# ELEVATING CARE

THE CHAIR'S INITIATIVES OF THE DEPARTMENT OF PEDIATRICS



#### ROUND 6 2017-2019



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The Chair's Initiatives is an internal grant program of the Department of Pediatrics at Children's Hospital of Philadelphia (CHOP) known for coalescing teams of doctors, nurses, social workers, scientists, computer programmers, administrators and many others to solve problems and improve care.

Since 2006, more than 45 teams have been awarded Chair's Initiatives grants, and gone on to improve outcomes and broaden impact at CHOP and beyond.

Round 6 (2017-2019) Initiatives tackle some of the most complex pediatric diseases, making a meaningful and lasting difference for children and families living with challenging diagnoses.

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#### CHAIR'S INITIATIVES: PEOPLE

Founded by: Alan Cohen, MD, then Physician-in-Chief and Chair, Department of Pediatrics, and Alison Marx, MBA, Vice Chair, Administration, Department of Pediatrics

Continues under: Joseph W. St. Geme III, MD, Chairman, Department of Pediatrics, and Physician-in-Chief

With oversight team: Maryann Chilkatowsky, MBA, Business Manager, Physician Practice, Kathy Shaw, MD, MSCE, Associate Chair, Quality and Safety, Alison Marx, MBA, and April Taylor, MS, MHA, CPP, Senior Director, Improvement and Project Management



"In a short time, we have grown into an internationally recognized program. We're helping children who are critically ill and those who are diagnostic dilemmas. We're making novel observations in research. And we're providing a unique training experience for students, residents, and fellows. We could not have done any of this without the support of the Chair's Initiatives."

- David T. Teachey, MD



### **ELEVATING CARE FOR CHILDREN WITH IMMUNE DYSREGULATION:** Hemophagocytic Syndromes Team

When it's working correctly, the immune system helps fight illness. But for children with hemophagocytic syndromes and other immune dysregulation disorders, the immune system malfunctions. It may be overactive, causing dangerous inflammation and organ damage, or underactive, leaving the child vulnerable to infection.

The disorders are rare, complex and difficult to diagnose, and they can be fatal. Sometimes children suffer for years with baffling, painful symptoms – and no answers.



An expert team, including immunologists, oncologists, rheumatologists, hematologists, neurologists, pathologists, clinical pharmacologists and basic scientists, meets once a week to discuss cases and map care together.



There is an outpatient clinic where patients with immune dysregulation or baffling symptoms see the team of experts.



There is an inpatient consult service so physicians throughout CHOP can call upon the team for guidance when they suspect immune dysregulation in patients.



The team established clear guidelines, available across the institution, for recognizing



There is a growing biorepository of samples from children with immune dysregulation, to inform research for better diagnostic tools and treatments.



The team has shared their findings with colleagues around the country and the world through lectures and other outreach, improving care for children far beyond CHOP.

However, if the disorders are diagnosed accurately and quickly, children can be successfully treated and even cured.

Supported by a Chair's Initiatives grant, a team of physicians from different specialties set out to establish a leading program for immune dysregulation disorders in children.

immune dysregulation, testing, treatment and other important steps in care.

chop.edu/round6.

### ELEVATING CARE FOR A DANGEROUS INFECTION: Pediatric Sepsis Program

Sepsis is a life-threatening infection that requires immediate care. Children with sepsis are often critically ill, requiring emergency treatment and sometimes admission to a pediatric or neonatal intensive care unit.

Sepsis occurs when the body's immune system goes into overdrive fighting an infection, and creates a chain reaction in the body. The body's inflammatory response can lead to organ failure and shock. Sepsis can result in loss of limbs, and life.

In pediatric sepsis, "Recognize, Survive, Thrive" is a mantra. It is crucial that healthcare teams recognize sepsis quickly. Once the diagnosis is made, an incredible level of care is required if the child is to not only survive, but also thrive.

With Chair's Initiatives funding, a team with emergency room and intensive care expertise built a program that has become an international leader in sepsis research and care.

## NOW



An electronic screening system for sepsis, developed by CHOP's Emergency Department, is used in several community sites through a partnership with the Hospital Association of Pennsylvania.



CHOP has the first comprehensive program dedicated to clinical care, quality improvement, education and research around pediatric sepsis.



CHOP has a dedicated follow-up program for survivors of pediatric sepsis. Patients are screened for long-term problems related to sepsis and families get the assistance they need to help their children thrive.



The sepsis team has developed an electronic surveillance algorithm, in collaboration with ARCUS, that allows tracking of epidemiologic trends across the institution. They hope to build an associated biorepository to help researchers learn about sepsis biology and, ultimately, tailor therapies.

To view the poster presentation for this program, please visit **chop.edu/round6**.

"We are incredibly proud to have built the first comprehensive program dedicated to improving pediatric sepsis care and outcomes. Chair's Initiatives support was instrumental in allowing us to build the groundwork for what we hope is a model program not only for patients at CHOP, but across the country and world."

– Fran Balamuth, MD, PhD





"Support from the Chair's Initiatives has been transformational. It began with an idea to design a multidisciplinary care model from scratch to better serve patients burdened with a severe disease and fragmented care. We now have strong partnerships between specialists in rheumatology and nephrology and a growing combined clinic. And after building a strong data infrastructure, we can now support quality improvement and research efficiently. We look forward to the next phases of our program and are incredibly grateful for the support." - Sandy Burnham, MD

Isabella, 11, a child with lupus

## **ELEVATING CARE** FOR YOUNG PEOPLE WITH LUPUS

Systemic lupus erythematosus is an autoimmune disorder that can cause inflammation and organ damage. In pediatrics, the disease most commonly affects females in their teens.

Lupus patients may suffer rashes, hair loss, nerve dysfunction, joint pain and fatigue. The disease can damage the heart, lungs, brain and kidneys – some patients end up in kidney failure. Lupus is known among doctors as a disease that is life-altering and



There is a new care index to keep track of whether each patient is well-managed or at-risk, based on factors such as medications, vaccinations and doctor visits.

There is a social worker at CHOP dedicated to patients with lupus.



There are new tools within CHOP's electronic health record system to help care teams plan before a visit by a patient with lupus.



There is a specialized clinic where lupus patients with kidney disease can see a rheumatologist, nephrologist, psychologist, social worker and others all on the same day.



There is a new method for collecting data about lupus patients, to inform research for better treatments.



and community partners.

To view the poster presentation for this program, please visit **chop.edu/round6**.

#### Integrating Care for Systemic Lupus Erythematosus

- difficult to manage: It has periods of flare-ups and remissions. It can be fatal. It is difficult to diagnose, and has no cure.
- With Chair's Initiatives funding, a team of rheumatologists, nephrologists, psychologists, social workers and others began an effort to closely examine how lupus care is delivered and to put systems in place to improve quality of care and patient outcomes.

- There is a Lupus Advisory Council that includes CHOP stakeholders, former patients, parents,

## ELEVATING CARE FOR DIABETES:

Social Risk-focused Community Health Worker Type 1 diabetes is a serious, even life-threatening diagnosis. The Diabetes Center at Children's Hospital of Philadelphia helps thousands of patients and families manage the disease.

Often, families with lower socioeconomic status or from vulnerable populations face circumstances so complex and stressful that they struggle to manage their child's illness. This can result in frequent emergency room visits, increased hospitalizations and higher complication rates.

A team of doctors, nurses and social workers decided there was a better way to help. Supported by a Chair's Initiatives grant, they added community health workers to their team – nonmedical staff who understand families' complex circumstances and can resolve housing, insurance, literacy and other challenges that affect children's health.

## NOW

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There are several community health workers on the diabetes team, visiting families at home. More than 80% of families asked to participate agreed.



A randomized trial is underway to measure how the program affects the health of children. Early results show a positive effect on hemoglobin Alc, a measure of diabetes control.



After community health workers identified social isolation as a challenge that families face, the team began holding community support group events. More than 60 families regularly attend.



The diabetes community health worker program was expanded to include newly diagnosed patients, patients who have long hospital stays, and patients at CHOP's satellite location in Lancaster, Pa. There is a plan to expand to type 2 diabetes patients.

There are training materials and other tools to help other areas of the hospital set up community health worker programs.

To view the poster presentation for this program, please visit **chop.edu/round6**.



"The Chair's Initiative empowered us to pilot an intervention that has grown into one of the most important programs in our Diabetes Center. With community health workers, we have reached families that we have previously not been able to engage and added a dimension of understanding and support that we cannot ever provide in a traditional appointment. The advice and support that we received from the Chair's Initiative team in developing this program was central to our success."

- Colin P. Hawkes, MD, MEd, PhD



"The Chair's Initiative allowed us to bring a concept to reality: a state-of-the art, family-centered clinic providing care for patients nationally and internationally. Opportunities through the Initiative included working in a 'think tank' setting with disciplines and entrepreneurs from across CHOP. One of the most enjoyable aspects was meeting bimonthly with other Chair's programs and learning from their challenges and successes. It was a fantastic experience and opened my eyes to CHOP's vast support system for building specialized programs."

Marissa Perman, MD

## ELEVATING CARE FOR A PAINFUL DISEASE:

#### Epidermolysis Bullosa Multidisciplinary Clinic

Epidermolysis bullosa (EB) is a rare and devastating disease that causes blistering of the skin and, sometimes, internal organs. There is no cure for EB.

Because of the blistering, children with EB experience terrible pain and itching, and can become anemic from blood loss. Their vocal chords and esophagus may become scarred, affecting the ability to breathe and swallow. Involvement of the gastrointestinal (GI) tract can cause GI and growth issues. Fingers and toes may fuse because of chronic wounds. Children with EB are at high risk for infection and skin cancer.

With Chair's Initiatives funding, dermatologist Marissa Perman, MD, built a team and program to elevate care for this vulnerable group of children and families.



"It's comforting to know you can go and reach out to them, and they can help any situation you're dealing with." - Tonetta, mother of Wilbur

NOW



There is a coordinated, family-centered EB interdisciplinary clinic. In one visit, patients see a slate of experts, including a dermatologist and wound care nurse practitioner, a gastroenterologist and nutritionist, a psychologist, a pain management specialist, a social worker, and physical and occupational therapists. Child life is present to support the families and patients through the extended clinic. They may also see surgeons, hematologists, and others in coordination with their EB clinic visit.



There is a new research coordinator to help enroll patients with EB in research trials, to find new ways to improve wound care and other aspects of EB care.

There is an annual EB Family Fun Day, where patients and families who often feel isolated and overwhelmed can relax and share experiences.



The team has approximately 100 patients, from as far away as Saudi Arabia.

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To view the poster presentation for this program, please visit **chop.edu/round6**.

## **ELEVATING** CARE FOR **CHILDREN** AT RISK FOR CANCER:

Cancer Surveillance Database

About 16,000 children younger than age 20 are diagnosed with cancer every year in the United States. Researchers estimate at least 10 percent of childhood cancer cases have a hereditary basis.

Identifying and monitoring children at risk for cancer through carefully planned screenings and care can improve their chances for survival. Siblings and other family members who may be at risk also benefit.

CHOP has had a leading program for children predisposed to cancer since 2005. With Chair's Initiatives funding, the team undertook several efforts to add depth and precision to the ability to identify and monitor at-risk children, and improve their outcomes.



to cancer, to inform their care and support efforts to better identify others in the future.

There is a database with information about every patient across CHOP with a predisposition



to inform research and create better diagnostic tools and treatments.

There is a biorepository of blood and tumor samples from at-risk children and families,



Every doctor and clinician across CHOP has access to the most up-to-date guidelines on how to identify children and families at hereditary risk for cancer.



There is a monthly clinic at which children predisposed to gastrointestinal cancers see a specialized team of oncologists and gastroenterologists for assessment and screening.



With better identification and awareness across the enterprise, volumes have grown for the Cancer Predisposition Program, as well as programs for children with diagnoses, such as Beckwith-Wiedemann syndrome and neurofibromatitis, that carry an increased risk for cancer.

To view the poster presentation for this program, please visit chop.edu/round6.

"The Chair's Initiative has allowed us to jumpstart our program by garnering additional support from Hospital and extramural sources to dramatically expand. We now have one of the largest and most comprehensive Cancer Predisposition Programs in the country, with expertise to manage virtually any known syndrome. We are focused on discovering new genes, developing enhanced surveillance methods, and eventually testing cancer prevention strategies in these high-risk individuals." Garrett Brodeur, MD



Alivya, 3, a Beckwith-Wiedemann syndrome patient, with her mother, McKenzie

#### CHAIR'S INITIATIVES PAST AND FUTURE: 2006 - 2021

#### ROUND1(2006-2008)

#### Access Nurse Advisor

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

Referring Physician Communication and Care Coordination

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

*Automated Appointment Reminders* To reduce the frequency of missed appointments.

*Center for Bone Health* To improve care for children with bone health concerns.

#### Center for Pediatric Eosinophilic Disorders

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

#### ADHD in Primary Care

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

Multidisciplinary Cancer Survivorship Program

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

#### Office of Fellowship Training

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.

#### Pediatric Knowledgebase

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.

*Sudden Cardiac Death Prevention* To prevent sudden cardiac death in children and adolescents.

#### ROUND 2 (2009-2011)

#### Chemotherapy Tracking System

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.

#### Intestinal Rehabilitation Program

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

From Knowledge to Practice: Developing the Infrastructure to Create and Implement Collaborative Clinical Pathways To incorporate evidence, best practice, and local expert consensus into easily accessible, shared models for use by clinical teams.

Anticoagulant Management Program To improve monitoring and care for children taking anticoagulants.

#### Unit-based Patient Safety Walk Rounds

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

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

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

#### ROUND 3 (2011-2013)

A Shared Decision-making Portal for Pediatric Chronic Illness 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.

Assuring Quality and Patient Safety at CHOP Community Pediatric Programs

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

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

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

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

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. *Minds Matter: Improving Pediatric Concussion Management* To improve care for children and adolescents by creating tools to standardize management of concussion in the CHOP Care Networ and to educate parents and patients.

#### Preventing Outpatient CLABSI

To reduce the at-home incidence of one of the most costly problem in healthcare – central line-associated bloodstream infections.

#### ROUND 4 (2013-2015)

COMEDO: A Computerized System to Assess Acne Patients and Develop Appropriate Treatment Recommendations To develop a smartphone app to standardize the approach to acne evaluation and treatment while ensuring adherence to expert guidelines and improving efficiency.

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

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

Thrombosis Prevention and Treatment in Cardiac Patients To create guidelines and care practices to prevent thrombosis (blood clots) and improve anticoagulant (blood thinner) management for cardiac patients.

Development and Evaluation of THRIVE (Texting, Health Resources to Inform, Motivate and Engage) To help adolescents stay engaged and adjust after cancer treatmen

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

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

#### Round 5 (2015-2017)

*Integrating Apps in Pediatric Practice (iApp)* To improve CHOP's ability to create, use and recommend health apps

Leveraging Predictive Analytics and Technology to Decrease Missed Appointments

To find new ways to identify and help families that miss appointments.

#### Fostering Health

To improve coordination of care for children in foster placement.

rk,	<i>Pediatric-to-Adult Medical System Transitions</i> To help those with chronic conditions and intellectual disabilities shift to adult care.
ns	<i>Developing a Hospital-wide Fertility Preservation Program</i> To offer fertility options to patients throughout the hospital.
	<i>An Integrative and Educational Pediatric Genomics Initiative</i> To improve the understanding and use of genetic tests.
	And the Future
	Round 7 (2019-2021)
	Adolescent Mobile Health Unit To bring sexual health services and other important services into youth communities.
	Leveraging the Baldrige Performance Excellence Framework to Embed Evidenced-Based Management Practices in Ambulatory Operations and Improve Patient Access to Care To improve outpatient appointments at CHOP.
	<i>Communicating and Connecting Mental Health Needs of Patients</i> To help children get the mental health services they need.
ıt.	<i>Debriefing – Broken Down and Rebuilt</i> To find new ways to learn and improve after clinical teams experience traumatic events.
gists	<i>Endocrine Late Effects After Cancer Therapy (ELECT) Program</i> To elevate care for childhood cancer survivors who experience endocrine-related effects after treatment.
	<i>Pulmonary and Allergy Problematic Asthma (PAPA) Clinic</i> To personalize and improve care for children with difficult- to-treat asthma.
5.	<i>Doctor-to-Doctor Teledermatology</i> To establish a system for primary care pediatricians and pediatric dermatologists to communicate through telemedicine.

Multidisciplinary Intervention Navigation Team (MINT) for

#### Elevating Care for Pediatric Sepsis

#### **Publications:**

Weiss SL, Balamuth F, Chilutti M, Ramos MJ, McBride P, Kelly NA, Payton KJ, Fitzgerald JC, Pennington JW. **Identification of Pediatric Sepsis for Epidemiologic Surveillance Using Electronic Clinical Data.** *Pediatric Critical Care Medicine*. 2020 Feb;21(2):113-121.

#### Presentations

May 2020: **"Early Recognition Of Pediatric Sepsis In Community Emergency Departments."** Poster Presentation, Pediatric Academic Societies (PAS) 2020 Meeting, Philadelphia, PA (cancelled for COVID). (Theresa Walls, Christopher Valente, Susan Yaeger, Matthew Palilonis, Maggie Miller, Fran Balamuth)

May 2020: **"Implementing an Electronic Sepsis Alert in a Community Pediatric Emergency Department."** Poster Presentation, Pediatric Academic Societies (PAS) 2020 Meeting, Philadelphia, PA (cancelled). (Ron Marchese, Rawahuddin Naseem, Bobbie Hawkins, Fran Balamuth)

February 2019: **"Sepsis huddles in the PICU: Understanding the impact on timely antibiotics, perceptions, and barriers."** Research Presentation at the 48th Society of Critical Care Medicine Annual Congress, San Diego, CA. (Chiotos K, Biedron L, Fitzgerald J, Robbins-Tighe S, Weiss SL, Woods-Hill C)

February 2019: **"Targeting vasoactives to warm versus cold pediatric septic shock."** Research Presentation at the 48th Society of Critical Care Medicine Annual Congress, San Diego, CA. (Walker S, Conlon T, Zhang B, Mensinger J, Fitzgerald J, Himebauch A, Glau C, Nishisaki A, Ranjit S, Nadkarni V, Weiss SL)

#### Elevating Care for Young People with Lupus

#### Presentations

March 2018: **"Pediatric Systemic Lupus Erythematosus for the General Pediatrician."** Hasbro Children's Hospital Pediatric Grand Rounds, Providence, Rhode Island. (Burnham)

July 2019: **"Quality Improvement in Pediatric Rheumatology: A Path to Improved Outcomes."** Boston Children's Hospital Rheumatology Grand Rounds, Boston, Massachusetts. (Burnham) September 2019: **"Quality Improvement in Pediatric Rheumatology: A Path to Improved Outcomes."** Pediatric Rheumatology Academic Half-Day Rounds. Hospital for Sick Children, Toronto, Canada. (Burnham)

October 2019: **"Improving the Quality of Care in Pediatric Lupus."** Pediatric Rheumatology Care & Outcomes Improvement Network Learning Session, Cincinnati, Ohio. (Burnham)

January 2020: **"Clinical Care of Children with Lupus."** Nephrology Grand Rounds. Children's Hospital of Philadelphia, Philadelphia, Pennsylvania. (Chang)

November 2020: **"Determinants of Variation in Pediatric Systemic Lupus Erythematosus Care Delivery."** American College of Rheumatology Annual Scientific Conference, virtual. (submitted)

#### Abstracts

**Lupus Care at CHOP: A Path to Improved Outcomes.** CHOP Quality & Safety Day. May, 2019.

#### Elevating Care for Children with Type 1 Diabetes

#### **Publications**

Lipman TH, Smith JA, Hawkes CP. **Community health workers and the care of children with type 1 diabetes.** *Journal of Pediatric Nursing.* 2019;49:111-112. PMID 31669494.

Lai CW, Hawkes CP, Lipman TH. **COVID-19 is worsening disparities in pediatric type 1 diabetes** – **expert opinion**. Philadelphia Inquirer, May 2020.

#### Presentations

October 2019: **"Community health workers improve outcomes in high-risk children with type 1 diabetes."** International Society for Pediatric and Adolescent Diabetes, Boston. (Hawkes CP)

August 2019: **"Care of children with diabetes and their families: Impact of community health workers."** International Family Nursing Conference, Washington DC. (Lipman TH, Wilson CL, Tuttle A, Morone J, Hawkes CP)

November 2018: **"Community Health Worker Initiative: Enhanced care management for complex patients."** Anchor Institutions Task Force, New York. (Lipman TH, Marx A, Hawkes CP)

#### Grants

Leonard Davis Institute of Health Economics: A \$20,000 grant to assess the impact of Community Health Workers in children with newly diagnosed type 1 diabetes

University of Pennsylvania School of Nursing: A \$10,000 grant to support the Diabetes Community Health Worker Program

#### Elevating Care for Children with Epidermolysis Bullosa

#### Presentations

February 2020: "**Innovative Approaches to Developing a Successful Multi-disciplinary Clinic.**" Children's Hospital of Philadelphia. (Perman & Wohl)

#### Grants

A \$39,000 grant from the EB Clinical Research Consortium to study pain catastrophizing and functional disability in pediatric epidermolysis bullosa patients and their caregivers

### Elevating Care for Children at Risk for Cancer

#### **Publications**

MacFarland SP, Zelley K, Surrey LF, Gallo D, Luo M, Raman P, Wertheim G, Hunger SP, Li MM, Brodeur GM. **Pediatric Somatic Tumor Sequencing Identifies Underlying Cancer Predisposition**. *JCO Precision Oncol*. 3: DOI: 10.1200/ PO.19.00062, Dec 2019.

#### Chair's Initiatives: ROUND 6 TEAM MEMBERS

**Elevating Care for Children with Immune Dysregulation**: *Hemophagocytic Syndromes Team* 

David Teachey, MD, Ed Behrens, MD, Kathleen Sullivan, MD, PhD, Anne Reilly, MD, MPH, Brian Fisher, DO, MPH, MSCE

#### **Elevating Care for a Dangerous Infection:** *Pediatric Sepsis*

Fran Balamuth, MD, PhD, Julie Fitzgerald, MD, PhD, Scott Weiss, MD, MSCE

#### **Elevating Care for Young People with Lupus:** *Integrating Care for Systemic Lupus Erthymatosus*

Sandy Burnham, MD, MSCE, Andrea Knight, MD, MSCE, Kevin Meyers, MBBCh, Joyce Chang, MD, MSCE, Madhura Pradhan, MD, MBBS, Stephanie Clark, MD, MPH, MSHP, Shobha Natarajan, MD, Matt Elias, MD, Jennifer Sherker, PsyD, Sheila Quinn, DO, Joy Ukaigwe, MS, Lynsey Cecere, MPA, David Rubin, MD, MSCE MacFarland SP, Duffy KA, Bhatti TR, Bagatell R, Balamuth NJ, Brodeur GM, Ganguly A, Mattei PA, Surrey LF, Balis FM, Kalish JM. **Diagnosis of Beckwith-Wiedemann Syndrome in Children Presenting with Wilms Tumor.** *Pediatr Blood Cancer.* 65(10): e27296, Oct 2018.

MacFarland SP, Mostoufi-Moab S, Zelley K, Mattei PA, States LJ, Bhatti TR, Duffy KA, Brodeur GM, Kalish JM. **Management of adrenal masses in patients with Beckwith-Wiedemann syndrome.** Pediatric Blood and Cancer. 00: e26432, January 2017.

MacFarland SP, Zelley K, Long JM, McKenna D, Mamula P, Domchek SM, Nathanson KL, Brodeur GM, Rustgi AK, Katona BW, Maxwell KN. **Earlier Colorectal Cancer Screening May Be Necessary In Patients With Li-Fraumeni Syndrome**. *Gastroenterology*. 156(1): 273-274, Jan 2019.

#### Grants

St. Baldrick's Foundation: A \$487,000 grant from 2020-2025 for the Childhood Cancer Predisposition Study (CCPS)

Alex's Lemonade Stand Foundation: A \$214,000 grant for a study called Impact of Germline Testing in a Pediatric Cancer Predisposition Clinic

#### **Elevating Care for Children with Diabetes:** Social Risk-focused Community Health Worker

Colin Hawkes, MD, MEd, PhD, Terri Lipman, PhD, CRNP, Alan Tuttle, MSW, LCSW, Jennifer Smith, MPH, Tawana Casey, Karen Huskey

#### **Elevating Care for a Painful Disease:** *Epidermolysis Bullosa Multidisciplinary Clinic*

Marissa Perman, MD, Judith Stellar, CRNP, Elizabeth Maxwell, MD, Lydia Rawlins, MEd, OTR/L, Kerri Recker, MOT, OTR/L, Colleen Macner, PT, DPT, Jessica Collins, PsyD, Leslie Castelo-Soccio, MD, PhD, F. Wickham Kraemer, MD, Christi Strawley, MSN, CRNP, FNP-C, Colleen Vicente, RD, LD, CNSC

**Elevating Care for Children at Risk for Cancer**: *Cancer Surveillance Database* 

Garrett Brodeur, MD, Jennifer Kalish, MD, PhD, Suzanna MacFarland, MD, Kristin Zelley, MS, LCGC

#### HELP US ELEVATE CARE

For information about how to support the Chair's Initiatives, please contact Robyn Lorfink at **lorfinkr@chop.edu**. With donor support, we can make an even bigger difference.

## Children's Hospital of Philadelphia

