

IMPROVING

BY LEAPS

AND BOUNDS

THE CHAIR'S INITIATIVES OF  
THE DEPARTMENT OF PEDIATRICS

ROUND 5  
2015-2017







*Christopher, 3, and his mom, Jennifer, are among the many families to benefit from the Chair's Initiatives.*

# WHAT'S INSIDE

The Chair's Initiatives of the Department of Pediatrics at Children's Hospital of Philadelphia is an internal grant program that provides seed funds to teams with great ideas for improving care. This booklet summarizes the Round 5 programs.

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The program was founded in 2006 by Alan Cohen, MD, then Chairman of the Department of Pediatrics (second from left in photo below) and Alison Marx, MBA, Operating Officer, Department of Pediatrics (second from right), and is now led by Marx, Joseph St. Geme III, MD, Chairman, Department of Pediatrics (right), and Kathy Shaw, MD, MSCE, Associate Chair for Patient Safety and Quality Improvement, Department of Pediatrics (left). Those leaders, and many others, recently gathered for a celebration of 10 years of excellence. See Pages 17 and 18.



# TOWARD LEADERSHIP IN HEALTH APPS

## Challenge

Parents and kids are turning to their phones for music, games...and healthcare. As one of the nation's top children's hospitals, CHOP is leading efforts to develop apps that improve pediatric healthcare. And CHOP providers and researchers are working together to understand how to integrate these apps into their practice to improve care.



*Patrick McMahon, MD, and Alex Fiks, MD, MSCE, review a dermatology app.*

## Goal

Improve and coalesce CHOP's institutional knowledge and innovation in using and creating apps that are not only engaging, but effective and of value to patients and families. A team of scientists, pediatricians and technologists was determined to find ways to connect these diverse groups across CHOP, to make certain that patients and families benefit from our expertise and research in the emerging area of digital health. The team also guided a new app through the complicated evaluation and implementation process to establish a model for future projects.

## Accomplishments

- Researched best practices by interviewing seven leading pediatric hospitals about approaches to digital health development and use.
- Surveyed more than 300 parents and caregivers about use of apps for their children's health and what they would like CHOP to provide.
- Surveyed CHOP researchers to identify "digital health" projects, including app development, and brought together a new digital health committee to connect researchers and technologists.
- Piloted an app with 200 families that allowed them to consult a pediatric dermatologist and get a prescription without visiting the office. The app was very helpful to families and will be put into broader use.

*"In 2017 alone, it is estimated that 80,000 new health apps came to market. Now, nearly a half-million health apps are available. But how do we know which apps are appropriate for children and their families and which are effective? The Chair's Initiatives grant helped us to begin to answer this very complicated question. Apps are everywhere — we want to make sure they work and are useful to children and their families, too!"*

– Linda Fleisher, PhD, MPH, and Alex Fiks, MD, MSCE

Details and  
next steps



# iAPP: Integrating Apps in Pediatric Practice

Linda Fleisher PhD, MPH & Alexander Fiks MD, MSCE

Department of Pediatrics Chair's Initiative

## Project Aims

1. To conduct an **external environmental scan** of health organizations to explore best-practice approaches for the development and integration of consumer-facing health apps into pediatric care.
2. To **identify and connect stakeholders and efforts** in consumer-facing mHealth apps at CHOP, and to outline the different avenues for **app development (defined broadly)** at CHOP.
3. To **pilot test the app development process through the implementation and evaluation of health apps** in CHOP practices.

## YR2 Accomplishments

### Aim 1: External Environmental Scan

- Developed a summary report of findings and shared with participating pediatric hospitals
- Shared key findings with Digital Health Strategic Planning consultants as formative research
- Presented findings at national implementation science meeting

### Aim 2: Identify, connect & map stakeholders and app development process at CHOP

1. **Perspectives of Parents/Caregivers --Exploring families' current use and perceptions of mHealth through clinic waiting room surveys at Dermatology, Endocrinology, Healthy Weight, and CHOP Care Network (Cobbs Creek and Coatesville) - N=310**
2. **Exploring the scope of digital health research at CHOP -**
  - Analysis of Current eSPA Portfolio – Digital Health research
  - Survey of CHOP Investigators to explore current/future projects, infrastructure needs and interest in collaboration N=86

1

Families commonly use mobile devices and download apps to promote child health.

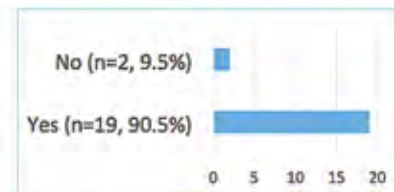
Our results suggest that steps should be taken to reduce mobile app costs for low income & minority families.

To broaden implementation in practice, doctors should consider recommending apps and addressing privacy concerns.

2

66 mHealth related projects identified in eSPA system

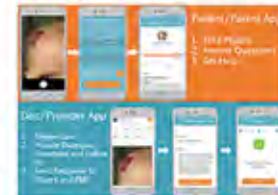
30 CHOP investigators identified as conducting mHealth-related projects



### Aim 3: Pilot Project 1, Dermatology app

**Pilot evaluation of CHOP Dermatology telemedicine app in progress – 200 families**

- A mobile health app allowing families to directly consult a pediatric dermatologist was feasible/usable, acceptable, and expedited care.
- Receipt of a prescription through the app was associated with increased user satisfaction.
- Future research should focus on reducing disparities in use.



**Telederm pilot approach is now being used for Office of Digital Health pilots**

## Sustainability

The iAPP project has been instrumental in 3 new CHOP initiatives

- **Leading newly formed mHealth Research Affinity Group (RAG) within CHOP Research Institute-** Led by Drs. Linda Fleisher, Nadia Dowshen, and Lisa Schwartz
- **Supporting research and evaluation for the Office of Digital Health - Fleisher**
- **Center for Innovation in Primary Care (The Possibilities Project) - Fiks**

# USING ANALYTICS TO HELP FAMILIES KEEP APPOINTMENTS

## Challenge

When patients do not show up for appointments, without cancelling in advance, patients, families and healthcare providers feel the impact. The patient's health can be affected, along with the efficiency and wait times in the provider's office. If we could predict which families might not show up, healthcare providers – in particular, pediatricians' offices – could reach out to help the families, and could also manage their days more efficiently, factoring in no-show probability to minimize the cascade of effects on staff and other families.

## Goal

Design a computer algorithm to predict the risk of a patient missing an appointment, and review and improve systems to help families keep appointments. The team on this initiative was large and drawn from numerous departments.

## Accomplishments

- Analyzed the enormous dataset of CHOP patient data and tested algorithms to find one that reliably predicted no-shows.
- Implemented the predictive model in 10 specialties, with 1,500 patients flagged as high risk for no-show in the first five months.
- Talked with families to better understand reasons for missing appointments, and started a "Ride Help" program to help with transportation.
- Improved CHOP's current text message system, resulting in an increase from 1,000 text appointment reminders per month to more than 50,000.
- Piloted a more sophisticated interactive texting system that helped reduce no-show rates and will now be used more broadly across CHOP.
- Developed an operational workflow to proactively intervene with families to work with them on some of their barriers to arriving for their appointments.



Bob Grundmeier, MD, with Christopher, 3

*"Our primary care pediatrics office has benefited tremendously from this project. The automated text message appointment reminder system has been very well received. All families who received the reminders appreciated them, and almost all those families made it to their appointments as well! We couldn't have made these improvements without the support of the Chair's Initiatives."*

– Robert Grundmeier, MD

Details and  
next steps



# PATTERNS: Predictive Analytic Technology To Eliminate Repeat No Shows

Luis Ahumada, PhD, Darlene Barkman, Rachel Biblow, Lisa Biggs, MD, Claire Bowers, Alisa Burnham, MD, Yong Chen, PhD, Maryann Chilkatowsky, Yuliya Chudnovskaya, Michele Czyzewski, Eugene Day, PhD, Rui Duan, Nicole Escobar, Jim Gay, Don Gaunt, Marie Gleason, MD, Jorge Guerra, Robert Grundmeier, MD, Hallam Hurt, MD, Michelle Lamar, Patricia Lee, John Martin, Tina Mercer, Debby McGrath, Tyler Moon, Laura Palacio, Joseph Plocione, DO, Natalie Plachter, Deborah Rafferty, Sarah Ramos, Justina Shults, PhD, Kim Smith-Whitley, MD, Gayle Stidsen-Smith, Lauren Tanzer, April Taylor, Melissa Tirado, Alan Tuttle, James Treat, MD, Paul Ufberg, DO, Ritu Verma, MD, Susan Wyeth

## Department of Pediatrics Chair's Initiative

### Background

Missed appointments contribute to a significant disruption for clinical staff, increased wait time for patients, clinic inefficiency and lost revenue for clinical practices. Through a patient and family survey the following was reported: 1) phone reminders are often not listened to or retrieved (message too long, not in preferred language, not at home), 2) there was a preference for text message reminders, 3) families wished to have appointment information accessible on their phone and 4) social issues such as transportation and financial insecurity were barriers to attending appointments.

To better manage the impact of missed appointments on clinical operations across the CHOP network, the PATTERNS Chair's Initiative used Epic data and predictive analytics to create a model to calculate missed appointment risk and predict the likelihood of a patient attending an appointment (or not).

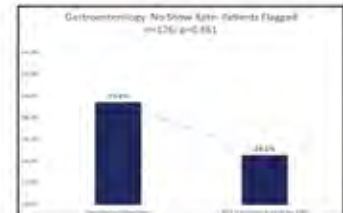
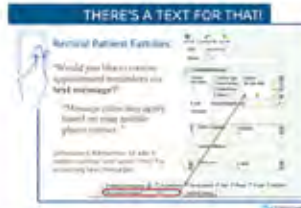
### Accomplishments

1. Tested four techniques – Logistic Regression, Support Vector Machine, Neural Networks and Random Forests for modeling patient appointment adherence behavior. Developed prediction rules to estimate the likelihood of no show at the patient and encounter level (model AUC 0.75-0.80). As of January 2018, predictive model implemented in 10 specialties with over 1,500 patients flagged as high risk for intervention. *Initial results for Gastroenterology shown.*
2. Assessed patient and family perspectives on reasons for non-attendance at appointments and communication preferences. Initiated Social Work travel assistance intervention in response to family feedback. Obtained Community Cares Grant to support transportation pilot with external vendor, *Circulation.*
3. Optimized current appointment reminder systems – Televox and MyCHOP including message re-configuration and direct appointment cancellation in Epic. Implemented new text messaging opt-in process within Epic resulting in an increase in text message reminders from <1,000 per month to over 50,000.
4. Completed successful pilot with *Patiently*, an interactive text messaging appointment reminder system, resulting in more advanced notification of appointment cancellations and a reduction in no show rates. *As of January 2018, approximately 50% of outpatient clinics are live on the new platform. Patients receiving text message reminders are more likely to show for scheduled appointments.*
5. Developed a robust discrete event simulation (DES) model to analyze the effect of changing no show rate on office efficiency.

### Ongoing Sustainability

- Obtained ongoing funding to support Social Work interventions.
- Ongoing implementation of the PATTERNS predictive model and *Patiently* appointment reminder platform across the enterprise.

### Results and Media



# IMPROVING HEALTHCARE FOR FOSTER CHILDREN



*Tyler, Jeremiah and Edward, with their foster parent, Ella, during a recent visit*

*“The Chair’s Initiatives provided the critical initial investment to develop a new clinical service for children placed into foster care. We have seen great benefits to children in collaborating with the child welfare system and ensuring they receive needed care while in the foster care system. The Chair’s Initiatives is a wonderful mechanism to be able to serve more children and address their unique healthcare needs.”*

– Philip V. Scribano, DO, MSCE, and Kristine Fortin, MD, MPH

## Challenge

When children are placed into foster care, the foster caregivers may not receive adequate health information. Children with asthma or allergies may not have their treatment follow them into foster care; those with depression may go without their medication. Lack of immunization and insurance records leads to delays in registering for school and seeing a pediatrician. And a population that’s already vulnerable faces even more barriers to safety and stability.

## Goal

Create a model for the successful, coordinated healthcare of children in foster care and ensure linkage to a medical home (primary care practice).

## Accomplishments

- Created a program specializing in the care of foster children. The Fostering Health Program includes pediatricians, a nurse coordinator, an occupational therapist and a social worker.
- Served more than 200 patients in the first year. After meticulous record gathering, the team sees the child and foster caregiver for a comprehensive visit. They provide prescriptions, make referrals to specialists and services, and help find a primary care pediatrician or “medical home” for each child. And the team creates a medical summary that will help the child continue to get the right care.
- Provided education about the program to local child welfare agencies, foster parent support groups, and colleagues.
- Developed innovative learning modules for medical students.
- Created a publicly accessible “clinical pathway” to guide medical teams on best practices in caring for children placed into foster care.

Details and  
next steps





# Fostering Healthcare Coordination of Children in Foster Care

Philip Scribano, DO, MSCE, Kristine Fortin, MD, MPH, Judy Dawson, RN, Marsha Gerdes, PhD, Anne-Ashley Field, OTR/L, Laura Popma, MSW, Kate Henry, MD, MSCE, Carla Parkin-Joseph, MD, Natalie Stavas, MD, Susan Friedman, MD

## Project Aims

- Establish a care coordination model for foster care children
- New clinical service that provides coordinated, comprehensive and timely medical care, followed by linkage to a medical home
- Disseminate knowledge about the health care of foster care children
- Enhanced communication with community providers and agencies
- Education of trainees, medical providers and child welfare professionals

## Clinical Accomplishments

- > 200 patients evaluated in first 12 months (3/2016-2/2017)

Table 1: Characteristics of patients served (N=210)

Characteristic	N (%)
Median age in years (min, max)	7 (0.2-17.9)
Foster care placement type	
Kinship	80 (29)
Non-relative	135 (64)
Group home	4 (2)
Other	4 (2)
Missing data	7 (3)
History of multiple placements	85 (40)

- Standardized, computerized screening tools were administered to assess social determinants as well as mental, behavioral and developmental health

Table 2: Results of standardized screening

Domain / Measure	Positive N (%)
<b>Autism</b>	
MCHAT (N=18)	5 (28)
<b>Development</b>	
SWYC developmental milestones (N=62)	29 (47)
<b>Emotional / behavioral</b>	
Baby Pediatric Symptom Checklist (N=12)	7 (58)
Preschool Pediatric Symptom Checklist (N=45)	21 (47)
Patient Health Questionnaire - 9 (N=49)	22 (45)
Pediatric Symptom Checklist - 17 (N=140)	46 (33)
<b>Social Determinants of Health</b>	
SWYC family questions (N=190)	17 (9)
<b>Substance abuse</b>	
CRAFFT (N=47)	4 (9)
<b>Trauma / Post traumatic stress disorder</b>	
Child PTSD Symptom Scale (N=95)	31 (33)

- Occupational Therapy Evaluations**
  - 88 patients received an evaluation
  - 47/88 (53%) had at least one significant finding warranting intervention

- Many patients required medications and referrals**

Table 3: Need for medications and referrals, N=210

Need	N (%)
Medication prescription	53 (25)
Any referral	179 (85)
Referrals by category	
Developmental / education referral	103 (49)
Medical subspecialty	88 (42)
Mental health	82 (39)

- A caregiver satisfaction survey** was developed
  - 30/31 (97%) of families agreed or strongly agreed that "the clinic appointment helped me understand the child's medical needs"
- Linkage to medical home**
  - Care coordinator works with families, community providers and agencies to establish a medical home

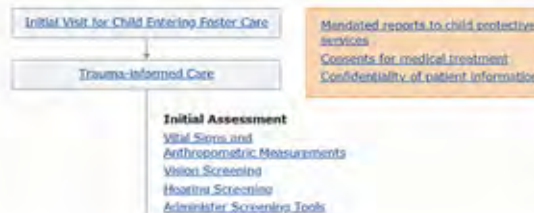
Table 4: Time to completed primary care appointment (N=44)

Time to completed primary care appointment	N (%)
≤ 2 months	15 (34)
≤ 3 months	26 (59)
≤ 6 months	34 (77)

## Educational Accomplishments

- A clinical pathway for the medical evaluation of children entering foster care was developed and is available at: <http://www.chop.edu/pathways>

### Pathway for Medical Evaluation of Children in Foster Care



- Publications** include a special edition of *Current Problems in Pediatric and Adolescent Health Care* focused on Foster Care and Health in the US

www.cppah.com

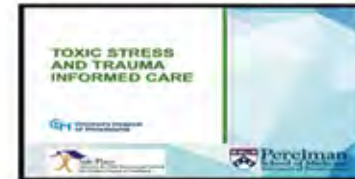
Volume 45 • Number 10 • October 2015 • Pages 291-322

## CURRENT PROBLEMS IN

## Pediatric and Adolescent Health Care

Foster Care and Health in the U.S.

- Information sessions about fostering health program at all 10 of the Philadelphia Community Umbrella Agencies (CUA)
  - Ten presentations at local and national conferences
  - Partnership with Philly Fosters, a foster parent support group, to provide foster parent trainings
  - Dr. Parkin-Joseph (fellow in Child Abuse Pediatrics) developed three computerized learning modules for all medical students on pediatrics rotation, using flipped classroom educational approach. Topics are:
    - Toxic stress and trauma informed care
    - Health care for children in foster care
    - Legal and policy issues related to providing care to children in foster care
- To date, >90 medical students received this educational offering.



## Next Steps

- Continue and expand clinical service delivery
- Pursue additional funding to sustain/ expand clinical services
- Develop learning modules for other audiences including attending physicians, foster parents, policy makers
- Pursue quality improvement opportunities for ongoing scholarly pursuits

# EXPANDING FERTILITY PRESERVATION FOR PATIENTS

## Challenge

Since 2004, Children's Hospital of Philadelphia has offered fertility preservation options for cancer patients, including sperm banking and egg or ovarian tissue freezing, as well as ovarian and testicular tissue cryopreservation for younger children. Patients with other diagnoses also faced fertility issues, but weren't always offered preservation options.

## Goal

Enhance fertility preservation services to cover more patients, including children and adolescents with nephrotic syndrome, vasculitis, sexual development disorders, and lupus, as well as transgender youth. This project was led by the same team that built the original program in oncology into the national leader in fertility preservation among pediatric hospitals.



*Some patients must undergo treatment that compromises their fertility.*

## Accomplishments

- Broadened list of specialties that refer patients for fertility consults to include immunology, hematology, rheumatology, nephrology, Gender and Sexuality Development Clinic, urology, genetics and others.
- Boosted fertility preservation consults (when a doctor or nurse meets with a patient to discuss risk and arrange for procedures) for non-cancer diagnoses. Non-oncology consults rose from 14 percent of total consults to 36 percent.
- Established connections with providers in urology, endocrinology, hematology, genetics and the Gender and Sexuality Development Clinic to collaborate on clinical care and research.
- Created a database for tracking fertility consults and procedures.

*“The Chair’s Initiatives provided key resources and expert guidance that allowed us to transform an existing service into a comprehensive program that reaches patients across the institution in need of fertility-related counseling and care.”*

– Claire Carlson, BSN, RN

Details and  
next steps



# Developing a Hospital Wide Fertility Preservation Program

Department of Pediatrics Chair's Initiative

Jill P. Ginsberg, MD, Claire Carlson, BSN, RN, Sue Ogle, CRNP

## Project Goal

Gonadal damage is a common consequence of treatment for pediatric malignancies. Non-oncologic conditions may also utilize treatments with potential impact on fertility. A multidisciplinary team approach can have a positive impact on referral patterns, appropriate risk counseling and access to fertility preservation options. With support from the Department of Pediatrics Chair's Initiative, a Hospital Wide Fertility Preservation Service was created to provide a clinical consultation service for offering education and counseling directly to patients across all hospital disciplines.

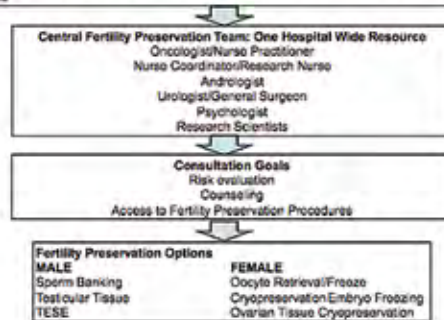
### Goals

- Increase hospital wide awareness among clinicians regarding risk factors for infertility and/or premature gonadal dysfunction and fertility preservation options
- Facilitate timely referrals for fertility preservation (sperm banking, oocyte/embryo freezing)
- Offer cutting edge, experimental options for fertility preservation (testicular and ovarian tissue cryopreservation) within the context of organized research protocols
- Collaborate on new research efforts, with a focus on long term outcomes for patients that pursue fertility preservation prior to treatment

## Interventions

### Populations at Risk for Impaired Fertility

- Oncologic diagnoses
- Non-Oncologic conditions receiving gonadotoxic treatments: [systemic lupus erythematosus](#), nephritis, [rheumatoid arthritis](#), [Wegener's granulomatosis](#), refractory nephrotic syndrome, CNS vasculitis
- Transgender males and females
- Disorders of Sexual Development (DSD): Turner's syndrome, Klinefelter's, androgen insufficiency syndromes, congenital adrenal hyperplasia, and mixed gonadal dysgenesis



## Results

### Referrals Pre & Post Initiative

	Pre July 2013- June 2015	Post July 2015- June 14, 2017
Total fertility consults	97	193
<b>Referring Division</b>		
Oncology	83	124
Immunology	5	7
Hematology	5	16
Rheumatology	3	4
Nephrology	1	2
Gender Non-Conforming Clinic	0	29
Neuro-Inflammatory	0	2
Genetics	0	1
Urology	0	2
Parent/Non-Medical Staff Referral	0	5
Other	0	1
<b>Fertility Preservation Procedures</b>		
Sperm Banking	48	58
Ovarian Tissue cryopreservation	23	17
Testicular tissue cryopreservation	14	12
Egg freezing	1	1
Consult no collection	11	106

### Major Accomplishments of the Initiative

- Developed presence as hospital wide fertility resource and increased divisional interaction outside of Oncology.
- Increased number of total fertility consults and number of consults from multiple divisions outside of Oncology.
- Identified opportunities for fertility related research collaborations across specialties.
- Created database for tracking fertility consults and fertility preservation procedures in SharePoint and developed Fertility Consult Visit Type and Consult Order in EPIC.
- 5 published manuscripts, 6 manuscripts submitted, 4 presentations and 4 press publications.
- Secured funding for future sustainability of the Fertility Preservation Service.

### Data Summary on Referral Patterns

Prior to the Chair's Initiative, 86% of referrals were from Oncology and 14% of referrals from other divisions. Post initiative, referrals from outside of Oncology more than doubled, with 36% of referrals from other divisions.

## Lessons Learned

A comprehensive model for fertility counseling provides accessible, high value fertility preservation care to pediatric and young adult patients with a wide variety of diagnoses. A centralized point of contact ensures timely referrals and risk based counseling, and streamlines access to fertility preservation procedures.

## Next Steps

- Develop established patient care plans/algorithms that include fertility counseling consult for all at risk patients
- Cultivate partnership with Gender Non-Conforming Clinic to improve understanding of fertility needs for transgender youth
- Identify other funding sources for future sustainability of service, including infrastructure, research and patient care costs

# IMPROVING UNDERSTANDING AND USE OF GENETIC TESTING

## Challenge

In the past decade, our ability to test the human genetic code has become much more sophisticated and much less expensive. In time, genetic testing may become as routine as a blood-pressure test. But many people — not only patients, but also doctors and other healthcare providers — don't have a deep understanding of genetics or genetic testing, and they don't know what to do with the results.

## Goal

Boost the understanding and the use of genetic testing across CHOP by providing better education for patients, families and providers about what it is, when to use it and how to interpret results.

## Accomplishments

- Developed 15 animated videos for families, including explanations of the basics of genetics, different types of testing, and more. The videos have been viewed more than 1,000 times.
- Created a “Genetics Champions” team at CHOP, including physicians and others from different specialties to serve as resources for colleagues with questions.
- Developed several animated videos for healthcare providers.
- Obtained approval, and a universal broad-scale sharing IRB protocol, to establish a large pool of genotypes (people's mapped genetic codes) and phenotypes (people's characteristics and conditions) for researchers to use across numerous studies.



*Aaron, 5, and his mom, Lauren, use an animated video to learn about genetics.*

*“The Chair’s Initiatives provided critical funding for an innovative education program that will have a lasting impact on families as well as provide support for colleagues in other fields of medicine. Funding for these types of initiatives is not readily available from outside agencies. The Chair’s Initiatives enabled us to develop a valuable resource that would otherwise not have been possible.”*

– Ian Krantz, MD, and Livija Medne, MS, LCGC

Details and  
next steps



# An Integrative and Educational Pediatric Genomics Initiative

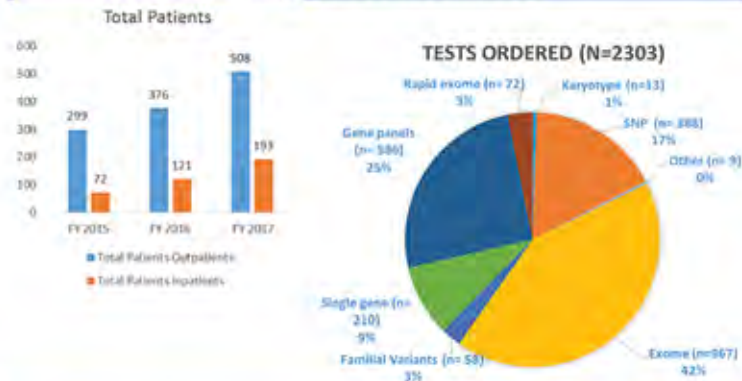
Livija Medne, MS CGC, Ian Krantz, MD IMGC team: Emma Bedoukian MS, CGC, Jennifer Tarpinian MS, CGC  
DGD team: Nancy Spinner PhD, Surabhi Mulchandani MS, CGC CHOP PR team: Jennifer Milloff, Lauren Rumsey, Frank Punzo

Department of Pediatrics Chair's Initiative

## Project Aim

- Develop online genomic medicine and testing educational modules for both families and clinicians
- Develop tracking tools of patient and family metrics
- Develop pre- and post-module genomics knowledge and genomic testing assessment for clinicians
- Recruit 'genetic champions' from all Divisions of Pediatrics
- Develop an IRB protocol to allow for anonymized use of exome (genomic) and clinical (phenotypic) data for research/discovery purposes

## Background Information



## Next Steps

- Complete specialty-specific and clinician educational modules:
- Work with Perelman School of Medicine at the University of Pennsylvania to develop Pediatric Genomic MOOCs based on the educational modules developed through the Chair's Initiative

## Top Five Accomplishments

1. Established CHOP "Genetic Champions" group:
  - Integrated into exome interpretation workflow and new test development
2. Developed and obtained approval for a broad-reaching IRB protocol to allow for sharing of genotypes, phenotypes and samples as a resource for CHOP and collaborators.
  - Over 500 subjects enrolled in this protocol to date.
3. Developed and launched genetic/genomic family educational modules:
  - 15 different family modules created:
    - Introduction to Genetics; Genetics Background; Genetic Variation; Overview of Genetic Inheritance; AD Inheritance; AR Inheritance; XL Inheritance; Mitochondrial Inheritance; Overview of Genetic Testing Modalities; Chromosomal Microarray Test; Karyotyping; Genome Sequencing Test; Exome Sequencing Test; Gene Panel Testing; Single Gene Analysis Test; Privacy Issues in Genetic Testing.
  - Specialty-specific and clinician-level modules: under development.
4. Collaborative efforts with the Family Advisory Council to beta-test the modules, which are currently being used in clinical practice by patients/families undergoing genetic testing through the Roberts IMGC.
5. Preliminary meetings with Perelman School of Medicine at the University of Pennsylvania to develop Pediatric Genomic MOOCs.



## Family Genomics Educational Module – Key Statistics

	Sessions	Users	Page views	Pages / session	Avg duration	Bounce rate	% New Users
1/10/17-3/17/17	149	123	835	5.6	5:36	35.57%	29.53
3/17/17 – 7/6/17	363	194	2701	7.44	3:43	26.72	23.4

# HELPING PATIENTS WITH INTELLECTUAL DISABILITIES AND CHRONIC ILLNESS TRANSITION TO ADULT CARE

## Challenge

As children with childhood-onset chronic illness and intellectual disability become adults, they require transition to adult-focused medical care. This process is challenging for those with intellectual disabilities and those whose health is so complex they need multiple specialists. Finding good adult doctors is only part of the challenge. Taking care of their health also means choosing the right insurance, ordering medical supplies and equipment, and making decisions about legal issues like whether a family member should have power of attorney or legal guardianship. All of this requires time, and a team.

## Goal

To improve and standardize CHOP's approach to transition to adult care for patients with intellectual disabilities and chronic health conditions. A team of doctors, nurse practitioners and social workers set out to ensure that this vulnerable population doesn't fall through the cracks.



Lamont, 28, with Adam Greenberg, CRNP, and Katherine Wu

## Accomplishments

- Created a consult service. Doctors, nurses and others at CHOP can now request consults for patients and families who need help.
- Established twice-weekly clinics. At their appointments, the patient and family see a team that helps with referrals, insurance and other needs and writes a comprehensive care plan to guide the adult doctors.
- In the pilot period, helped more than 80 patients with conditions including cerebral palsy, epilepsy, cystic fibrosis, and severe autism. About 70 percent of patients had an intellectual disability. Demand is high: The team is on track to receive consults for 200 patients per academic year.
- Built a network of adult general practitioners and specialists willing to accept young adult patients.
- Began building a registry in order to proactively identify patients who will need these specialized transition services.

*“The Chair’s Initiatives was integral in providing support for our multidisciplinary team that aids adolescent and young adults. Now a fully operational clinic that has received over 150 consults this year, our program began with a small pilot effort via the Chair’s Initiatives.”*

– Dava Szalda, MD, MSHP

Details and  
next steps



## Multidisciplinary Intervention Navigation Team (MINT): Clinical Quality Improvement Program for Complex Patient Transfers from CHOP to Adult-Focused Medical Care

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Department of Pediatrics Chair's Initiative

### Problem Statement

For young adults with medical complexity and/or intellectual disability (ID), few care models exist to coordinate the transition of primary and secondary care, home health, medical supply, medical decision-making, and community resource needs.

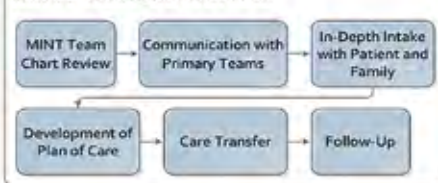
### Objective

To standardize pediatric to adult healthcare transfers of adults with complex healthcare needs through a tiered and multi-modal population-based intervention.

### Intervention Bundle for Complex Patients

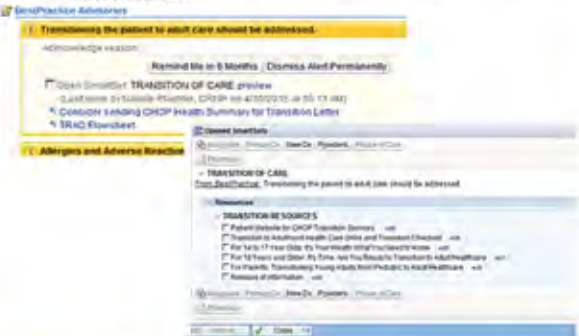
- Starting October 2015, we partnered with 7 medical and surgical divisions in a free-standing children's hospital and neighboring adult medical system to develop transition interventions based on medical complexity.
- Eligibility:** Adult patients with ≥2 specialists or intellectual disability
- Intervention:** Referral to MINT, a multidisciplinary consult service consisting of Med-Peds trained physician, nurse practitioner, social worker, and youth community health worker (YCHW)

#### MINT Consult Service



### Intervention Bundle for All Chronic Patients

- Eligibility:** All adult patients with a chronic illness belonging to a partnered division
- Interventions:**
  - Identify division transition champions;
  - Pilot EPIC-based clinical decision supports;
  - Develop divisional transition guidelines;
  - Identify adult providers; and
  - Run psychoeducational workshops for patients and families.



### Results

Table 1. Demographics of Complex Patients (MINT Referrals)

Age, mean (range)	21 (17-43)
No. of specialists, median (range)	3 (Range: 1-8)
Number of patients with IDD, n (%)	42 (70%)

### Results

#### CLINICAL

- Received over 80 patient consults
- Assisted 30% of patients with legal guardianship
- Assisted 30% of patients with insurance issues
- Referred 27% of patients to our YCHW

#### RESEARCH

- Presented at SGIM, PAS, APHA
- Submitted 2 PCORI proposals, an R01
- I-ACT for Epilepsy HRSA Transition grant 9/1/16-8/31/19; \$1.2 M
- At least 4 manuscripts in process

#### OPERATIONS

- Began with 7 partner Divisions; now have 13
- Developed large adult provider network
- Ongoing Transition Special Interest Group (TSIG) meetings
- REACH events – psychoeducational events
- 7 Divisions using best practice advisories

#### EDUCATION

- MOC credit for faculty working on transition
- QI project for all 3<sup>rd</sup> year Med-Peds residents
- Engaged and educated a variety of students and trainees in our work

### Next Steps

Continue transition program, evaluation, and build out of Epic-based tools, including patient registry; publish these results.

# PUBLICATIONS AND GRANTS, ROUND 5

## iAPP: Integrating Apps in Pediatric Practice

### Publications

Fiks A, et al. **Usability, Acceptability, and Impact of a Pediatric Teledermatology Mobile Health Application.** *Telemedicine and e-Health* 2017.

Fleisher L, Fiks A. **From Pilot to Practice: Implementing and Disseminating Innovation, Essentials in Population Health.** *White Paper Series, Children's Hospital Association* 2017.

### Presentations

Sykes E, **Disparities in Parent Attitudes Toward and Use of Mobile Health,** Eastern Societies for Pediatric Research Meeting, Philadelphia, March 2017.

Berrigan L, **Direct-to-Consumer Pediatric Dermatology,** Eastern Societies for Pediatric Research Meeting, Philadelphia, March 2017.

Fleisher L, **Integrating Emergent mHealth Apps Into Pediatric Practice: A Mixed Method Implementation Project,** 9th Annual Academy of Health Conference on the Science of Dissemination and Implementation, Washington, DC, Dec. 2016.

Fleisher L, **Consumer Perspective Regarding mHealth Effectiveness & Security,** Annual IEEE Wireless Health Conference, Bethesda, MD, Oct. 2016.

Berrigan L, **Feasibility, Acceptability and Impact of a Pediatric Teledermatology Mobile Health Application,** iHealth Clinical Informatics Conference, San Francisco, May 2017.

Fiks A, **Direct-to-Consumer Pediatric Dermatology,** Pediatric Academic Societies Meeting, San Francisco, May 2017.

Fleisher L, Fiks A, **From Pilot to Practice: Implementing and Disseminating Innovation,** Children's Hospital Association, national webinar.

Fleisher L, **Using Implementation Science Frameworks to Guide the Integration of Evidence-based mHealth Into Pediatric Care,** International Society of Research on the Internet, Berlin, Oct. 2017.

## PATTERNS: PREDICTIVE ANALYTIC TECHNOLOGY TO ELIMINATE REPEAT NO-SHOWS

### Presentations

Institute for Patient- and Family-Centered Care International Conference on Patient- and Family-Centered Care, **No Show, Oh No! Engaging patients and families in improving appointment adherence,** Baltimore, MD, June 2018.

Children's Hospital Association Quality and Safety in Children's Health Conference, **Getting Patients to Their Clinic Visit: There's a Text for That!,** San Diego, CA, March 2018.

Society for Social Work Leadership in Healthcare (SSWLH) Annual Meeting, **Predictive Analytic Technology to Eliminate No-Shows,** Baltimore, MD, Oct. 2017.

Association of Administrators in Academic Pediatrics (AAP) Regional Meeting, **Leveraging Quality Improvement and Predictive Analytics to Decrease Missed Appointments,** Philadelphia, Oct. 2017.

National Association of Healthcare Quality (NAHQ) Annual Conference, **Leveraging Quality Improvement and Predictive Analytics to Decrease Missed Appointments,** Cincinnati, OH, Sept. 2017.



## FOSTERING HEALTHCARE COORDINATION OF CHILDREN IN FOSTER CARE

### Publications

Scribano PV. **Charting the Course of Improved Health for Children in Foster Care.** *Curr Probl Pediatr Adolesc Health Care* 2015;45(10):282-285.

Deutsch SA, Fortin K. **Physical Health Problems and Barriers to Optimal Health Care Among Children in Foster Care.** *Curr Probl Pediatr Adolesc Health Care.* 2015; 45(10): 286-291.

Deutsch SA, Lynch A, Zlotnik S, Matone M, Kreider A, Noonan K. **Mental Health, Behavioral and Developmental Issues for Youth in Foster Care.** *Curr Probl Pediatr Adolesc Health Care.* 2015;45(10):292-297.

Schilling S, Fortin K, Forkey H. **Medical Management and Trauma-informed Care for Children in Foster Care.** *Curr Probl Pediatr Adolesc Health Care.* 2015;45(10):298-305.

Lockwood KK, Friedman S, Christian CW. **Permanency and the Foster Care System.** *Curr Probl Pediatr Adolesc Health Care.* 2015; 45(10): 306-315.

Zlotnik S, Wilson L, Scribano PV, Wood J, Noonan K. **Mandates for Collaboration: Health Care and Child Welfare Policy and Practice Reforms Create the Platform for Improved Health for Children in Foster Care.** *Curr Probl Pediatr Adolesc Health Care.* 2015;45(10):316-322.

Fortin K, Scribano P, Lockwood K, Gerdes M, Friedman S, Lin W. **Medical Evaluation of Child Entering Foster Care - Clinical Pathway.** <http://www.chop.edu/clinical-pathway/medical-evaluation-child-entering-foster-care>

*These “pathways” are publicly available on the CHOP website and are used by clinicians around the world.*

Greiner M, Beal S, Nause K, Staat MA, Dexheimer J, Scribano PV. **Laboratory Screening for Children Entering Foster Care.** *Pediatrics* 2017;140(6);e20163778.

Scribano PV. **Trends in the US Foster Care System.** *APSAC Advisor* 2018; 30(2).

Brennan B, Stavas N, Christian C. **The physical health needs of children in foster care.** *APSAC Advisor* 2018; 30(2): 12-16.

Bennett CE, Henry MK, Wood JN. **Meeting the developmental, behavioral and mental health needs of children in foster care.** *APSAC Advisor* 2018; 30(2): 17-23.

Parkin-Joseph C, Sondhi Lews N, Fortin K: **Medical Education and Foster Care.** *APSAC Advisor* 2018; 30(2): 24-26.

### Presentations

Scribano PV, **Determining Healthcare Utilization of Children in Foster Care Using the Electronic Health Record,** Foster Care, Adoption and Kinship Care Council Program, American Academy of Pediatrics National Conference, Washington, DC, Oct. 2015.

Scribano PV, **Fostering Health: Care Coordination of Children in Foster Care,** Fostering Health: A Convening of Stakeholders in Philadelphia’s Child Welfare System Symposium, Philadelphia, June 2016.

Scribano PV, **The Effect of Foster Care Placement on Health Care Utilization,** Ray E. Helfer Society Meeting, Tucson, AZ, April 2016.

Fortin K, Scribano PV, Friedman S, Dawson J, Lockwood K, Gerdes M, Lynch A, Field AA, Popma L, Deutsch S, Parkin-Joseph C, Stavas N, **Fostering Health Program: Improving Quality and Safety of Medical Care for Children in Foster Care Through Care Coordination and Clinical Pathway Development,** Children’s Hospital of Philadelphia 6th Annual Quality and Safety Day, May 2016.

Scribano PV, **Making the Case for Foster Health: A Primer on the Healthcare Needs of Children in Foster Care,** Court Appointed Special Advocates (CASA) Philadelphia Speaker Series, Philadelphia, March 2017.

*continued >*

# PUBLICATIONS AND GRANTS, ROUND 5

Parkin-Joseph C, Fortin K, Scribano PV, **Flipping the Script: Innovative Approach to Child Abuse Pediatrics Medical Education to Improve Dissemination in Competitive Medical School and Residency Curricula**, Ray E. Helfer Society Annual Meeting, Denver, April 2017.

Fortin K, Terrell L, Berkoff M, Greiner M, **Addressing Medical Recommendations for Children in Foster Care: Implementation Strategies, Evidence-based Practices, and Different Clinical Models by Current Successful Foster Clinics**, Ray Helfer Society Annual Meeting, Denver, April 2017.

Fortin K, **Medical Issues for Children in Foster Care: An Overview for Foster Families**, Montana Prevent Child Abuse and Neglect Conference, Helena, MT, April 2017.

Fortin K, Field AA, Dawson J, Parkin-Joseph C, **Navigating the Healthcare Needs of Children in Foster Care, One Child, Many Hands** – Field Center National Conference on Child Welfare, Philadelphia, June 2017.

Fortin K, Friedman S, Parkin-Joseph C, Stavas N, Henry K, Dawson J, Scribano P. **Fostering Health Program: Improving access to care and safety for children in foster care with asthma**. Children's Hospital of Philadelphia 7th Annual Quality and Safety Day, May, 2017.

Fortin K. **Fostering Health: How to become a medical home for Children and Youth in Foster Care**. American Academy of Pediatrics, Delaware Chapter and Nemours Alfred I DuPont Hospital for Children. Milford, Delaware, August, 2017.

Dawson J, Field AA, Fortin K **Fostering Health Program**, Together as Adoptive Parents Inc., Monthly parent group meeting, Philadelphia PA, May, 2018.

## Grants

Fortin K. **Linking Asthmatic Foster Children to Services**. American Academy of Pediatrics CATCH grant, 2017-18. Total: \$10,000

Bennett C. **Ray Helfer Society Career Development Award in Child Abuse Research**. A pilot study to identify best practices for implementation of a positive parenting training program in the foster care population. Total: \$14,595

Scribano PV. **Kohl's Foundation 2017-19**. CHOP Healthy Kids, Safe Communities. (Total: \$223,331 to Safe Place: Center for Child Protection and Health)

## CREATING A HOSPITAL-WIDE FERTILITY PRESERVATION PROGRAM

### Publications

Sullivan-Pyke CS, Carlson CA, Prewitt M, Gracia CR, Ginsberg JP. **Ovarian Tissue Cryopreservation (OTC) in Prepubertal Girls and Young Women: An Analysis of Parents' and Patients' Decision-Making**. *Journal of Assisted Reproduction and Genetics*, accepted for publication Jan. 2018.

Carlson CA, Kolon TF, Mattei P, Hobbie W, Gracia CR, Ogle S, Ginsberg JP. **Developing a Hospital-Wide Fertility Preservation Service for Pediatric and Young Adult Patients**. *J Adolesc Health*. 2017;61(5):571-576.

DiNofia AM, Wang X, Yannekis G, Ogle S, Hobbie WL, Carlson CA, Ginsberg JP. **Analysis of Semen Parameters in a Young Cohort of Cancer Patients**. *Pediatr Blood Cancer*. 2017;64(2):381-386.

Long CJ, Ginsberg JP, Kolon TF. **Fertility Preservation in Children and Adolescents With Cancer**. *Urology*. 2016;91:190-196. Review.



### Abstracts and Presentations

Persky R, Gruschow S, Carlson C, Ginsberg J, Dowshen N, **Attitudes Towards Fertility Preservation Among Transgender Youth and Their Parents**, Pediatric Academic Societies Meeting, May 2018, Toronto. *Submitted*.

Sullivan-Pyke CS, Carlson CA, Prewitt M, Gracia CR, Ginsberg JP. **Ovarian Tissue Cryopreservation (OTC) in Prepubertal Girls and Young Women: An Analysis of Parents' and Patients' Decision-Making**, American Society for Reproductive Medicine, Oct. 2017, San Antonio, TX.

Oncofertility Fellow Symposium. Nov. 2016, Chicago.

### Funding/Grants

Wolfson Fund: A \$500,000 endowment for female fertility preservation is being built in installments over 5 years and then will exist in perpetuity. Starting July 2020, this will provide \$25,000 annually.

M & T Bank: \$10,000, applied to existing Wolfson fund

CHOP Research Institute: \$35,000 per year for fertility-related patient care costs through July 2020

## MULTIDISCIPLINARY INTERVENTION NAVIGATION TEAM (MINT) FOR PEDIATRIC TO ADULT CARE TRANSFERS

### Presentations

Steinway C, Gable JL, Jan S, and MINT, **Transitioning to Adult Care: Supporting Youth with Special Health Care Needs**. PolicyLab at Children's Hospital of Philadelphia, 2017.

Wu K, Steinway C, Jan S, Greenberg A, Trachtenberg S, Szalda S, **A Model for Transition from Pediatric to Adult Healthcare using a Youth Community Health Worker**. Poster Presentation, APHA Annual Meeting and Exposition, Atlanta, GA, Nov. 2017.

Jan S, Steinway C, Greenberg A, Szalda D, Wu K, Trachtenberg S, Kim R, **A Tiered Approach to Transitioning Young Adults with Medical Complexity or Intellectual Disability to Adult Care**. Pediatric Academic Societies Meeting, San Francisco, CA, May 2017.

Jan S, Steinway C, Greenberg A, Szalda D, Wu K, Kim R, Trachtenberg SW, **A Tiered Approach to Transitioning Young Adults with Medical Complexity or Intellectual Disability to Adult Care**. Society of General Internal Medicine Annual Meeting, April 2017.

Steinway C, Szalda D, Trachtenberg S, Greenberg A, Wu K, Jan S, **Multidisciplinary Intervention Navigation Team (MINT): Clinical Program Quality Improvement**. 144th American Public Health Association (APHA) Annual Meeting and Exposition, Denver, CO, Nov. 2016.

Szalda D, Steinway C, Greenberg A, Trachtenberg S, Wu K, Jan S, **Multidisciplinary Intervention Navigation Team (MINT): A Clinical Service for Pediatric to Adult Medical Systems Transitions for Medically Complex Young Adults**. Poster Presentation, 8th Annual Health Care Transition Research Consortium Research Symposium, Houston, TX, Oct. 2016.

Greenberg A, Szalda D, Steinway C, Trachtenberg S, Miller R, Varney O, Jan S, **Transfer Engagement Lessons Learned (TELL): Using Patient Perspectives to Inform and Improve Transition Processes**. 2016 Annual Meeting of the Society of Adolescent Health and Medicine, Washington, DC, March 2016.

Steinway C, Trachtenberg S, Greenberg A, Jan S, **Challenges to Transitioning Patients from Pediatric to Adult Healthcare**. 143rd American Public Health Association Annual Meeting and Exposition, Chicago IL, Nov. 2015.



# A DECADE OF EXCELLENCE

For more than 10 years, the Chair's Initiatives, an internal grant program of the Department of Pediatrics at Children's Hospital of Philadelphia, has been incubating amazing projects and programs that improve care for children.

The participants gathered in the fall of 2017 to celebrate.



*Chair's Initiatives participants*

## 5 ROUNDS WITH 33 INITIATIVES

92 MDs  
18 PhDs

11 RNs and NPs  
24 Staff

157 Publications  
253 Presentations

\$17 million in  
External Funding





*CHOP President and CEO Madeline Bell addresses the crowd.*



*Joseph St. Geme III, MD, and Alan Cohen, MD*



*The Chair's Initiatives Oversight Team: Maryann Chilkatowsky, MBA, Kathy Shaw, MD, MSCE, Alison Marx, MBA, Lauren Tanzer, MBA, MS, PMP, and April Taylor, MS, MHA, CPPS*



*The team from Minds Matter: Improving Pediatric Concussion Management*



*A poster at the event showing the many Chair's Initiatives participants.*

# IT STARTED WITH A CHAIR'S INITIATIVE

## ROUND 1 (2006-2008)

### Access Nurse Advisor

#### Goal

To improve appointment and care coordination for families seen by numerous specialties at CHOP.

#### And now...

...the Access Nurse Advisor role oversees the Complex Scheduling Service, which has scheduled over 29,000 appointments for patients and families who wish to coordinate appointments with three or more specialists on the same day.

### Referring Physician Communication and Care Coordination

#### Goal

To improve communication, partnership, and coordination between primary care physicians and subspecialties in the care of children with chronic and acute conditions.

#### And now...

...we have contributed to the spreading of best practices and the creation of a strong foundation for care coordination, continuity of care, communication, and coordination across the organization, including 1-800-TRY-CHOP.

### Automated Appointment Reminders

#### Goal

To reduce the frequency of missed appointments.

#### And now...

...an automated appointment reminder system was implemented at more than 115 locations in the CHOP network, providing timely information to patients and families prior to their scheduled appointments.

### Center for Bone Health

#### Goal

To improve care for children with bone health concerns.

#### And now...

...we have a well established Center for Bone Health that draws patients, regionally and internationally, with over 4,000 patient encounters since its inception.

### Center for Pediatric Eosinophilic Disorders

#### Goal

To improve care for children with the rare allergic disorder eosinophilic esophagitis and other eosinophilic disorders.

#### And now...

...we are an NIH-funded center with clinical, translational, and basic science research on rare allergic disorders. The initiative has allowed us to do bench-to-bedside research with ongoing breakthrough research.

### ADHD in Primary Care

#### Goal

To develop a better model of care for children with attention deficit hyperactivity disorder (ADHD) at the primary care level.

#### And now...

...the ADHD Care Assistant is available in the electronic medical record for the CHOP Primary Care Network to improve the care of patients with ADHD. The ADHD Care Assistant has been used for approximately 2,350 children.



## Multidisciplinary Cancer Survivorship Program

### Goal

To improve the care of the growing population of survivors of childhood cancer with multiple chronic medical conditions.

### And now...

...it is a thriving and comprehensive clinical service that provides exceptional care to pediatric cancer survivors with complex medical needs. The program includes same-day, same-clinic access to varied specialists, with over 400 patients served by the clinic, accounting for over 4,000 specialist visits.



## Office of Fellowship Training

### Goal

To strengthen the fellowship programs at CHOP, with a focus on recruiting and training physician leaders in pediatric subspecialties, developing strategies to enhance learning and teaching, and anticipating and helping to meet subspecialty workforce needs.

### And now...

...the Office of Fellowship Programs provides infrastructure and resources to support programming for fellows in over 50 fellowship programs at CHOP.

## Pediatric Knowledgebase

### Goal

To create a web-based application that combines data about lifesaving drugs with data about individual patients to help doctors make decisions in prescribing drugs and to improve pharmacotherapeutic outcomes in pediatrics.

### And now...

...a prototype web-based application to help clinicians make safe prescribing decisions and reduce medication errors for tacrolimus and methotrexate was tested and received a half million dollars in external funding.

## Sudden Cardiac Death Prevention

### Goal

To prevent sudden cardiac death in children and adolescents.

### And now...

...the Heart Health Screening Study, Youth Heart Watch, and Youth Heart Watch Clinic have provided significant service to the community, including partnering with 200 schools to screen over 2,500 children with electrocardiography. Over \$2.5 million in grant funding was received.

# IT STARTED WITH A CHAIR'S INITIATIVE

## ROUND 2 (2009-2011)

### Chemotherapy Tracking System

#### Goal

To enhance the safety of chemotherapy administration by reducing errors through computerizing records of cancer patients' complex drug regimens and enhancing availability of information across all care settings.

#### And now...

...we have an updated electronic roadmap and "standard operating procedures" to reduce chemotherapy errors among oncology patients across all care settings.

### Intestinal Rehabilitation Program

#### Goal

To coordinate and improve care for children with severe conditions that cause intestinal failure.

#### And now...

...there is a multidisciplinary outpatient clinic and an inpatient consult team to guide management of patients with intestinal failure and to provide critical continuity across both settings for these extremely complex patients. Since its inception, the program has consulted on nearly 300 children, actively follows 175 children, and has accomplished a successful transition from intravenous to enteral nutrition in over 150 children.

### From Knowledge to Practice: Developing the Infrastructure to Create and Implement Collaborative Clinical Pathways

#### Goal

To incorporate evidence, best practice, and local expert consensus into easily accessible, shared mental models for use by clinical teams at the point of care to facilitate the delivery of high quality medical care. Clinical pathways aim to standardize care for a specific clinical problem, process, procedure, or episode in a defined population.

#### And now...

...Clinical Pathways is an official program in the Office of Clinical Quality Improvement. There are over 110 pathways available world-wide with almost 15,000 website views monthly.

### Anticoagulant Management Program

#### Goal

To improve monitoring and care for children taking anticoagulants.

#### And now...

...there is a fully deployed Cardiac Anticoagulation Program, including a full-time pharmacist to monitor every inpatient on anticoagulants and a nurse to visit and educate every patient on anticoagulants before discharge.

### Unit-based Patient Safety Walk rounds

#### Goal

To create infrastructure within the clinical microsystem to support local quality improvement and patient safety.

#### And now...

...Unit Leadership Partners is an established group which brings nursing and medical leadership together to promote and improve the quality of patient care and provide an opportunity for multidisciplinary discussion and decision making.

### Department of Pediatrics CHOPLink (EPIC) Implementation, Quality and Safety Team

#### Goal

To develop an arena for clinical input into electronic health record initiatives, prioritization of projects and performance metrics.

#### And now...

...we have a monthly forum where over 20 clinicians, information services leaders and administrators meet to prioritize and implement improvements to the electronic health record to enhance the experience for patients and clinicians.



## ROUND 3 (2011-2013)

### A Shared Decision-Making Portal for Pediatric Chronic Illness

#### Goal

To design and test a computer portal for the families of children with asthma to educate families, track symptoms between visits, and boost communication between the family and their primary care pediatrician.

#### And now...

...hundreds of families and clinicians have used the MyAsthma portal to manage asthma care for pediatric patients. The initiative is supported by over a half million dollars in external funding.

### Assuring Quality and Patient Safety at CHOP Community Pediatric Programs

#### Goal

To define, test, and implement a system to monitor the quality of care in CHOP programs at community hospitals.

#### And now...

...ten of CHOP's affiliated community hospitals have robust metrics to measure quality of care in the Emergency Department, Inpatient General Pediatrics, and Neonatology.

### Improving Hospital Care and Service Delivery For Individuals with Autism Spectrum Disorders

#### Goal

To develop better tools and strategies for care for children with autism in 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.

#### And now...

...there are 27 publications and numerous presentations describing the work by CHOP to screen and identify patients with autism and other developmental issues before healthcare appointments to proactively manage the patient and family experience.

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

#### Goal

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.

#### And now...

...there is the Adult Care at CHOP Program, a clinical consult program for young adults (ages 24 years and older) admitted to CHOP and a young adult transition-focused clinic within an internal medicine practice at the University of Pennsylvania to help facilitate the transition to adult care.

### Minds Matter: Improving Pediatric Concussion Management

#### Goal

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.

#### And now...

...we have an internationally recognized comprehensive program for pediatric concussion, from research to clinical care and patient advocacy, which has received over \$9.5 million dollars in external funding, presented at 55 forums, and authored 19 publications.

### Preventing Outpatient CLABSI

#### Goal

To reduce the at-home incidence of one of the most costly problems in healthcare — central line associated blood stream infections. This 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.

#### And now...

...we attained a 50% decrease in outpatient CLABSI for all CHOP patients while fostering partnerships with external home healthcare agencies to facilitate training in CLABSI prevention techniques for CHOP patients at home.

*continued >*

# IT STARTED WITH A CHAIR'S INITIATIVE

## ROUND 4 (2013-2015)

### COMEDO: A Computerized System to Assess Acne Patients and Develop Appropriate Treatment Recommendations

#### Goal

To develop a smartphone app to standardize the approach to acne evaluation and treatment while ensuring adherence to expert guidelines and improving efficiency.

#### And now...

...dermatologists and computer specialists have developed an app that will help standardize and improve care of adolescents with acne treated by their primary care pediatricians.

### Enhancing Providers' Ability to Respond Effectively to Peer Bullying and Victimization

#### Goal

To develop tools to assist clinicians and educators in the prevention of bullying among children and adolescents.

#### And now...

...over 100,000 patients per year are screened for bullying as part of well-child visits in all primary care sites, Adolescent Medicine, Healthy Weight, and Developmental and Behavioral Pediatrics.

### Thrombosis Prevention and Treatment in Cardiac Patients

#### Goal

To create guidelines and care practices to prevent thrombosis (blood clots) and improve anticoagulant (blood thinner) management for cardiac patients.

#### And now...

...the Cardiac Anticoagulation and Thrombosis Program, a joint cardiology/hematology program, has been developed to standardize the management of cardiac inpatients and outpatients on thrombosis prevention and treatment. The team has consulted on 581 inpatients and follows about 60 outpatients.

### Development and Evaluation of THRIVE (Texting, Health Resources to Inform, Motivate and Engage)

#### Goal

To help adolescents stay engaged and adjust after cancer treatment.

#### And now...

...we have valuable knowledge regarding how a text message intervention can help adolescents and young adults completing cancer treatment stay healthy and adjust to life after cancer.

### Identification, Remediation, and Prevention of a Chronic Glucocorticoid Therapy Adverse Effects

#### Goal

To create guidelines for the safer use of steroids in children through collaboration among rheumatologists, endocrinologists, nephrologists and other experts.

#### And now...

...there is greater standardization regarding the identification and treatment of steroid-induced adrenal insufficiency throughout CHOP. "Pathway for the Child at Risk for HPA Suppression: Stress Steroid Dosing and Weaning Recommendations" is one of the most highly used pathways — over 15,000 views of the clinical pathway, with 90% of views from external (non-CHOP) users.





# THE FUTURE

## ROUND 6 (2017-2019)

### **Comprehensive Cancer Predisposition and Surveillance Program**

#### **Goal**

To increase identification and surveillance of the predisposition to develop childhood cancer due to a heritable germline mutation in order to track, understand and improve outcomes.

### **Community Health Worker Initiative: Enhanced Care Management for Complex Patients**

#### **Goal**

To build evidence and infrastructure for enhanced care management through the development of a generalizable and scalable community health worker role at CHOP.

Four of the initiatives involve the common theme of providing multidisciplinary care for rare diseases. Our goal is to work collaboratively across teams and in partnership with institutional resources/experts to develop a framework and toolkit for needs assessments, program design, implementation, evaluation and outcome measurement.

### **Center for Sepsis Excellence**

#### **Goal**

To leverage existing clinical, research, and quality improvement initiatives, and to establish CHOP as the premier center for treatment of pediatric sepsis.

### **An Integrated Multi-disciplinary Hemophagocytic Syndromes Team of Excellence**

#### **Goal**

To develop a unique, internationally renowned, multidisciplinary team focused on the diagnosis and management of patients with hemophagocytic syndromes (HS).

### **Epidermolysis Bullosa Multidisciplinary Clinic**

#### **Goal**

To provide coordinated, state-of-the art, and family-centered care for patients with epidermolysis bullosa (EB), a rare, inherited blistering disease that leads to skin fragility.

### **Integrating Lupus Care**

#### **Goal**

To engage a CHOP Integrated Lupus Team to support patients with pediatric systemic lupus erythematosus (pSLE) and their caregivers to improve the value of pSLE healthcare delivery.

# BOOST BRILLIANCE

The Chair's Initiatives is an internal grant program at Children's Hospital of Philadelphia. It funds multidisciplinary teams 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 [giving.chop.edu](https://giving.chop.edu).

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Every day, teams at Children's Hospital of Philadelphia make breakthroughs that transform children's lives. Since our founding in 1855 as the nation's first children's hospital, we have made extraordinary discoveries, trained generations of leaders, and advocated for children everywhere. Our pediatric research program, one of the largest in the country, has set a new standard for scientific innovation around the world. As a nonprofit charitable organization, we rely on the generous support of donors who are inspired by our work — and our mission.

