

SUMMER 2017

Pediatric

PERSPECTIVES

ADVANCING PATIENT CARE SERVICES AT ST. LOUIS CHILDREN'S HOSPITAL



**Respiratory care protocol
addresses chronic lung disease**

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ON THE Cover

Name, title caption to come
See story on page 6.

SUMMER 2017

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From Peggy

Pediatric population health

What is it and what is SLCH doing about it?

pulmonary disease or heart failure. However, the concept of population health begins with children. If we do a good job of keeping kids healthy, they are more likely to grow up to become healthy adults and ultimately will require less costly care as they age.

In this issue of *Pediatric Perspectives*, you will read about some of the work being done here to promote the health of children in our community. Many of you are familiar with our Healthy Kids Express vans that deliver screening, asthma care and dental care at numerous schools and community settings. These vans have been a core part of our community outreach program for many years. Currently we are also working with the St. Louis Public School system to develop a program that will place nurses and educational support counselors (social workers) in four St. Louis City Schools starting this summer.

Another new initiative in the child population health area is a program started by BJC called Raising St. Louis, which has now been transitioned over to our Child Advocacy and Outreach (CHAO) team for management. Raising St. Louis enrolls mothers from zip codes in our area with the highest risk for infant mortality and health disparities during pregnancy. The program provides home-based support for them from birth to age 8. The goal is to have children reach third grade healthy and reading at grade level. The in-home support is provided through a partnership with Nurses for Newborns and Parents as Teachers, two well-respected community-based programs.

Population health is a term that became popular following the passage of the Affordable Care Act. The goals of population health are to develop strategies to keep people well, provide an excellent health care experience and to reduce the overall cost of health care. In delivering population health, accountability and risk shifts to health care providers, rather than insurance companies. The major focus thus far has been in the adult population, and particularly adults with chronic conditions like diabetes, chronic

pulmonary disease or heart failure. However, the concept of population health begins with children. If we do a good job of keeping kids healthy, they are more likely to grow up to become healthy adults and ultimately will require less costly care as they age.

Other efforts aimed at community and population health are less far along, and we will report on those in future issues. Some involve more school-based health initiatives, and some involve expansion of community mental health resources for children and youth. While there is much that still needs to be done, you can be assured that SLCH is at the forefront of population health for children in the St. Louis region. ●

Peggy

Peggy Gordin, MS, RN, NEA-BC, FAAN, is SLCH's Vice President of Patient Care Services. She can be reached at Peggy.Gordin@bjc.org.

“The concept of population health begins with children. If we do a good job of keeping kids healthy, they are more likely to grow up to become healthy adults and ultimately will require less costly care as they age.”

– Peggy Gordin



An SLCH therapy dog visits oncology patient Bryor Lacey and Amy Monohan, MSN, RN.

Donor-funded programs help children emotionally, not just medically. These programs include the **Clown Docs, music and art therapy, therapy dogs, and Child Life Services**. Children also need distractions from stressful treatments. They need treatments explained in a way they can understand. When little Grace, a 10-year-old battling cancer, received a bald American Girl doll from her favorite Child Life Services provider, she was better able to cope with losing her hair. And when Caysen, a 3-year-old waiting in the hospital for a heart transplant, showed signs of depression, his caregivers arranged a trip to the Saint Louis Zoo for him and his family. The outing lifted his spirits and strengthened his resolve to fight for his right to a healthy childhood.

Donations fund programs and services that benefit kids medically, emotionally

the **SLCH Foundation** enlists the support of generous donors to help ensure a bright, healthy childhood for every child. Donors know they are making a meaningful investment in expert pediatric care, impactful advocacy and outreach, and research to understand diseases that threaten to rob children of their chance to be kids.

Enhancing the patient experience

Physicians, nurses, staff, and volunteers stand by the families they serve with expert pediatric care. The Foundation helps them help patients by funding such programs as the Family Care Fund and by ensuring every child in need is treated regardless of a family's ability to pay.

Expanding community outreach

Access to preventive medicine should not depend on geographical location. To this end, donors support the **Healthy Kids Express** effort. These specially equipped and staffed vans roll through underserved communities delivering asthma and dental care, plus vision and hearing screening. School sites are chosen based on risk factors such as the percentage of children on free/reduced lunches, nurse-to-pupil ratio, distance to federally qualified health centers and health information per ZIP code.

The donor-funded **Victims of Violence** outreach program grew out of a pilot study showing that mentoring young victims of violence in ways to avert another attack reduced the likelihood of a repeat visit to the emergency department. After being assaulted by several classmates at her high school, Erica, age 17, was treated in the SLCH Emergency Department. She suffered a concussion and injuries to her eye and back.

Genai Houser, one of the Victims of Violence Program's social workers, became Erica's mentor. Houser worked to gain Erica's trust, meeting with her regularly at a safe spot near Erica's home or school in a neighborhood much like Houser's own as a child. "You can almost become numb to the violent acts you see every day," Houser says. "Most of the kids we work with think of it as a normal part of life. Our challenge is to help them understand that it isn't, and that there are actions they can personally take to avoid the escalation of violence and keep themselves safe."

Still grieving after the shooting death of her father, Erica slowly began opening up. Houser helped her process her loss and move beyond past conflicts. Because Erica was resistant to returning to school, Houser

“You can almost become numb to the violent acts you see every day. Most of the kids we work with think of it as a normal part of life. Our challenge is to help them understand that it isn't, and that there are actions they can personally take to avoid the escalation of violence and keep themselves safe.”

– Genai Houser, social worker, Victims of Violence

encouraged her to get her General Education Diploma (GED) and pursue training to be a medical assistant. "I'm not an easy person to know," Erica says. "I don't trust a lot of people. But Ms. Houser never gave up on me."

Funding innovative research

In 2006 SLCH and Washington University School of Medicine became partners in addressing the disparity between public funding for adult disease and that for childhood disease. The resulting **Children's Discovery Institute** has awarded more than \$50 million in seed funding for physician/scientists throughout the Washington University campus interested in pediatric research. Findings from the 171 research grants awarded have generated more than \$222 million in funding from external sources such as the NIH.

The Institute creates innovative collaborations among expert scientists to strive for breakthroughs in pediatric medicine. Researchers seek ways to enlist a child's immune system to fight cancer. They collaborate on studies to learn how congenital heart disease, lung diseases, and metabolic disorders develop.

Precision medicine holds promise for sparking innovation and deepening the understanding of childhood disease for decades to come. The National Institutes for Health defines precision medicine as an emerging approach for disease treatment and prevention that considers individual variability in genes, environment, and lifestyle for each person. This approach will allow doctors and researchers to predict more accurately which treatment and prevention strategies for a disease will work in which groups of people. It contrasts with a "one-size-fits-all" approach.

For example, researchers **Todd Fehniger, MD, PhD**, and co-investigators **Jeffrey Bednarski, MD, PhD**, and **Rizwan Romee, MD**, will conduct a personalized clinical trial to determine whether a cellular immunotherapy strategy shown to be promising in adults will be effective in children. This treatment uses a type of white blood cell called "natural killer" cells, which can be trained and activated in the lab and unleashed to destroy leukemia cells in the patient. ●



Clown Docs

out of the hospital, into our neighborhoods

Healthy Kids Express



Asthma coaching improves health outcomes

Asthma afflicts about 20 percent of children in St. Louis, accounting for about 15 million missed school days each year. **SLCH's Child Health Advocacy and Outreach Department** uses asthma coaches to help address this problem by working with children in three distinct settings: Washington University's Severe Asthma Clinic for Kids, hospital units (inpatient), and in schools (outpatient) through a mobile program. Nurses and physicians in these settings refer families who meet criteria to the asthma coaching program.



Yulanda Tomlin-Watson, left, and Charis Johnson serve as asthma coaches for Healthy Kids Express.

asthma coaching leads to improved health outcomes by helping families control their child's asthma. Asthma coaches address medical factors by:

- Providing education on inhaler use
- Identifying warning signs of asthma
- Understanding the child's Asthma Action Plan (AAP)
- Acting as a liaison with the child's doctor by attending appointments

In collaboration with social workers, asthma coaches go beyond health care and health education and work toward mitigating social factors. They help coordinate with housing, utilities, transportation, insurance, medication delivery, clothing, and food.

At Severe Asthma Clinic for Kids, asthma coaches help primarily with medical factors. In the inpatient and outpatient settings, asthma coaches help with both medical and social factors.

To measure success, asthma coaches set goals when they begin working with families. Examples of goals include:

- Reading an asthma education booklet
- Keeping medications organized
- Refilling and using medications as prescribed
- Monitoring symptoms/albuterol use
- Making the child's Asthma Action Plan available to all caregivers
- Speaking with school staff about the child's asthma
- Scheduling pulmonary appointments

Asthma coach patients are enrolled for an average of 12 to 18 months. Since 2013, of the 37 asthma coach patients who graduated or were discharged from the program, 97 percent reached a goal.

When asthma is controlled, it improves school attendance, which can lead to educational success. One limitation for some patients is the lack of specific school absenteeism data to better link asthma coaching to school outcomes, and work is being done to make that data available. ●

For more information contact
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Since 2013, of the 37 asthma coach patients who graduated or were discharged from the program, 97 percent reached a goal.



Kristin Anderson, RRT, NPS, led a team to develop a pediatric respiratory care protocol.

Respiratory care protocol addresses chronic lung disease

Respiratory therapist-driven protocols have been widely used for the adult patient population since the 1990s. Most institutions have adopted these protocols as standard of care based on evidence-based medicine. In newborn medicine and pediatrics, these protocols have been slower to develop. This is due to the varying patient population (age, weight, numerous differing disease process). Therapist-driven protocols in the neonatal and pediatric populations are now being formed.

Two protocols have been created and implemented at St. Louis Children's Hospital. One began approximately two years ago by **Kristin Anderson, RRT, NPS**. She set out to develop a protocol for the use of heated humidified high-flow nasal cannula therapy (HFNC). High-flow nasal cannula has become a widely used tool for patients in intensive care units. Initially, HFNC was used as a mode of support in premature neonates. The success in this patient population fostered the use of this device as a mode of support for pediatric patients with respiratory distress. (Heated and humidified gases create comfort and flows that meet or exceed the patient's inspiratory flow demands.) Numerous published observational studies propose that the use of HFNC can decrease the work of breathing, decrease the need for intubation and improve ventilation in newborn and pediatric patients with respiratory distress.

With the increased use of this protocol at SLCH, there has been a wide range of practitioner views on the procedures for initiation and

weaning from HFNC. Historically, patients on HFNC have flow rates weaned based on daily orders. This led to increased time in the ICU and overall lengths of stay.

Anderson worked with stakeholders including the medical directors of all three intensive care units. They developed a weight-based protocol that would span the varying patient population in the Newborn ICU, Pediatric ICU and Heart Center. The protocol guides the therapist to the appropriate starting flow rate and fraction of inspired oxygen.. It also allows for the respiratory therapist to increase or decrease the flow rate

based upon clinical factors through every four-hour assessment leading to possible discontinuation. Once an order is placed to wean per protocol, the therapist will assess and possibly wean every four hours. Once a change has been made, the therapist will follow up with re-assessments to ensure patient stability. Communication with the care team occurs and is a critical part of the protocol to ensure success. The protocol also provides guidance for the RT on when to increase respiratory support for the patient. This allows for quicker response to weaning or increased support as needed.

The protocol was implemented in all three intensive care units in December 2016. New data will be compared to data prior to implementation of the protocol to assess patient outcomes. The goal is to determine if this protocol can help decrease the rate of chronic lung disease in neonates as well as decrease the length of stay in the ICU for the pediatric patient with respiratory insufficiency. ●



The success in this patient population fostered the use of this device as a mode of support for pediatric patients with respiratory distress. A major benefit of heated and humidified gases allows for comfort and flows that meet or exceed the patient's inspiratory flow demands.



Shan'Neco Fennoy,
manager, Raising St. Louis

Raising St. Louis

a collaborative approach to nurture healthy childhoods

High infant mortality rates disproportionately affect the St. Louis region. The infant mortality rate is the number of deaths of children under age one per 1,000 live births. In 2013, St. Louis City had a staggering rate of 11.2, compared to 7.3 for all of Missouri; the nationwide objective is to reduce the rate to 6.0 by 2020.

Infant mortality determinants are complex. Underlying factors include: health care access, nutrition, housing and neighborhood conditions, transportation, education, and income. These factors can contribute to babies being born prematurely, being underweight, or not reaching their first birthday at all. Inequalities in the social determinants of health are accelerated by the challenges families face in navigating the complicated health care system. Capable moms and dads, with the best interest at heart for their child, often need support to find resources during and after pregnancy.

In 2014, **Raising St. Louis** was created. The goal is for all children born in St. Louis City to be healthy and reading at grade level by third grade. Raising St. Louis is a collaboration of two home visitation programs, Nurses for Newborns (NFN) and Parents as Teachers (PAT). The agencies work with families during prenatal months and early childhood years to establish a healthy base for children to start their lives. Core program aspects include: evidence-based at-home screenings and care, support groups, father engagement, and resource and service referrals.

Early outcomes are promising:

- 62 babies were delivered during the first two years of implementation.

By the end of the second year:

- 85 percent of all births were carried to full term.
- 82 percent were delivered at a normal birth weight.

Results indicate that longer program exposure may lead to more favorable birth outcomes:

- 100 percent of moms who enrolled during their first trimester carried to full term and delivered at a normal birth weight.
- 84 percent of those enrolled during the second trimester carried to full term and at a normal birth weight.
- For moms enrolled during the third trimester, 93 percent reached full term and 86 percent delivered at a normal birth weight.
- 71 percent of moms reported receiving adequate prenatal care by the end of year two.

Stress and Depression

Moms are also screened with the Everyday Stressors Index and the Edinburgh Postnatal Depression Scale. These tools help identify moms who may benefit from help navigating resource options for coping with stress and depression before it starts to dramatically affect their child or their overall quality of life.

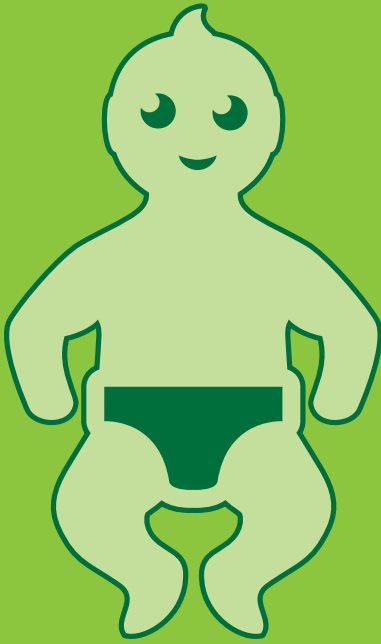
- 49 percent of moms reported excessively high stress levels while prenatal.
- 40 percent of moms reported excessively high stress levels while postnatal.
- 16 percent of postnatal moms scored as depressed or severely depressed at the end of year two.

No child health indicator assessments during the first two years of implementation indicated concern for potential developmental delays or socio-emotional concerns for any child.

Raising St. Louis is doing its part to contribute to the hospital's mission of doing what's right for kids. The program is expected to serve and empower an additional 50 families in 2017. ●

For more information, contact
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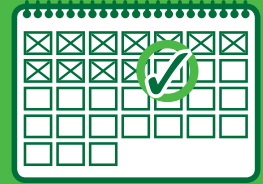
Promising Outcomes



During first
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62

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Early Program Exposure

moms enrolled during first trimester

100%

full term & normal birth weight

moms enrolled during second trimester

84%

full term & normal birth weight

moms enrolled during third trimester

93% | 84%

full term normal birth weight





PET
scans

pet
therapy

The mission of St. Louis Children's Hospital is simple.

We do what's right for kids.

That means we always put children's health first by providing high-quality health care in a warm and supportive environment.

Children's Hospital is a not-for-profit hospital that enlists the charitable support of a growing community of donors to become Guardians of Childhood.

Thanks to generous donor support, St. Louis Children's Hospital can deliver on its mission to do what's right for kids by providing compassionate care for the little things and expert pediatric care for the big things.

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