

SAFER

The Chair's Initiatives of the
Department of Pediatrics

ROUND

2011 – 2013

3

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The Chair's Initiatives: Brilliance Booster

ROUND
2011 – 2013

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As one of the top pediatric hospitals in the world, The Children's Hospital of Philadelphia is populated by extremely bright, innovative and motivated physicians, nurses and other professionals. They often have great ideas to improve patient care and safety — but need funding and other resources in order to get those ideas off the ground. The Chair's Initiatives of the Department of Pediatrics is an internal grant program that provides two years of seed money, collaboration and support to teams as they tackle some of the toughest problems in healthcare.



Alan R. Cohen, M.D.



Alison Marx



Kathy Shaw, M.D., M.S.C.E.



Joseph W. St. Geme III, M.D.

The 22 teams funded since the program's inception in 2006 have established a track record of excellence and accomplishment. They have:

- traveled around the country and the world to give presentations at more than 175 conferences and other events for colleagues in healthcare, as well as parents, school staff and others
- published approximately 90 articles in respected journals related to their initiatives
- received 27 grants worth approximately \$7.4 million to further their efforts after Chair's Initiatives funding ended
- been featured in hundreds of national and international news stories

Most notably, they have found ways to provide better, safer care for children and their families. This booklet provides details about the accomplishments of Round 3 of the Chair's Initiatives.

Leading Change: The Chair's Initiatives program was founded in 2006 by Alan R. Cohen, M.D., then Physician-in-Chief, and Alison Marx, Operating Officer, Department of Pediatrics, and is now led by Joseph W. St. Geme III, M.D., Physician-in-Chief, along with Marx and Kathy Shaw, M.D., M.S.C.E., Patient Safety Officer, Department of Pediatrics, and Chief, Division of Emergency Medicine.

The six projects selected for the third round of Chair's Initiatives were funded from 2011 to 2013 and continued the history of excellence.

Minds Matter: Improving Pediatric Concussion Management (page 2)

Defining guidelines for concussion care in emergency rooms, primary care practices, sports medicine and other settings

Assuring Quality and Safety at CHOP Community Pediatric Programs (page 4)

Implementing a system to ensure that care at CHOP-affiliated units and programs at local hospitals is as excellent as at CHOP

A Shared Decision-making Portal for Pediatric Chronic Illness (page 6)

Designing a computer portal shared by parents and clinicians to improve communication and care for asthma

Improving Hospital Care for and Service Delivery to Individuals with Autism Spectrum Disorders (page 8)

Finding better ways to communicate with and care for patients with autism

Preventing Outpatient Central Line-associated Bloodstream Infections (page 10)

Reducing the at-home incidence of one of the most costly problems in healthcare

Transitioning from Pediatric to Adult Services: A Primary-care-based Model (page 12)

Helping young people with chronic illness move to — and stay with — adult primary care providers

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Minds Matter: Improving Pediatric Concussion Management

Challenge

Every year thousands of children and adolescents suffer concussion. In recent years, awareness of concussion has grown rapidly, and visits to the doctor for suspected concussion have increased dramatically.

Care for concussion may be provided by multiple teams, including emergency room staff, primary care pediatricians and sports medicine physicians. This can result in fragmented care and inconsistent advice, and the child may not receive the proper follow-up care.

With Chair's Initiatives funding, a team set out to improve care for children and adolescents with concussion by creating tools to standardize and streamline management of concussion in the CHOP Care Network, and to educate parents and patients.

Team

Christina Master, M.D.

Kristy Arbogast, Ph.D.

Matthew Grady, M.D.

Mark Zonfrillo, M.D., M.S.C.E.

Michael Nance, M.D.

James Callahan, M.D.

Flaura Winston, M.D., Ph.D.

Suzanne Hill, B.A.

Roni Robinson, R.N., M.S.N., C.R.N.P.

Accomplishments

- The team created a tool in CHOP's electronic medical record system to help primary care physicians evaluate concussion. The tool is now widely used in CHOP-affiliated primary care practices.
- The team created a website, www.chop.edu/concussion, with information for parents, kids, school staff, coaches and healthcare providers. Visits to the site average 3,000 per month.
- The team held a conference for healthcare providers and school staff, providing information on the basics of concussion care. Nearly 160 attended. The second annual conference will be held in April 2014.
- Many calls from parents about concussion were coming in to CHOP's After Hours Program call center. The team trained nurses who staff the call center in triaging suspected concussion.
- The team updated a "head trauma pathway," a computer guideline for care widely used by CHOP Emergency Department staff, to include concussion-specific information.
- The team began to define parameters for a concussion registry, a database of information about concussion cases that will inform scientific research to improve care.
- To date, the team has seven peer-reviewed publications, and has completed more than 20 presentations at scientific gatherings and more than 40 presentations at community events.





Minds Matter: Improving Pediatric Concussion Management

Department of Pediatrics Chair's Initiatives

Project Goal

To develop a comprehensive pediatric concussion management program throughout the CHOP Network by creating an evidence-based tool-kit that will streamline pediatric concussion care Network-wide

Implementation/Accomplishments

1. Epic Smart Set and Trainings: May-July 2012

- 5 sessions trained CHOP primary care providers in concussion management including use of newly created Epic SmartSet (released in July 2012) for evaluating patients with suspected concussion; follow up training in November 2013
- Trained nearly 100 primary care clinicians from across the CHOP care network, including one designated "Concussion Champion" from each care network location

2. Website: www.chop.edu/concussion

- Phase 1: June 2012 centralized all of the concussion information on the newly created www.chop.edu/concussion; outdated information throughout the CHOP web was removed;
- Phase 2: April 2013 included sections specific to families, healthcare providers, school staff and coaches, and will be supplemented with multimedia content, including Q&A videos in Summer 2013

3. CME Conference: April 6, 2013; April 2014 conference scheduled in collaboration with Penn

- Standing room only crowd of nearly 160 (representing 8 states and 2 countries) for the 1st Annual "Diagnosis and Management of Child and Adolescent Concussion: A Primer for Primary Care Providers and Educators" Conference. The daylong event included 11 sessions for clinicians and educators ranging from "Standard Concussion Treatment" to "Concussion in the Classroom"

4. After Hours Program: September 2012

- Updated the After Hours Program call center telephone triage guidelines for head injury to align them with the CHOP concussion management guidelines.
- Trained the triage nurses on the new guidelines and have continued to work with the After Hours Program to further improve the guidelines.

5. Materials: Patient Family Education (PFEs) and ED Head Trauma Pathway

- May 2012 updated CHOP Emergency Department's Head Trauma Pathway with concussion-specific information
- June 2012 Released 2 PFE's, "Understanding your Child's Condition- Facts About Concussion" & "Helping Your Child Recover-Coping After a Concussion. Available on the website and the intranet, integrated into the Epic SmartSet and the Emergency Department's discharge instructions

6. Follow-on funding: received follow-on funding for continued activities

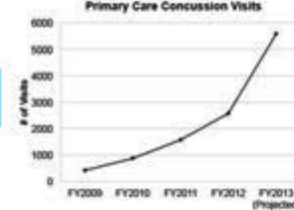
- CHOP Women's Committee, NXT Lacrosse/Philadelphia Wings Lacrosse, UPenn ITMAT program

Challenges/Barriers/Next Steps

- Clinical demand greater than currently available resources
- Best practices still evolving; need to provide ongoing education to primary care to maximize their concussion management practices
- Science is incomplete; need for pediatric research, and CHOP can play a prominent role based on volume and expertise

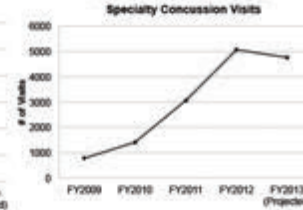
Project Measures and Tools

Primary Care



- Total Visits FY09-13: 7,819 visits
- Concussion camps at each Care Network Site
- Targeted, hands-on training
- New Epic SmartSet used 3192 times in 10 months
- 67% of those diagnosed with concussion at primary care used Epic SmartSet

Specialty Care



- Total Visits FY09-13 12,810 visits
- Concussion registry specifications defined
- Obtained partial hospital funding for concussion nurse practitioner who coordinates care

After Hours



- Trained all 23 After Hours triage nurses
- Head Trauma Triage Guidelines Updated; used 1661 times in 8 months
- 62.9% of patients who were seen within 24 hours, as directed, received diagnosis of concussion

Education/Outreach



- Created new website
 - Average of 3,000 per month
- >1000 downloads of PFEs
- CME Conference for primary care/schools
- 40+ presentations to community groups
- Legislative advocacy – Safe Kids USA, Congressional panel on NCAA concussion law

Publications & Presentations

- Peer-reviewed Publications: 7 (2 in press)
- Scientific Presentations: >20
- Community Presentations: >40

Publications

- Arbogast KB, McGinley AD, Master CL, Grady MF, Robinson RL, Zonfrillo MR. Cognitive rest and school-based recommendations following pediatric concussion: the need for primary care support tools. *Clinical Pediatrics*. 2013;52(5):393-398.
 - Zonfrillo MR, Master CL, Grady MF, Winston FK, Callahan JM, Arbogast KB. Pediatric providers' self-reported knowledge, practices and attitudes about concussion. *Pediatrics* 2012;130(6): 1120-1125.
- Pediatric Annals Special Issue on Concussion (Guest Editors)**
- Master CL, Grady MF. Office-Based Management of Pediatric and Adolescent Concussion. *Pediatric Annals*. 2012;41(9):1-6.
 - Master CL, Gioia GA, Leddy JJ, Grady MF. Importance of "Return-to-Learn" in Pediatric and Adolescent Concussion. *Pediatric Annals*. 2012;41(9):1-6.
 - Vidal PG, Goodman AM, Colin A, Leddy JJ, Grady MF. Rehabilitation strategies for prolonged recovery in pediatric and adolescent concussion. *Pediatric Annals*. 2012;41(9):1-7.
 - Darby DG, Master CL, Grady MF. Computerized neurocognitive testing in the medical evaluation of sports concussion. *Pediatric Annals*. 2012;41(9):371-6.
 - Grady MF, Master CL, Gioia GA. Concussion Pathophysiology: Rationale for Physical and Cognitive Rest. *Pediatric Annals*. 2012;41(9): 377-82.

Selected Scientific Presentations

- Robinson RL. Consequences of Inaccurate Assessment of Concussion. 14th Annual Advance Practice Nursing Conference, Philadelphia, Pennsylvania, May 2013
- Corwin DJ, Master CL, Arbogast KB, Zonfrillo MR. Cognitive and Emotional Morbidity Following Youth Concussions. Poster Presentation, Pediatric Academic Societies' 2013 Annual Meeting and American Medical Society for Sports Medicine Annual Meeting, San Diego, CA, April 2013
- Corwin DJ, Arbogast KB, Zonfrillo MR, Grady MF, Master CL. Vestibular deficits and rehabilitation following youth concussion. Oral Poster Rising with Research Presentation, American Medical Society for Sports Medicine Annual Meeting, San Diego, CA, April 2013.
- McGinley AD, Arbogast KB, Master CL, Grady MF, Zonfrillo MR. Emphasis on standardized return to play recommendations for pediatric concussion management. Poster Presentation, 2nd Penn State Concussion in Athletics Conference, 2012
- Master CL, Zonfrillo MR, Grady MF, Arbogast KB. Clinician knowledge and provision of cognitive rest recommendations for pediatric concussion. Poster Presentation, American Medical Society for Sports Medicine, Poster Presentation, John M. Templeton Jr. Pediatric Trauma Symposium, Poster Presentation, Pediatric Academic Societies' 2012 Annual Meetings, 2012.
- Arbogast KB, McGinley A, Master CL, Grady MF, Zonfrillo MR. Primary care emphasis on school-based recommendations for pediatric concussion management. Platform Presentation, Pediatric Academic Societies' 2012 Annual Meeting, 2012.
- Master CL, Zonfrillo MR, Arbogast KB, Robinson RL, Grady MF. Clinician understanding of cognitive rest in pediatric concussion management. Oral Poster Rising with Research Presentation, American Medical Society for Sports Medicine Annual Meeting, Atlanta, Georgia, April 2012
- McGinley AD, Zonfrillo MR, Master CL, Grady MF, Arbogast KB. General pediatric and emergency medicine providers' self-reported practices and attitudes surrounding concussion management. Poster Presentation, Children's Hospital of Philadelphia's Research Poster Day, and Pediatric Academic Societies' 2012 Annual Meeting, 2012.
- Master CL, Zonfrillo MR, Arbogast KB, Robinson RL, Grady MF. Clinician Understanding of Cognitive Rest in Pediatric Concussion Management. Templeton Pediatric Trauma Symposium, Philadelphia, Pennsylvania, March 2012.

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Assuring Quality and Safety at CHOP Community Pediatric Programs

Challenge

As healthcare has evolved, most major institutions have grown far beyond the walls of the original hospital. How can care be standardized and measured across multiple sites, to ensure the patient receives the highest quality, safest care no matter the location?

As part of its Care Network, The Children's Hospital of Philadelphia provides staff for pediatric care at several community hospitals, including emergency department care, general pediatric care, and neonatal intensive care. With Chair's Initiatives funding, this team set out to define, test and implement a system to monitor the quality of care in CHOP programs at community hospitals. The end goal: to ensure that care at every CHOP site is as excellent as care at the Main Campus.

Team

Mark Joffe, M.D.

Mark Ogino, M.D.

Jeffrey Gerdes, M.D.

Carrie Hufnal-Miller, M.D.

Jan Boswinkel, M.D.

Jeffrey Seiden, M.D.

Kathy Shaw, M.D.,
M.S.C.E.

Brandon Calderon

Joseph Fillipoli

John Chuo, M.D.

John Sestito

Karen Pinsky, M.D.

April Taylor

Accomplishments

- The team identified 13 metrics to measure quality of care at community sites, in emergency medicine, general pediatrics and neonatology. For example, one metric measures the time it takes for a child with asthma who comes to an emergency room to receive a steroid medication. Another measures the incidence of a certain type of bloodstream infection in neonates.
- Eighteen practices within 10 community hospitals began to track the metrics at their sites.
- The team began creating a system for a central collection site for data from all locations, accommodating varying computer systems and methods of data collection.
- Each site now routinely analyzes data, and the sites (grouped by specialty) confer to discuss data and methods for improvement.
- The team continues to analyze data to determine whether the implementation of a monitoring system has improved care. Because some trends in the metrics are cyclical, analysis becomes more meaningful with time.





Assuring Quality and Safety at CHOP Community Pediatric Programs

Department of Pediatrics – Chair's Initiative

Jan Boswinkel, Brandon Calderon, John Chuo, Jeff Gerdes, Carrie Hufnal-Miller, Debbie McKetta, Karen Pinsky, Jeff Seiden, Kathy Shaw, April Taylor

Objective

To design, test and implement a quality monitoring system to ensure that pediatric care delivered throughout the CHOP outreach network meets the highest quality standards through standardization of practice and data transparency.

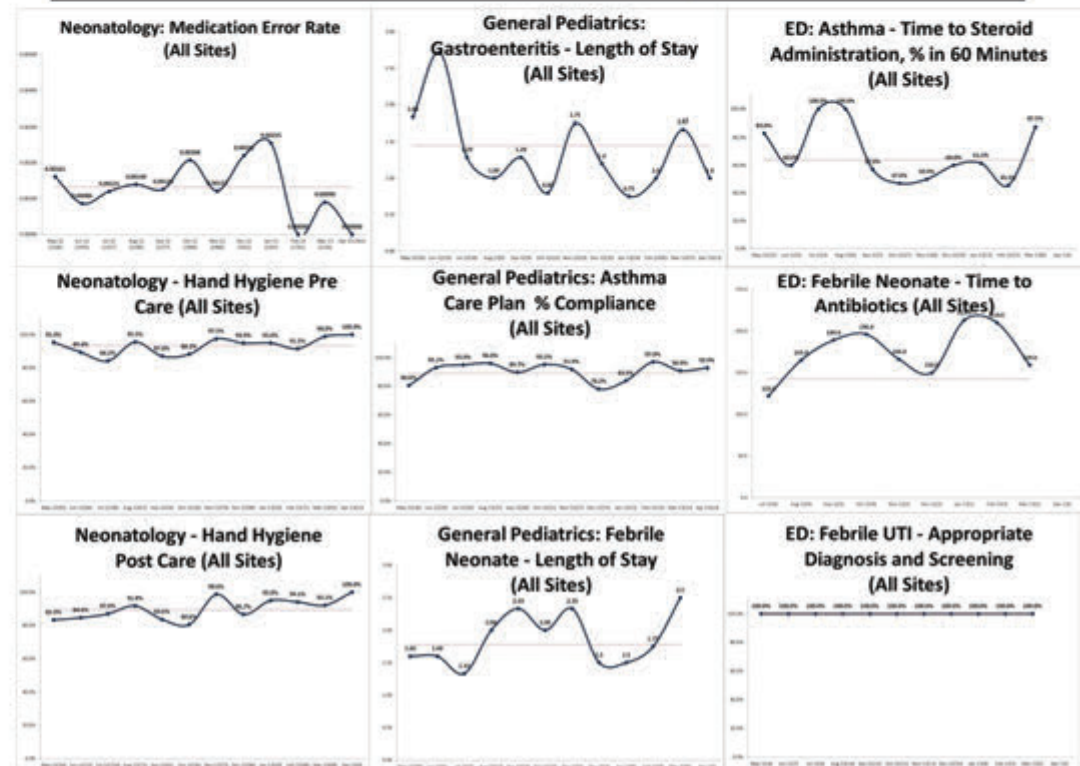
Accomplishments

- Thirteen quality metrics defined based on existing pathways, clinical guidelines and practices at CHOP Main within the divisions of Emergency Medicine, General Pediatrics and Neonatology.
 - Eighteen clinical practices within 10 community partner hospital sites actively track the defined metrics.
- RedCap online database successfully implemented with central data submission, collation and reporting across all community partner hospital sites. Site-by-site comparison of metric performance and overall sub-specialty average performance reviewed monthly.
 - Qlikview "real-time" automated report system developed and currently in final round of pilot testing.
- Infrastructure created within each sub-specialty area to routinely analyze data and assess improvement across community partner hospitals sites. Sub-specialty areas have instituted regular network conference calls to discuss quality and patient safety data and initiatives.
- Early reports suggest that ongoing assessment and data transparency at partner community hospital sites has led to improved performance.
 - Neonatology has used the network data to identify vulnerable areas of care for each community partner hospital. Areas of concern are given an importance factor (based on how often the item is identified as an area of concern) and impact factor (based on the actions taken). Identified concerns have led to actions which improved patient care management, communication, monitoring and many other areas.

Quality Metrics

METRICS BY SPECIALTY:

EMERGENCY MEDICINE	GENERAL PEDIATRICS	NEONATOLOGY
Time to Abx Febrile Neonate	Asthma Care Plan	CLABSI Rate
Time to Steroid for Asthma	Antibiotic Use for Bronchiolitis	Hand Hygiene Compliance
UTI Pathway Compliance	Gastroenteritis LOS	Medication Error Rate
Head CT Utilization Rate	Febrile Infant LOS	Local Project Assessment Score
Medication Error Rate	Medication Error Rate	



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A Shared Decision-making Portal for Pediatric Chronic Illness

Challenge

Screen-time is a big part of nearly everyone's life now, as laptops, tablets, phones and other iterations of the computer continue to proliferate. Finding effective ways to use these tools to improve healthcare is complicated — and important.

With Chair's Initiatives funding, this team set out to design and test a computer portal for the families of children with asthma. The tool could be used to educate families, track symptoms between visits, and boost communication between the family and their primary care pediatrician. The end goal: to improve the health of children with asthma.

Team

Alexander Fiks, M.D., M.S.C.E.

Robert Grundmeier, M.D.

Trude Haecker, M.D.

Peter White, Ph.D.

Dean Karavite, M.S.

Elena DeBartolo

Stephanie Mayne, M.H.S.

Ryan J. O'Hara

LeMar Davidson, M.S.

Accomplishments

- After a survey of nearly 60 parents, pediatricians and others, the team designed a working portal called MyAsthma Portal.
- The portal was implemented at three primary care pediatric practices, with 30 families participating.
- The portal helps parents and children define goals that can guide asthma care.
- Based on input from the parents about severity and timing of symptoms, the portal alerts the parent and the pediatric practice when asthma is poorly controlled, and the practice calls the parents to ensure appropriate steps are taken.
- The team is evaluating whether the portal improved care, using the 30 families in the pilot program and 30 control families (who didn't use the portal). Measures include whether emergency department visits and hospitalizations declined among patients who used the portal, and whether treatment adherence and goal attainment rose.
- The team plans to use MyAsthma Portal as a basis for developing a portal for ADHD and other conditions.
- The team has received a grant that will allow the portal to be tested in a much larger pilot program, nationally.





A Shared Decision Making Portal for Pediatric Chronic Illness

Alexander Fiks, MD, MSCE^{1,3}, Elena DeBartolo¹, Dean Karavite, MS², Stephanie Mayne, MHS¹, Ryan J. O'Hara², LeMar Davidson, MS², Trude Haecker, MD², Robert Grundmeier, MD^{2,3}
PolicyLab¹, Center for Biomedical Informatics² at The Children's Hospital of Philadelphia, and the Department of Pediatrics³ at the University of Pennsylvania School of Medicine, Philadelphia, United States

Department of Pediatrics Chair's Initiative

Project Goal

To develop and test an electronic medical record-based shared decision making portal that engages families and clinicians in the care of pediatric chronic illness.

Interventions and Accomplishments

Stakeholders Interviewed	Total
Parents	7
Pediatrician	24
Nurse Practitioner	6
Other Nurse	17
Clinical Pharmacist	1
Chief of Compliance	1
Attorney	1
Risk Management	1
TOTAL:	58

Top 5 Accomplishments:

1. Designed a working portal based on user specified requirements.
2. Successfully implemented the portal at three sites during pilot. Those enrolled in the portal became active users.
3. The portal system has identified poor asthma control and side effects between patient office visits. Results were then sent to practices which followed up with patients/families to address problems.
4. Manuscript submitted to an informatics journal. Data collection underway for a second manuscript.
5. Pilot data from this Chair's Initiative was used to submit a grant to fund a large-scale, national evaluation of the portal.

Performance Measures



Success Factors and Barriers

Portal Will:

1. Work with Epic and MyChart
2. Provide education
3. Capture treatment preferences, current symptoms, and side effects
4. Identify and track progress towards families' goals
5. Provide decision support to clinicians and families
6. Be sustainable as part of operations

Potential challenges:

1. Accessibility
2. Reaching low literacy groups
3. Preventing system misuse/ensuring safety
4. Integrating with workflows: ensuring information is used and not lost
5. Fostering shared family and clinical team expectations

Patient Portal Results

Parent Interface

MyAsthma 1 Asthma Education 2 Care Plan 3 Care Team

Check-in Survey 4 Goals 5 Concerns

✓ You are up to date!

Next check-in: October 1, 2012
Last check-in: September 3, 2012

Parent's Goal: To not have to go to the emergency department for asthma

Child's Goal: To be able to run and play with friends

Year concerns (sorted by your rating):

Medication side effects impact on life
Steroids impacting growth
Taking too much medication
Time to manage medications

Check-in Survey Timeline

	2011	2012										
	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec
Asthma Control	Good	Good	Good	Good	Good	Good	Good	Good	Good	Good	Good	Good
Managing concerns	Good	Good	Good	Good	Good	Good	Good	Good	Good	Good	Good	Good
Asthma Plans	Good	Good	Good	Good	Good	Good	Good	Good	Good	Good	Good	Good
Medication side effects	Good	Good	Good	Good	Good	Good	Good	Good	Good	Good	Good	Good
Control by month	Good	Good	Good	Good	Good	Good	Good	Good	Good	Good	Good	Good
MD/Physician Care and Hospitalization	Good	Good	Good	Good	Good	Good	Good	Good	Good	Good	Good	Good
Symptoms with air	Good	Good	Good	Good	Good	Good	Good	Good	Good	Good	Good	Good
Symptoms at night	Good	Good	Good	Good	Good	Good	Good	Good	Good	Good	Good	Good
Medication side effects	Good	Good	Good	Good	Good	Good	Good	Good	Good	Good	Good	Good
Time to manage medications	Good	Good	Good	Good	Good	Good	Good	Good	Good	Good	Good	Good

MyAsthma Portal Features

1. Asthma Education
 - a. Parent and child-specific asthma content available within the portal.
 - b. PDF handouts and Videos
 - c. Clinicians are able to recommend education tailored to patient-specific needs
2. Access to Asthma Care Plans
3. Summary of the Child's Care Team
4. Parent and child goals elicited and tracked
5. Parent concerns gathered and prioritized
6. A timeline tracks asthma status based on survey responses for easy interpretation
7. Decision support for clinicians and families

Clinician Interface

MyChart Asthma Patient Portal

Parent's Goal: To not have to go to the emergency department for asthma

Child's Goal: To be able to run and play with friends

Concerns (sorted by rating): Medication side effects impact on life, Steroids impacting growth, Taking too much medication, Time to manage medications

Parent Reported Control Survey

	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec
Asthma Control	Good	Good	Good	Good	Good	Good	Good	Good	Good	Good	Good	Good
Taking meds as prescribed	Good	Good	Good	Good	Good	Good	Good	Good	Good	Good	Good	Good

Asthma Patient-Family Education (PFE): Review and recommend...

Control Tool: Last filed by Parent 9/2/2012 (Fill out September Control Tool...)

Assessment: Symptoms are UNCONTROLLED based on:

- Asthma symptoms with activity every other day
- Asthma symptoms while asleep every other day
- Use of quick relief medicine every day
- Two oral steroid courses

Severity: Severe-Persistent (problem list noted 1/15/12)

Tests: Spirometry...not on file

Medication: Click for Asthma Smart Set

Care Plan: On file (click to access form)

Education: Review and recommend...

Preliminary Results

- Enrolled 30 users to date
 - 77% have completed at least one monthly follow-up survey
- Family use of the portal has identified poor asthma control between office visits
 - Through >100 monthly check-in surveys with 23 families: 4 uncontrolled asthma, 13 poorly controlled asthma, 1 medication side effects
 - Results were automatically sent to the practices and prompted follow-up by MyChart message or phone call

Alerts for Parents

Check-in Results

Your child's asthma is: **POORLY CONTROLLED**

Instructions: Please call your doctor's office at 215-555-0888 to discuss your child's asthma control.

The results of the check-in have been sent to your doctor's office.

You can always call or [click a message](#) your doctor's office with any questions.
If this is a medical emergency please call 911.

Clear

Conclusion and Next Steps

- The MyAsthma Portal now supports safe, high-quality asthma care at CHOP.
- This custom software, embedded in the EMR, provides a model for improving the quality and safety of care in varied conditions and clinical settings.
- Future studies will adapt the system for an ADHD portal.
- The MyAsthma Portal is now being implemented nationally as part of a study to explore the possibility of using health information technology to support shared decision making as part of the federal Meaningful Use Program.

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Improving Hospital Care for and Service Delivery to Individuals with Autism Spectrum Disorders

Challenge

Children with autism have different reactions to medical procedures and other facets of healthcare. They require different approaches to ensure they are kept safe and that the care provided is the most effective.

For example, pain measurement systems that ask the patient to rank pain on a scale of 1-10 or choose from cartoon faces expressing more or less distress are not ideal for children with autism, who have difficulty reading facial expressions and who, when asked to choose a number between 1 and 10, might pick their favorite number.

With Chair's Initiatives funding, a team at CHOP began to develop better tools and strategies for care for children with autism. They focused on the sedation unit, where children are given sedatives or tranquilizers before tests and procedures that require them to remain still, such as an MRI or spinal tap.

Team

Eron Friedlaender, M.D., M.P.H.

Judith Miller, Ph.D.

Jan Boswinkel, M.D.

Amy Kratchman

Susan Levy, M.D.

Terisa Gabrielsen, Ph.D.

Meghan Davignon, M.D.

Accomplishments

- The team piloted a screening system to identify patients with autism or other developmental issues before their appointment. During scheduling, the parent is asked whether the child has developmental delays or special communication needs. The screening, which takes less than a minute, may be incorporated into scheduling Hospital-wide.
- The team created tools to help children and staff in the sedation unit, including a unit-specific screening system, tip sheets for staff, and social stories and “first-then” boards (preparation and coping tools that help children with autism).
- The team developed new recommendations for pain assessment for children with autism.
- The team created an interdisciplinary autism work group to share learning and strategies among units and specialties at CHOP.
- The team improved communication with parents. For example, the sedation unit's website now has a “Children with Special Needs” section.
- The team improved staff training tools, including an “autism care” learning module on the “Learning-Link” employee training site.
- With other hospitals, the team began work on best practice guidelines for an autism-friendly hospital.



Improving Hospital Care and Service Delivery to Individuals with Autism Spectrum Disorders: A Pilot Program of Model Care Delivery within the Sedation Unit

Department of Pediatrics Chair's Initiative

Eron Friedlaender, MD MPH, Judith Miller, PhD, Jan Boswinkel, MD, Amy Kratchman, Susan Levy, MD

Project Aims

Needs Assessment (Phase 1):

- 1) Identify strategies used in completing medical interventions for children with Autism Spectrum Disorders safely and effectively.
- 2) Identify strengths and deficiencies in staff knowledge of interaction with and assessment of individuals with Autism Spectrum Disorders.
- 3) Identify hospital environmental factors that interfere with or facilitate care.

Pilot Program (Phase 2): Model Care Delivery within the Sedation Unit

To identify and pilot intervention strategies that will help improve quality of care for patients with autism in the sedation unit. (IV Placement RCT grew out of this aim)

Pain Assessment:

To describe how children with an Autism Spectrum Disorder understand and communicate about pain.

Outcomes

NEEDS ASSESSMENT Key Concept: individualized care

- 1) Need improved capacity for productive provider-patient interactions, through better provider education, family preparation/empowerment and communication.
- 2) Need adaptive healthcare system with flexibility in patient flow and the physical environment.
- 3) Need for systematic identification of patients with autism to facilitate preparation and individualized care.

PILOT PROGRAM: Data at baseline indicated patient, family and staff safety were most prevalent concerns. Outcomes survey developed and piloted, will be administered in June, 2013.

PAIN ASSESSMENT: In describing pain, patients with autism prefer pointing, and cannot indicate severity on standard intensity scales.

IV PLACEMENT RCT: Patients tolerated IV placement better than expected by observation and parent report. (Preliminary data, collection not completed)

Barriers

- No systematic way of identifying patients with autism prior to visit
- Large staff, multiple shifts present barriers to comprehensive training
- Slow mail transit time for IV kits

Last Updated: (5/24/2013)

Success Factors

- Participation and support of Sedation Unit leadership and Child Life
- More detailed triage procedures
- Super users identified and trained
- Enthusiastic response from key personnel
- Multiple training formats
- Parents empowered to do their own preparations in advance

Accomplishments

Universal Screening, Behavioral Safety Issues: Piloted in Endocrine

Screened 458 patients at point of scheduling, 21% had developmental/behavioral diagnoses. Screening takes less than one minute (99%) and was easy for parents to answer (100%)

1. Is there a behavioral diagnosis or developmental delay that staff should be aware of? (17%)
2. Does your child have special communication needs? (5% = Yes)
3. Does your child sit still for a haircut, dentist, or doctor's exam? (6% = No)

Unit Specific Triage Procedure – Piloted in Sedation Unit

1. Is there a behavioral diagnosis or developmental delay that staff should be aware of?

(Drop Down) Autism, Asperger's, PDD-NOS, Global Delay, Anxiety, ADHD, Intellectual Disability, Conduct Disorder

2. Is your child verbal or non-verbal?

(Yes) Does he have a communication device? If so, bring it (record in EMR).

3. Does your child cooperate with taking oral medications?

(Yes) If there is a special method for helping your child take oral medications, please bring it with you to the hospital.
(No) How have you administered medications in the past?

4. Are there any specific triggers that upset your child in a medical environment?

Over stimulating environment, anticipation of pain, previous negative experience, Other: Specify.

5. Is there anything that calms your child in a medical environment or when he gets upset?

(Yes) Please describe what to do or bring calming items (record in EMR).

Intervention Tools Piloted in Sedation Unit

Social Stories	Visual Schedules
First/Then Boards	Tip Sheets
Letters to Families	Special Needs Info. on Website

Training in the Sedation Unit

Nurses station talks,
Lectures during CEU time, Safety Huddles, Super Users

Hospital Wide Implementation of Training and Intervention

Learning Link for Autism Care –Summer 2013

Autism Pathway – Fall 2013

Interdisciplinary Autism Work Group established, coordination of parent and staff interventions 9 South, 5 West, CPRU, ongoing roll out to other units

Partnerships with Other Hospitals

Contacted other hospitals to join complementary projects

Beginning work on creation of best practice guidelines for autism care in hospitals

The screenshot shows the CHOP website's Pediatric Sedation Unit page. It features a navigation bar with links for 'Health Information', 'For Patients and Visitors', 'Specialties and Services', and 'Locations'. The main content area has a 'New Website' banner and a section titled 'Pediatric Sedation Unit' with a video player. Below the video is a section for 'Autism spectrum disorder care at CHOP' with a description and a link to 'Web Videos'. The video player shows a woman speaking, and the video title is 'Autism Care at CHOP - A Parent's Perspective'.

Next Steps and Sustainability

- EPIC work order for behavioral safety flag to identify patients.
- Approval and implementation of universal screening and unit specific triage procedures.

SAFER

Preventing Outpatient Central Line-associated Bloodstream Infections (CLABSI)



Challenge

Central lines are long-term IV lines that are used for a variety of purposes, including delivering medicines such as chemotherapy drugs and delivering nutrients for patients with compromised digestive tracts. Central line-associated bloodstream infections (CLABSI) cause many deaths and cost the healthcare system billions of dollars every year. Along with many hospitals, CHOP has made a concerted effort to reduce CLABSI rates in inpatients.

Some patients go home with central lines, and the care of the line is then in the hands of parents and home healthcare nurses. This Chair's Initiatives team, including an oncologist, surgeon, gastroenterologist, home healthcare administrator and others, decided to apply learning from inpatient CLABSI efforts to the outpatient setting, as well as define and address prevention challenges unique to outpatients.

Team

Christina Bales, M.D.

Allison Ballantine, M.D.

Millie Boettcher, M.S.N., C.R.N.P.

Susan Coffin, M.D., M.P.H.

Joy Collins, M.D.

Lori Kramer, R.N., A.V.P.

Mark Magnusson, M.D., Ph.D.

Maria Mascarenhas, M.D.

Anne Reilly, M.D.

Susan Rettig, B.S.N., R.N.

Accomplishments

- The team's efforts resulted in a 50 percent drop in outpatient CLABSI for all CHOP patients.
- The team developed an education and infection prevention kit for parents/caregivers.
- The team increased use of one CLABSI prevention tactic, ethanol locks, in patients with central lines for nutrients; this resulted in a dramatic decrease in infections for that group.
- The team established relationships with home healthcare organizations to facilitate training in CLABSI prevention techniques for CHOP patients at home.
- The team began collecting data about outpatient CLABSI; a comparison between outpatient and inpatient rates showed they correlate closely.
- The team created the permanent position of nurse coordinator for outpatient CLABSI.



Preventing Outpatient CLABSI

A Department of Pediatrics Chair's Initiative

Project Goal

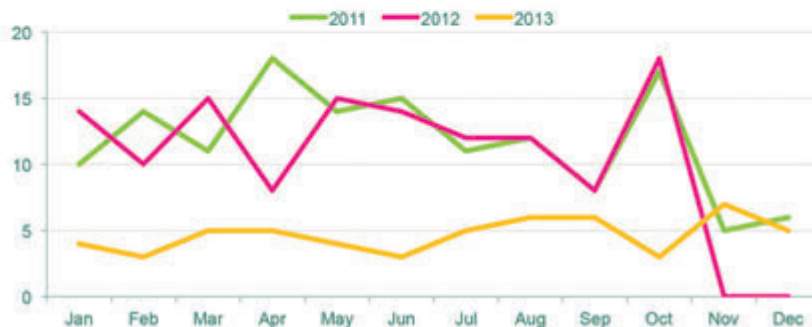
To reduce the incidence of central line-associated bloodstream infections in the outpatient/ homecare setting through education, implementation of evidence-based practices, and data tracking and enhanced communication.

Accomplishments

- 1) Reduced outpatient CLABSI numbers for all CHOP patients by over 50% .
- 2) Instituted bedside reviews for CLABSI acquired in outpatient settings. Data collected for 85 reviews as of January 2014
- 3) Instituted and increased use of ethanol locks for high risk patients at risk for CLABSI; 90% decrease in outpatient CLABSI for patients on home TPN as part of the Intestinal Rehabilitation Program
- 4) Reduced outpatient CLABSI in Oncology patients by 22% from 2012-2013
- 5) Created a permanent position of nurse coordinator for outpatient CLABSI to ensure ongoing work and data collection in this area

Performance Measures

CHOP Outpatient CLABSI numbers reduced by over half.



Performance Measures, cont.

Oncology Outpatient CLABSI rates reduced by 22%:

2012	0.46 infections/1000 patient line days
2013	0.36 infections/1000patient line days

Addition of use of ethanol lock prophylaxis in high risk patients on home TPN reduced CLABSI by 90% in the short term:

Pre-lock CLABSI rate
0.23 CLABSI/patient mo = 2.8 CLABSI/pt yr

Post-lock CLABSI rate
0.021 CLABSI/patient mo = 0.26 CLABSI/pt yr

Conclusions

Reinforcement of established central line care practices, education, and judicious use of ethanol lock prophylaxis have reduced CLABSI in the outpatient settings at CHOP.

Future Directions

Ethanol lock trials are ongoing in selected inpatient and additional outpatient settings.

Other Outpatient CLABSI team will use ongoing data collection and analysis to identify new opportunities to further reduce outpatient CLABSI.

Updated March 2014

Challenge

The time when a young adult must transition from pediatric to adult healthcare can be difficult. Some have trouble finding an adult doctor, and their care may lag and their health suffer. There have been numerous efforts at CHOP to improve the transition from pediatric to adult specialists, such as gastroenterologists.

Finding a good adult primary care provider is as important as finding specialists, especially for patients with chronic conditions. A Chair's Initiatives team decided to analyze the needs of young adult patients with chronic conditions in CHOP-affiliated primary care practices, and then create tools to help them successfully transition to adult primary care.

Team

Oana Tomescu, M.D., Ph.D.

Nadja Peter, M.D.

Symme Trachtenberg, M.S.W., L.S.W.

Elyse Salek

Nadavya Stollon

Elizabeth Wallis, M.D.

Lisa Schwartz, Ph.D.

Caren Steinway

Accomplishments

- The team used CHOP data to identify more than 400 patients, 19 years or older, with chronic conditions at CHOP primary care practices and enrolled 32 in a randomized controlled pilot feasibility study.
- The team identified important clinical and demographic information about the patients, such as insurance type, complexity of illness, and whether an intellectual disability or behavioral health disorder exists.
- The team provided study patients with varying levels of transition support including a transition consult and/or a transition "Carebinder," and continues to collect and analyze data to determine whether the interventions have improved transition to adult care and patient and provider satisfaction with the transition experience.
- The team surveyed over 300 primary care doctors and nurses and medical and surgical specialists about transition expectations and identified major barriers to transition including lack of personnel to deliver services; limited time; parental reluctance; and patient attitudes.
- The team identified adult primary care providers willing to care for patients with chronic conditions.
- The team established a young adult transition-focused clinic within a larger University of Pennsylvania internal medicine practice and launched the Adult Care at CHOP Program, a clinical consult program for young adults (ages 24 years and older) admitted to CHOP.
- The team developed materials to help with transition for both patients and providers, including updating the www.chop.edu/transition website, developing a community transition resource list and adult provider list for patients, and creating a "transition summary" for pediatric providers to fill out in CHOP's electronic medical record system.
- The CHOP Division of Social Work is offering part-time salary support for the continuation of transition initiatives.





Transitioning from Pediatric to Adult Services: A Primary Care Based Model

Last Updated: (3/25/14)

Department of Pediatrics Chair's Initiative: Dana Tomasco, Nadia Pater, Symme Trachtenberg, Elyse Salik, Natavija Stotton, Caren Steinway, Elizabeth Wallis & Lisa Schwartz

Project Goal, Aims and Methods

Goal: To improve transition for patients ≥ 19 years with chronic conditions in CHOP Primary Care practices.

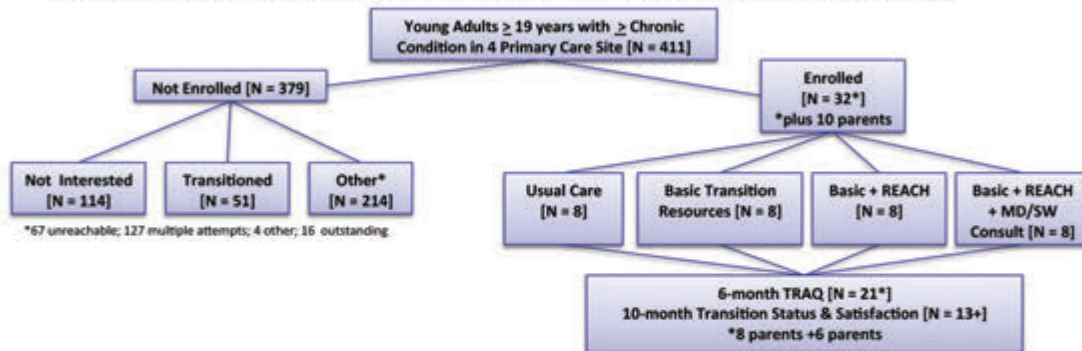
Aim 1: To improve transition-related and self-care skills in patients.

Aim 2: To improve transition-related satisfaction for patients, families and providers.

Aim 3: To improve successful transition to adult providers.

Methods:

- 1: Pilot feasibility study in CHOP Primary Care Network evaluating multiple transition interventions.
- 2: Disseminate Provider survey to understand current transition practices at CHOP.
- 3: Develop transition-related materials, resources and services for improving care and future dissemination.



Accomplishments

Top 5 Accomplishments:

1. Described the clinical and demographic characteristics and health care utilization of a large population of young adults with chronic conditions in need of transition services within the CHOP primary care system.
2. Piloted a multi-arm transition intervention for this population, improving the understanding of intervention feasibility, patient transition needs, and barriers to participation.
3. Implemented an inpatient transition consult program (as part of the formal Adult Care at CHOP Consult Service) to address transition needs for inpatients (based on our initial data showing poor utilization of outpatient resources).
4. Identified adult primary care providers throughout the Philadelphia area who are qualified and willing to care for this patient population, and established a young adult clinic based within a U of Penn internal medicine practice.
5. Designed and implemented a *Transition Summary* template in EPIC; measured utilization by CHOP Care Network PCPs.

Additional Accomplishments:

- Developed transition materials including Community Resource list, Adult Provider list, REACH for Independence group curriculum & manual, www.chop.edu/transition website updates & Transition Consult visit template ; available for dissemination.
- Numerous presentations to and collaborations with local, state and national transition organizations .
- Initiated additional REACH groups (e.g. REACH for Epilepsy).
- Surveyed over 300 primary care doctors and nurses and medical and surgical specialists about transition expectations.

Next Steps

- Continue to collect and analyze data to determine whether the interventions have improved transition to adult care and patient and provider satisfaction with the transition experience.
- Continue the REACH and Carebinder programs, website updates and the Transition Special Interest Group activities.
- Continue partnership with MyChart and EPIC to make transition resources more accessible for providers.
- Continue to analyze data on provider survey results, patient reported outcomes and post-treatment health care utilization.

Performance Measures

PILOT STUDY: Baseline Summary	
Demographic & Clinical Characteristics	n (%)
Gender	
Male	13 (42)
Female	18 (58)
Race	
Black	17 (57)
White	9 (30)
Other	4 (14)
Insurance Type	
Medicaid	22 (71)
Non-Medicaid	7 (23)
Self-pay	2 (6)
Behavioral Health Disorder	
Yes	11 (35)
No	20 (65)
Intellectual Disability	
Yes	8 (25)
No	24 (75)
Complexity of Illness	
One Complex Chronic Condition (CCC)	10 (31)
Multi-organ or multiple CCC	12 (38)
1 or more CCC + Intellectual Disability	9 (28)
Multiple CCC + Technology	1 (3)
Dependence	

PILOT STUDY: TRAQ Baseline Scores			
Variable	Mean*	SD	n
Teen Self-Management (summary domain score)	4.0	0.60	27
Understand payment for meds?	2.8		21
Know what health insurance covers?	3.0		27
Call doctor about changes in your health?	4.2		26
Teen Self-Advocacy (summary domain score)	4.3	0.37	27
Fill out med history forms?	4.5		27
Make list of questions before doctors' visits?	2.2		21
Request accommodations & support you need?	3.1		20
Parent Self-Management Overall (summary score)	2.0	9.96	10
Parent Self-Advocacy (summary score)	2.9	1.07	10

*score > 4 good self-advocacy or disease management ability

PROVIDER SURVEY: Transition/Self-Care Expectations of Pediatric Providers				
Question	Yes n(%)	No n(%)	Sometimes n(%)	Mean age*
Age ask pts instead of parents about medical history?	182 (73)	69 (27)		12.6
Age ask pts instead of parents about medications?	179 (71)	71 (28)		13.4
See pts alone routinely?	53 (21)	67 (27)	128 (52)	
Primary Care Providers	30 (46)	6 (9)	8 (26)	
Medical Specialists	23 (15)	38 (25)	91 (60)	
Surgical Specialists	0 (0)	23 (74)	8 (26)	
Age address pts in plan of care discussions?	169 (68)	78 (32)		14
Age pts should participate in med decision making?	196 (79)	51 (21)		14.8
Age expect pts to manage meds independently?	189 (75)	62 (25)		15.2
Age discuss transition with pts?	217 (89)	27 (11)		16.3

*differences in mean ages for each skill, p<0.02 for all

PROVIDER SURVEY: Completion Summary		
Variable	n(%)	Mean (sd)
Gender		
Male	88 (35)	
Female	162 (65)	
Practitioner Type		
Physician	175 (71)	
NP/PA	78 (29)	
Specialty		
Primary Care	66 (26)	
Medical Specialty	154 (66)	
Surgical Specialty	31 (12)	
Years in Practice		18.8 (11)
Clinical Sessions per week		5.3 (2.8)

PROVIDER SURVEY: Transition/Self-Care Expectations by Provider Type				
	Primary Care Mean (sd)	Medical Specialty Mean (sd)	Surgical Specialty Mean (sd)	*p-value
Age ask pts about meds	12.9 (2.6)	13.4 (3.1)	15.3 (2.4)	0.02
Age expect pts to manage meds independently	14.5 (2.1)	15.4 (2.7)	15.6 (1.7)	0.02
Age expect pts to participate in med decision making	14.4 (2.6)	15.0 (3.0)	14.5 (3.4)	0.31
Age discuss transition with pts	17.1 (1.7)	16.1 (3.4)	16.3 (4.2)	<0.0001

*adjusted for gender, years in practice, clinical sessions per week

Barriers or Success Factors

- Recruitment and engagement of young adult population difficult
 - Need to help patients internalize healthcare as a top priority sooner (e.g. earlier transition preparation); Data reveal that primary care physicians are more readily doing this than specialists/surgeons.
 - Consider offering ecologically and developmentally sensitive interventions via technology and/or at already scheduled appointments.
- Barriers to transition
 - Insurance greatest knowledge deficit reported by patients/families and a significant service provision barrier due to discrepancy of plans accepted.
 - Top 4 barriers identified by providers include: 1) lack of personnel to implement/deliver services; 2) limited time; 3) Parental reluctance to transition; 4) Patient attitudes and reluctance to transition.

The Chair's Initiatives: Publications, Presentations and Grants

ROUND
2011 – 2013

A Shared Decision-making Portal for Pediatric Chronic Illness

Presentations

Fiks AG, Mayne S, Karavite D, DeBartolo E, O'Hara R, Davidson L, Gruver R, Suh A, Grundmeier R. **Improving Patient Safety and Quality through a Shared Decision Making Portal for Pediatric Asthma**, platform presentation, CHOP Quality and Patient Safety Day 2013.

DeBartolo E, Fiks AG, Mayne S, Karavite D. **Designing a Shared Decision Making Portal for Pediatric Chronic Illness**, poster presentation, CHOP Research Poster Day 2012.

Fiks AG, Grundmeier RW. **Practice-Based Research Using the Electronic Health Record**, invited lecture, Informatics Grand Rounds, The Johns Hopkins University School of Medicine, Baltimore, Md.

Grants

\$500,000 grant from AHRQ (R18 HS022689-01) to study the feasibility of using portals to satisfy meaningful use requirements. We will adapt the portal content and include 10 practices from around the country (part of the American Academy of Pediatrics' PROS Network) as well as 10 CHOP practices.

Publications

Fiks AG, Mayne S, Karavite DJ, DeBartolo E, Grundmeier RW. **A Shared e-Decision Support Portal for Pediatric Asthma**. *J Ambul Care Manage*. 2014;37(2):120-126.

Improving Hospital Care for and Service Delivery to Individuals with Autism Spectrum Disorders

Presentations

Friedlaender E. **Let's Make the Connection: A Multidisciplinary Approach to Caring for Children with Autism**, The Road to Success for the Child Life Specialist Caring for Families and Professionals One Day at a Time in the Emergency Department, Philadelphia, Sept. 2011.

Friedlaender E. **ED Care of Children with Special Needs**, Intensive Course in Pediatric Emergency Medicine, Philadelphia, Nov. 2011.

Davignon M. **Care of the Child with Autism Spectrum Disorder Undergoing Routine Hospital-Based Procedures: A Needs Assessment**, presentation of research-in-progress at the Maternal Child Health Bureau Developmental Behavioral Pediatrics Conference, Providence, RI, March 2012.

Friedlaender E. **Next Steps into Adolescence: Supporting Parents and Caretakers through Turbulent Times**, Greentree-La Salle University 6th Annual Autism Conference, Building Bridges: Supportive Practices from Birth to Adulthood, Philadelphia, April 2012.

Friedlaender E. **Psychopharmacology of Autism Spectrum Disorders**, Next Steps for Adolescents Workshop, Philadelphia, April-Sept. 2012.

Davignon M, Friedlaender E. **Care of the Child with Autism Spectrum Disorders Undergoing Hospital Based Procedures**, Philadelphia Regional Conference on Developmental Disabilities, Challenges and Triumphs: Past, Present, and Future, Philadelphia, May 2012.

Davignon M. **Care for Children with Autism Spectrum Disorders in the Hospital**, Department of Physical Disabilities and Rehabilitation Lecture Series, CHOP, May 2012.

Davignon M. **Improving Hospital Care for and Service Delivery to Individuals with Autism Spectrum Disorders: A Pilot Program of Model Care Delivery within the Sedation Unit**, Association of Administrators in Academic Pediatrics National Conference, Philadelphia, Sept. 2012.

Friedlaender E, Lavelle J, Steinmiller E. **A Threat to Self and Others: Restraint Use in Managing Psychiatric Emergencies**, Serious Safety Event Morbidity and Mortality Presentation, CHOP, Nov. 2012.

Friedlaender E. **Hospital Care for Children with Autism Spectrum Disorders**, Department of Child and Adolescent Psychiatry and Behavioral Science Quarterly Meeting, CHOP, March 2013.

Friedlaender E, Fein J. **Behavioral Health Care in the Pediatric Emergency Department**, Emergency Department Nursing Grand Rounds, CHOP, April 2013.

Friedlaender E. **Hospital Care for Children with Autism Spectrum Disorders**, RN MD Grand Rounds, CHOP, April 2013.

Davignon M. **Care of the Child with Autism Spectrum Disorder Undergoing Routine Hospital-based Procedures: A Needs Assessment**, Maternal and Child Health Bureau Developmental Behavioral Pediatrics Training Annual Meeting, Stamford, CT, April 2013.

Friedlaender E. **Improving Care for Patients with Autism Spectrum Disorders**, Quality and Patient Safety Day, CHOP, May 2013.

Davignon M. **Parent and Provider Perspectives on Hospital Care for Children with Autism Spectrum Disorders**, Neurodevelopmental Symposium presentation, CHOP, May 2013.

Friedlaender E, Davignon M, Gabrielsen T, Miller J. **Improving Hospital-Based Services and Care to Individuals with Autism Spectrum Disorder (ASD)**, submitted as workshop for Pediatric Academic Societies Meeting, Vancouver, May 2014.

Grants

Friedlaender E, Ely E. **Pain Assessment in Children with Autism Spectrum Disorders**, Mayday Fund, \$30,000.

Publications

Davignon MN, Friedlaender E, Cronholm PF, Paciotti B, Levy SE. **Parent and provider perspectives on procedural care for children with autism spectrum disorders**. *J Dev Behav Pediatr*. 2014;35(3):207-215.

Davignon M, Friedlaender E, Cronholm P, Paciotti B, Levy S. **Parent and provider Perspectives on Procedural Care for Children with Autism Spectrum Disorders**, submitted to BMC Health Services Research.

Davignon M, Miller J, Cronholm P, Paciotti B, Friedlaender E. **Interventions to Facilitate Procedural Care of Children with Autism Spectrum Disorders: Family Preparation**, in preparation.

Gabrielsen T, Davignon M, Miller J, Cronholm P, Paciotti B, Friedlaender E. **Interventions to Facilitate Procedural Care of Children with Autism Spectrum Disorders: Systems-Level Changes**, in preparation.

Abstracts

Davignon M, Friedlaender E, Levy S. **Facilitators and Barriers to care of Children with Autism Spectrum Disorders Undergoing Procedures**, International Meeting of Autism Research, San Sebastian, Spain, May 2013.

Miller J, Friedlaender E. **Autism Spectrum Disorders in the Hospital: Making it Easier for Children, Families, and Staff**, International Meeting of Autism Research, San Sebastian, Spain, May 2013.

Gurtman A, Mollen C, Levy S, Friedlaender E. **Implications of MRI in Children with Autism Spectrum Disorder**, Pediatric Academic Societies' Annual Meeting, Philadelphia, May 2013.

Ely E, Lim M, Carpenter K, Friedlaender E. **Pain Assessment of Children with Autism Spectrum Disorders**, Ninth International Symposium on Pediatric Pain, Stockholm, June 2013.

Friedlaender E, Miller J, Davignon M, Gabrielsen T, Levy S. **Autism Spectrum Disorders in the Hospital: Making it Easier for Children, Families, and Staff**, CHOP 2013 Quality and Patient Safety Day, Philadelphia.

Minds Matter: Improving Pediatric Concussion Management

Presentations

From 2011-2013 members of the Minds Matter team completed more than 60 presentations, with audiences including parents, principals, teachers, coaches, school nurses, trauma surgeons, nursing students, primary care pediatricians and nurse practitioners, community hospitals, neurosurgeons, Congress, emergency room staff, and many others. Here are a few of the presentations:

Winston F, Congressional Testimony, Subcommittee on Health, Energy and Commerce, Washington, DC, March 2012.

Nance M, Robinson R, Houseknecht E, **Concussion Management: Keeping aHEAD**, Ninth Annual Topics Explored: Pediatric Surgical and Trauma Nursing Conference, Philadelphia, Nov. 2011.

Robinson R, **The Concussed Student: Updates on Return to School & Play**, School Nurse Association of Pennsylvania Annual Conference, State College PA, April 2012.

Kirschen M, **Update on Concussion Diagnosis and Management**, Neurosurgery practice, University of Cape Town, Cape Town, South Africa, Jan. 2012.

Arbogast KB, McGinley AD, Master CL, Grady MF, Zonfrillo MR, **Primary Care Emphasis on School-Based Recommendations for Pediatric Concussion Management**, Pediatric Academic Societies Annual Meeting, Boston, MA, April-May 2012.

Zonfrillo M, **Pediatric Concussion, Emergency Medicine Residency Grand Rounds**, York Hospital, York, PA, March 2012.

Grady M, **Concussion Update**, 13th Annual Philadelphia Sports Congress, University of Pennsylvania, June 2012.

Grady M, **Concussion: Pathophysiology and Implications for Return to School**, 11th Annual Disabilities Conference, University of Scranton.

Master CL, **Congressional Panel Concussions in Athletics**, hosted by Congressman Charlie Dent and Congresswoman Beatty, November 21, 2013.

Zonfrillo M, **Emergency department evaluation and management of pediatric concussion and mild traumatic brain injury**, Society for Academic Emergency Medicine Annual Meeting, Atlanta, GA, May 2013.

Callahan J, **Sports-Related Concussion: What is the Emergency Physician's Role?**, American College of Emergency Physicians Advanced Pediatric Emergency Medicine Assembly, National Harbor, MD.

Callahan J, **Concussion in Sports: Back in Action**, First International Congress in Pediatric Emergency Medicine, Hospital Infantil de Mexico Federico Gomez, Mexico City, May 2012.

Nance M, Wiebe D, **Neurocognitive Evaluation of Mild Traumatic Brain Injury in Children Treated and Released from the Emergency Department**, Annual Meeting of the American Public Health Association, Washington DC, Nov. 2011.

Grants

ITMAT UPHS/CHOP/ITMAT Comparative Effectiveness Research Pilot Studies: Evidence for the Role of Cognitive Rest and Vestibular Rehabilitation in the Management of Acute Pediatric and Adolescent Concussion, \$40,000

The Children's Hospital of Philadelphia Women's Committee granted the Minds Matter Program \$52,020 for an eye-tracking device.

Publications

Arbogast KB, McGinley AD, Master CL, Grady MF, Robinson RL, Zonfrillo MR. **Cognitive rest and school-based recommendations following pediatric concussion: the need for primary care support tools.** *Clinical Pediatrics*. 2013;52(5):393-398.

Zonfrillo MR, Master CL, Grady MF, Winston FK, Callahan JM, Arbogast KB. **Pediatric providers' self-reported knowledge, practices and attitudes about concussion.** *Pediatrics*. 2012;130(6): 1120-1125.

Pediatric Annals Special Issue on Concussion (Guest Editors)

Master, CL, Grady MF. **Office-Based Management of Pediatric and Adolescent Concussion.** *Pediatric Annals*. 2012;41(9):1-6.

Master CL, Gioia GA, Leddy JJ, Grady MF. **Importance of 'Return-to-Learn' in Pediatric and Adolescent Concussion.** *Pediatric Annals*. 2012;41(9):1-6.

Vidal PG, Goodman AM, Colin A, Leddy JJ, Grady MF. **Rehabilitation strategies for prolonged recovery in pediatric and adolescent concussion.** *Pediatric Annals*. 2012;41(9):1-7.

Darby DG, Master CL, Grady MF. **Computerized neurocognitive testing in the medical evaluation of sports concussion.** *Pediatric Annals*. 2012;41(9):371-6.

Grady MF, Master CL, Gioia GA. **Concussion Pathophysiology: Rationale for Physical and Cognitive Rest.** *Pediatric Annals*. 2012;41(9): 377-82.

Media:

Members of the Minds Matter team have contributed to or been featured in more than 70 media stories about concussion all over the United States and the world, in *philly.com*, The Philadelphia Tribune, WITF, Boston Herald, *U.S. News & World Report*, Toronto Telegraph, The Baltimore Sun, The Denver Post, Chicago Tribune, Fox News, Reuters and many other media outlets.

Transitioning from Pediatric to Adult Services: A Primary-care-based Model

Presentations

Wallis EM, Tomescu O, Schwartz LA, Salek E, Trachtenberg S, Stollon N, Peter N, **Transitioning Children with Chronic Illness to Adult Healthcare: Practices of Pediatric Clinicians**, 14th Chronic Illness and Disability Conference Research Symposium, Houston, TX, Oct. 2013.

Stollon N, Trachtenberg S, **Integrating Healthcare and Post-High School Transition: Lessons From Two Program Models**, Association for University Centers on Disabilities (AUCD) Conference, Washington DC, Nov. 2013.

Trachtenberg S, Stollon N, **Engaging Teens in Transition: Lessons Learned and New Directions, Association of Maternal and Child Health Programs Annual Conference.** Washington DC, January 25-28, 2014.



The Chair's Initiatives

Past

Round 1 (2006–2008)

Access Nurse Advisor and Care Coordination

Developing nursing roles, systems and tools to support patients, families and providers in coordinating both access and care

ADHD in Primary Care

Creating computer tools, conferences and other supports to help primary care pediatricians learn and manage patients with attention deficit hyperactivity disorder

Automated Appointment Reminders

Implementing a computerized system to place standardized reminder calls across specialties to support continuity of care

Center for Bone Health

Providing specialized care for children with poor bone health and helping establish international care guidelines

Center for Pediatric Eosinophilic Disorders

Providing specialized care for rare allergic disorders

Database Development

Developing databases and web-based applications to support physicians in research and care

Multidisciplinary Cancer Survivorship Program

Creating a monthly clinic where cancer survivors see numerous specialists with expertise in the late effects of cancer treatment

Office of Fellowship Programs

Coordinating and streamlining application, evaluation, curriculum development and accreditation for all fellowship programs in Pediatrics

Pediatric Knowledgebase

Creating a web-based application that combines data about drugs with data about individual patients to help improve outcomes

Sudden Cardiac Death Prevention

Providing screenings for undiagnosed heart irregularities in children and teens, and training in CPR and automated external defibrillators for schools

Round 2 (2008-2010)

Anticoagulant Management Program

Improving monitoring and care for children taking “blood thinners”

Chemotherapy Tracking Project

Computerizing records of cancer patients' complex drug regimens

CHOPLink Implementation, Quality and Patient Safety

Linking clinicians with computer specialists to ensure technology improves care

Collaborative Clinical Pathways

Establishing a framework so that computerized care guidelines widely used by residents and other physicians can be created more easily

Intestinal Rehabilitation Program

Coordinating and improving care for children with severe conditions that cause intestinal failure

Unit-based Patient Safety Walk-rounds

Providing a forum for the safety concerns of families and staff

Future

Current Initiatives: Round 4 (2013-2015)

COMEDO for Acne

Developing an app doctors can use in assessing and treating acne patients

Recognizing and Addressing Peer Bullying

Designing tools to help primary care pediatricians and other providers identify bullying and respond effectively

Identification, Remediation and Prevention of Chronic Glucocorticoid Therapy Effects

Developing standards to identify, monitor, remediate and prevent the serious side effects of chronic steroid use

Thrombosis Prevention and Treatment in Cardiac Patients

Developing strategies to reduce the incidence and complications of blood clots in cardiac patients

Text Messaging Interventions

Studying the effectiveness of texting in improving knowledge and health promotion for adolescents and young adults completing treatment for cancer



Boost Brilliance

The Chair's Initiatives is an internal grant program at The Children's Hospital of Philadelphia. It funds physicians, nurses, computer specialists and others who focus their knowledge and team-building skills on areas for improvement at CHOP.

The program represents an excellent opportunity for donors interested in helping incredibly bright, motivated teams quickly bring about change that benefits patients and families. For more information call 267-426-5332 or visit GIFTofCHILDHOOD.org.

 The Children's Hospital of Philadelphia®
Hope lives here.®

Founded in 1855, The Children's Hospital of Philadelphia is the birthplace of pediatric medicine in America. Throughout its history, a passionate spirit of innovation has driven this renowned institution to pursue scientific discovery, establish the highest standards of patient care, train future leaders in pediatrics, and advocate for children's health. A haven of hope for children and families worldwide, CHOP is a nonprofit charitable organization that relies on the generous support of its donors to continue to set the global standard for pediatric care.

www.chop.edu

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