement project and planned experiment. *Pediatrics*. Aug 2012;130(2):e415-422.

25. Joffe NE, Lynch-Jordan A, Ting TV, et al. The utility of the PedsQL Rheumatology Module as an outcome measure in juvenile fibromyalgia. *Arthritis Care Res (Hoboken)*. May 17 2013.
26. Kaminski GM, Britto MT, Schoettker PJ, Farber SL, Muething S, Kotagal UR. Developing capable quality improvement leaders. *BMJ Qual Saf*. Nov 2012;21(11):903-911.
27. Kaminski GM, Britto MT, Schoettker PJ, Farber SL, Muething S, Kotagal UR. Republished: developing capable quality improvement leaders. *Postgrad Med J*. Feb 2013;89(1048):78-86.
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30. Lipstein EA, Lovell DJ, Denson LA, et al. Parents' information needs in tumor necrosis factor-alpha inhibitor treatment decisions. *J Pediatr Gastroenterol Nutr*. Mar 2013;56(3):244-250.
31. Lipstein EA, Muething KA, Dodds CM, Britto MT. "I'm the one taking it": adolescent participation in chronic disease treatment decisions. *J Adolesc Health*. Aug 2013;53(2):253-259.
32. Luberto C, Cotton S, McLeish A, Mingione C, O'Bryan E. Mindfulness Skills and Emotion Regulation: the Mediating Role of Coping Self-Efficacy. *Mindfulness*. 2013/02/01 2013:1-8.
33. Marino BS, Lipkin PH, Newburger JW, et al. Neurodevelopmental outcomes in children with congenital heart disease: evaluation and management: a scientific statement from the American Heart Association. *Circulation*. Aug 28 2012;126(9):1143-1172.
34. Parker MW, Schaffzin JK, Lo Vecchio A, et al. Rapid adoption of *Lactobacillus rhamnosus* GG for acute gastroenteritis. *Pediatrics*. Mar 2013;131 Suppl 1:S96-102.
35. Seid M, D'Amico EJ, Varni JW, et al. The in vivo adherence intervention for at risk adolescents with asthma: report of a randomized pilot trial. *Journal of pediatric psychology*. 2012;37(4):390-403.
36. Szaflarski M, Kudel I, Cotton S, Leonard AC, Tsevat J, Ritchey PN. Multidimensional assessment of spirituality/religion in patients with HIV: conceptual framework and empirical refinement. *J Relig Health*. Dec 2012;51(4):1239-1260.
37. Valenzuela JM, Vaughn LM, Crosby LE, Strong H, Kissling A, Mitchell MJ. Understanding the experiences of youth living with sickle cell disease: a photovoice pilot. *Fam Community Health*. 2013;36(2):97-108.
38. Villa CR, Marino BS, Jacobs JP, Cooper DS. Intensive care and perioperative management of neonates with functionally univentricular hearts. *World journal for pediatric & congenital heart surgery*. Jul 1 2012;3(3):359-363.
39. Wray J, Franklin R, Brown K, Cassedy A, Marino BS. Testing the pediatric cardiac quality of life inventory in the United kingdom. *Acta paediatrica (Oslo, Norway : 1992)*. Feb 2013;102(2):e68-73.

Grant Support in FY13

Project Direct

Acceleration to Expertise: Simulation as a Tool to Improve the Recognition of Sepsis

AHRQ 04/01/11-03/31/14 \$1.031.931

1R18HS020455-01

PI: Geis

Co-PI: **Byczkowski**

Adherence and Psychosocial Factors Related to Spirituality: Examining Causality to Inform an Intervention

Cystic Fibrosis Foundation 12/1/2012-11/30/2013 \$37,940

PI: **Grosseohme**

Breathing Retraining in African-American Adolescents with Asthma

US/CCHMC CCTST 2013-2014

PI: **Cotton**

Bringing Neighborhood Phenotypes and Geomarkers to the Bedside for Children with Asthma

Proctor Scholar Award, CCHMC 2013-Present

PI: **Beck**

Building Modular Pediatric Chronic Disease Registries for QI and CE Research		
AHRQ	09/01/10-08/31/13	\$9,042,411
R01HS020024-01		
PI: Hutton		
Collaborator(s): Britto		
Center of Excellence on Quality of Care Measures for Children with Complex Needs		
AHRQ	03/01/11-02/28/15	\$655,832
U18 CHIPRA Pediatric Healthcare Quality Measures Program Centers of Excellence		
PI: Mangione-Smith		
Site PI: Britto		
Determinants of Health-Related Quality of Life for Children with JIA		
NIH/NIAMS	05/01/08-04/30/13	\$1,124,423
P60-AR047784		
Co-PI: Glass, Seid		
Center Collaborator(s): Britto		
Developing Quality Measures to Access Pediatric Inpatient Respiratory Care		
NHLBI	12/01/08-11/30/13	\$3,293,636
1R01HL088503-01		
PI: Mangione-Smith		
Site PI: Britto		
Do Serum Biochemical and Hematopoietic, and Stool Biomarkers Predict Low Cardiac Index in Patients with Fontan Physiology?		
Children's Heart Foundation	01/01/12-12/31/13	\$200,000
PI: Marino		
Efficacy of Integrative Care Therapies in Hospitalized Children/Adolescents		
CCHMC	2013-2016	
PI: Cotton		
Greater Cincinnati Asthma Risks Study		
NIH	2012-Present	
1R01A188116		
Co-PI: Beck		
The Heart Institute Neurodevelopmental and Educational Clinic		
Kindervelt Foundation	07/01/12 – 06/30/16	\$2,000,000
PI: Heart Institute Executive Co-Directors		
Center Collaborator : Marino		
HPV Vaccine Decision Aid Development		
CCHMC Place Outcomes Research Award	07/01/11-06/30/13	\$119,998
PI: Widdice		
Center Collaborator: Brinkman		
Impact of SCD Patient Portal on Transition to Adult Care		
CCHMC Place Outcomes Award	07/01/11-Present	\$60,000/yr
PI: Crosby		

Improving Home Environmental Risk Assessment and Enhancing Referrals for Housing Code Enforcement for Children with Asthma

Center for Clinical and Translational Science and Training (CCTST) 2011-2012 \$15,315
PI: **Beck**

Improving Parents' TNF- α Inhibitor Treatment Decisions

Cincinnati Children's Hospital Place Outcomes Research Award
PI: **Lipstein** 07/01/2011-06/30/2013 \$103,984

Improving Sickle Cell Transitions of Care through Health Information Technology, Phase 1

AHRQ 08/30/12-05/29/14 \$62,834
HHS2902010000331/HHS209032001T
Site PI: **Britto**

Improving STI Results Notification and Partner Services

CCTST/NIH 11/01/10-10/31/12 \$200,000
2K12HD051953-06
Co-Investigator: **Byczkowski**

Infant Nutrition Intervention Partnership: Cincinnati Children's Hospital Medical Center and Freestore Foodbank

Proctor & Gamble 2011-Present \$50,000
Co-Investigator: **Beck**

Magnetic Resonance Elastography in Fontan Patients

Society of Pediatric Radiology 09/01/13-08/31/14 \$10,000
New Investigator Pilot Grant
PI: Wallihan
Collaborator: **Marino**

Medication Continuity Among Children Treated for ADHD

NIMH 12/01/09-11/30/14 \$821,499
Patient Oriented-Career Development Award (PA-09-043)
PI: **Brinkman**

Open Source Science: Transforming Chronic Care

NIH/NIDDK 10/01/09-09/13/14 \$7,831,713
R01DK085719
Co-PI's: Margolis/Seid
Co-Investigator: **Britto**

Outcomes in Patients Requiring More than a Single Course of ECMO Therapy

ELSO Research Grant 07/01/12 -06/30/13 \$10,000
PI: Cooper
Center Collaborator – **Marino**

Outcomes Research in Children with Complex Congenital Heart Disease

Cincinnati Children's Hospital Research Foundation 07/01/07-06/30/13 \$4,263,710
PI: **Marino**

Parental Adherence to CF Homecare: Research Chaplaincy Career Commitment		
NIH/NICHD	08/13/10-05/31/15	\$590,000
PI: Grossoehme		
Patient-Provider Interventions to Improve the Transition to Adult Care in SCD		
NIH/NHLBI	2011-Present	\$431,170/yr
K07HL108720		
PI: Crosby		
Pursuing Perfection in Pediatric Therapeutics		
AHRQ	10/01/11-09/30/16	\$850,000
1U19HS021114		
PI: Lannon		
Center Collaborator: Brinkman		
Pursuing Perfection in Pediatric Therapeutics (sub-project: Shared Decision Making in Pediatric Rheumatology).		
AHRQ	10/01/11-09/30/16	\$849,999
1U19HS021114		
PI: Lannon		
Center Collaborator: Lipstein		
Pursuing Perfection in Pediatric Therapeutics		
AHRQ	09/30/2011-08/31/16	\$555,555
U19HS021114		
PI: Lannon		
Co-Investigator: Morgan DeWitt		
Resilience in Emergency Department Workers Following Workplace Violence		
Robert Wood Johnson Foundation	09/01/12-08/31/15	\$349,979
PI: Gillespie		
Co-Investigator: Byczkowski		
Resuscitation Using Novel Impedance Threshold Device in Pediatrics		
NIH/NHLBI SBIR Grant	08/01/12-07/31/14	\$369,638
2R44 HL083541-03A1		
PI: Lurie		
Center Collaborator: Marino		
Shared Decision Making to Improve Care and Outcomes for Children with Autism		
CCHMC Place Outcomes Research Award	07/01/13 – 06/30/15	\$60,000
Co-PI's: Anixt and Brinkman		
Shared Decision Making In Pediatric Chronic Conditions: Biologics in IBD and JIA		
NIH		
PI: Lipstein		
Social networks and adherence in adolescents with CF		
Place Outcomes Award	07/01/12-06/30/14	\$120,000
PI: Grossoehme		

Spiritual Intervention in a Medical Home for Patients with Sickle Cell Disease

NIH 2010-2013 \$810,610
R01HD059879-01
PI: YI
Co-Investigator: **Britto**

STAT-ED Suicidal Teens Assessing Treatment after an Emergency Department Visit

DHHS, CDC 09/30/12-09/29/15 \$1,198,415
1R01CE002129-01
PI: Grupp-Phelan
Co-Investigator: **Byczkowski**

Transitional Telehealth Home Care: REACH

National Institute of Nursing Research 09/21/11 – 06/30/16 \$696,557
2 R01 NR002093
PI: Medoff-Cooper
Center Collaborator: **Marino**

Understanding Mechanisms of Fontan Failure and Key Predictors for Patient Outcome

AHRQ 02/01/10-01/31/14 \$116,903
1 R01 HL098252-01
PI: Yoganathan
Center Collaborator: **Marino**

Grants in Review

[Project Direct](#)

RCT of the In Vivo Intervention for Youth with Asthma CCC

R01HL114550 07/01/12-06/30/17
NIH
PI: Michael Seid
Co-Investigator: **Britto**

A Social Ecological CBPR Approach for Addressing Latino Child Health Disparities

1R24MD008052-01 01/01/13-12/31/15
NIH
PI: Lisa Vaughn
Co-Investigator: **Britto**

Adolescent Controlled Text Messaging to Improve Asthma Medication Adherence in Primary Care

1R21HL119826-01 07/01/13-06/30/15
NIH
PI: **Britto**

Developing New Technologies to Improve ADHD Medication Continuity

R34 MH101155-02 04/01/14-03/31/17
NIMH
PI: **Brinkman**