

Helping Kids Get At-Home Care

Story by Kate Marple & Erin Dexter

What would you do if your one-year old child depended on a ventilator to breathe, and the home nursing care needed to monitor it wasn't available? Would you keep your child in the hospital indefinitely? Would you quit your job to be home with your child, and stay up all night to make sure they didn't stop breathing? Would you put them in a long-term nursing facility 80 miles away where they'd have the care they needed, but where you wouldn't see them for days at a time? In 2015, for several parents in Washington State, the heartbreaking answer to all these questions was yes.



SEATTLE CHILDREN'S HOSPITAL

Seattle, Washington

<http://www.seattlechildrens.org/>

Seattle Children's is a pediatric hospital and research institute.

The hospital's **medical-legal partnership** with the Northwest Justice Project has provided legal services to patients and their families since 2008.



POLICY CHANGE SNAPSHOT

When children on ventilators were unable to leave the hospital due to a home-nursing shortage caused by low Medicaid reimbursement rates, the medical-legal partnership at Seattle Children's sued the state Medicaid Director and the Director of the Healthcare Authority to help kids return home. They then turned their attention to advocacy with the state agencies to fix the reimbursement rates.



The medical-legal partnership team gathered at Odessa Brown Children's Clinic — a community clinic of Seattle Children's Hospital and one of the MLP's partnering health sites — for their monthly staff meeting. **Photo credit** (above): Anya Morgan. **Photo credit** (to the right): Vorada Savengseuksa



The best option for these kids is to return home with nursing care where they can be with their families, grow developmentally, and avoid exposure to other diseases that could compromise their immune systems.

A variety of medical conditions — from birth defects to lung disease — can obstruct airways and require tracheostomy tubes to keep them open and clear. Those tubes have to be monitored twenty-four hours a day to make sure they don't become plugged; sometimes a ventilator is also needed. While some of these conditions will correct over time, these tubes are commonly needed for prolonged periods of time, even years.

When nothing else is wrong medically, the best option for these kids is to return home with nursing care where they can be with their families, grow developmentally, and avoid exposure to other diseases that could compromise their immune systems. But in 2015, many Washington families on Medicaid couldn't find nurses willing to take these jobs, in part because the Medicaid reimbursement rate for at-home nurses averaged almost \$10 per hour less than rates for other nursing positions, so kids were staying months longer than medically necessary at places like Seattle Children's Hospital.

AT THE TIME OF
THE LAWSUIT,

275
CRITICALLY ILL

Washington children were eligible to receive in-home care. Dozens of them were hospitalized unnecessarily, or were not receiving the amount of home care they were entitled to.



Providers began asking the medical-legal partnership attorneys questions about kids that the hospital was essentially boarding — young children on ventilators who didn't need to be at the hospital, but who couldn't be released without proper at-home care. Besides being unnecessary for the kids, the prolonged hospital stays were costly for Seattle Children's. Room and board alone totaled thousands of dollars a day; by comparison, the same amount could pay for round-the-clock care from a registered nurse for four days, at the private insurance pay rate. The questions providers asked attorneys were always the same: How do we get these kids in-home care? What is the state required to do?

The law was clear: The Americans with Disabilities Act says if Medicaid eligible individuals can be served in the community, they must be, and they must be given necessary supports to do so. And Medicaid laws state that with kids, care must be both paid for and arranged. In this case, Medicaid was willing to pay for the in-home care, but they weren't able to arrange for the nurses needed to carry it out.

The MLP attorneys asked social workers at Seattle Children's if they could identify specific patients who had been unable to find home nursing care. Six families with young children came forward. Some of their kids were still in the hospital, some were at home with insufficient care, and some had moved to long-term facilities two hours away where their parents could not see them every day. The MLP attorneys tried unsuccessfully to get the Healthcare Authority to make accommodations for these children. Then in October 2015, they filed a lawsuit, suing the state Medicaid Director, the Director of the Healthcare Authority, and the Healthcare Authority itself on behalf of the six families.

But these families weren't alone. At the time of the lawsuit, approximately 275 critically ill Washington children were eligible to receive in-home care. Dozens of them were hospitalized unnecessarily, or were not receiving the amount of home care they were entitled to.

The Medicaid reimbursement rate for at-home nurses averaged almost \$10 per hour less than rates for other nursing positions.



All policy work our MLP engages in is partially about solving a clinic problem identified by providers, in this case a serious and expensive discharge problem. But it was ultimately about giving kids a shot at their best life, and putting families back together. Every parent can understand the need to get their kid home.



Lindy MacMillan
MLP ATTORNEY

In January 2016, the judge ordered that under federal law, the state had the obligation to arrange for the skilled nursing care that had been authorized for the children who were named in the lawsuit, and that the state must fulfill its obligation to these children.

The successful lawsuit provided momentum for state legislation that passed in July 2016, raising the Medicaid reimbursement rate for home nursing care by \$10 per hour and making it more equitable with other nursing rates in the state. This change eliminated what was widely viewed as the biggest barrier to filling at-home care positions, not just for the six kids in the lawsuit, but for all Washington families eligible for these services.

Since these changes took effect, MLP attorneys have had fewer consults with Seattle Children's providers regarding authorization of home care for children dependent on ventilators. Cases do still come up where providers are struggling to discharge a kid and find home care, but when they do, there are now steps in place to better advocate for those patients.



**READ MORE STORIES IN THE
MLP PATIENTS-TO-POLICY SERIES AT:**
www.medical-legalpartnership.org/impact/stories

This story series is possible thanks to generous support from

THE KRESGE FOUNDATION

Eliminating Hurdles to Life-Changing Medication

Story by Kate Marple & Erin Dexter

The moment you're exposed to the HIV virus, a clock starts ticking. You have 72-hours to begin taking medication that greatly reduces your risk of contracting the virus, and the sooner you start taking it, the more effective it is.



WHITMAN-WALKER HEALTH

Washington, D.C.

<https://www.whitman-walker.org/>

Whitman-Walker Health is a Federally Qualified Health Center with a special expertise in Lesbian, Gay, Bisexual, Transgender, and Queer (LGBTQ) and HIV care.

The health center's **medical-legal partnership** is in-house; it has employed lawyers for its patients since 1986. Today, its legal department has 10 attorneys and two paralegals, along with 15 insurance navigators.



POLICY CHANGE SNAPSHOT

Whitman-Walker Health's medical-legal partnership worked with insurance companies to remove requirements forcing Post-Exposure Prophylaxis medications (PEP) to be filled by mail. By doing so, they ensured people who were exposed to the HIV virus could get the medication they needed filled at a local pharmacy within the 72-hour window when the drug can be effective in preventing the transmission of HIV.

Whitman-Walker Health's Red Carpet Service



If you go to Whitman-Walker Health in Washington, D.C. and report an exposure, it triggers their “red carpet service.” This means you don’t wait for an appointment; you see a nurse and an insurance navigator immediately, and leave with a prescription for a Post-Exposure Prophylaxis medication (PEP) that you can walk over and fill at the in-house pharmacy. But with effective treatment conditional on speed, this is where things can come to a halt.

When the pharmacist keys in the prescription, for some health plans, PEP comes up as a mail-order drug, which usually means that you fill out a slip, go home, and wait — much longer than 72 hours — for your medication to arrive by mail. This is because insurance companies were able to negotiate the best price for PEP as a mail-order drug. While it seems crazy that a time-sensitive medication would ever be considered for mail-order service, PEP has more than one use, and when it’s being taken regularly and on a schedule for other purposes, receiving it by mail may be reasonable. But it does nothing to help people who have a short window to prevent the contraction of HIV.



Fill Out a Mail-Order Slip for PEP at the In-House Pharmacy



Go Home and Wait Longer Than 72 Hours for PEP to Arrive in the Mail



Immediately Fill a 30-Day Supply of PEP at the In-House Pharmacy

Again and again over the last few years, this problem came up at Whitman-Walker: a patient was fast tracked through the clinic only to hit a stumbling block at the pharmacy counter. “Whitman-Walker sees an average of twenty-five people every month who need PEP for HIV exposure. Getting them the medication they need is critical not only to their health, but also to controlling the spread of HIV broadly,” said Dr. Sarah Henn, Senior Director for Healthcare Operations and Medical Services.

Over the last several years, pharmacists, technicians, and insurance advocates at Whitman-Walker have spent countless hours on the phone with insurance companies explaining why patients can’t wait for the drugs to arrive by mail and seeking an exception. “Sometimes, with hours of advocacy, we could get companies to make an exception,” said Erin Loubier, Senior Director for Health and Legal Integration and Payment Innovation at Whitman-Walker. “But it would come down to the wire. It was really dangerous for our patients, and incredibly burdensome for our staff.”

Pharmacists at Whitman-Walker reported the problem to the health center’s operations committee, which looks at how patients move through care at the health center and solves problems like this one. After interviewing pharmacy staff and insurance navigators, the health center’s legal services and policy teams drafted a letter to the two insurance companies with these barriers explaining in medical detail why patients couldn’t wait for this medication to arrive by mail, and asking the companies to change their policies and allow PEP to be filled immediately at the pharmacy without wait or additional cost-sharing.

Whitman-Walker sees an average of twenty-five people every month who need PEP for HIV exposure. Getting them the medication they need is critical not only to their health, but also to controlling the spread of HIV broadly.

Dr. Sarah Henn

SENIOR DIRECTOR FOR HEALTHCARE OPERATIONS AND MEDICAL SERVICES



Removing this last barrier is what will ensure that anyone anywhere who needs this medication can walk into a pharmacy with a prescription and leave with PEP in hand without delay.



Guillaume Bagal

POLICY ASSOCIATE AT WHITMAN-WALKER

Within a week, Whitman-Walker heard back from both companies. The first one removed all utilization restrictions, including the mail order requirement for PEP prescriptions. The second company implemented an automatic override, allowing a 30-day supply for PEP medication to be filled if a pharmacist called to request one.

“This is the kind of systemic problem we only know about because we are part of the care team embedded in the health center,” said Ms. Loubier. “It was our pharmacists raising an operational problem that allowed us to see this roadblock to fast and effective care for these patients. Our legal services team works tirelessly to respond to individual needs of patients, but we also help identify trends in individual needs to use policy solutions to remove barriers like this one so our team can provide the best possible care.”

Whitman-Walker is not done yet. For the second insurance company, getting patients this medication still hinges on a staff member making a call, which remains burdensome and, most importantly, can slow down and even prevent the medications being administered on time. They are working to eliminate any utilization requirements—including this one—for PEP medications. Guillaume Bagal, the Policy Associate at Whitman-Walker who is handling the follow up with the insurance company, knows the stakes. “Removing this last barrier is what will ensure that anyone anywhere who needs this medication can walk into a pharmacy with a prescription and leave with PEP in hand without delay,” he said. “And that’s our goal, to give everyone the very best chance to prevent the contraction of HIV.”



**READ MORE STORIES IN THE
MLP PATIENTS-TO-POLICY SERIES AT:**

www.medical-legalpartnership.org/impact/stories

This story series is possible thanks to generous support from

THE KRESGE FOUNDATION

Keeping Children Safe from Lead Poisoning

Story by Kate Marple & Erin Dexter

The first sign that a home has a lead hazard is usually when a child tests positive for lead poisoning. Despite the fact that more than four million children in the United States live in federally assisted housing and many of those units are decades old, homes are not assessed for lead hazards before families move in. Because of Chicago's old housing stock, providers at Erie Family Health Centers vigilantly check children's lead levels every six months until the child is four, and whenever there is a new risk factor introduced into a child's environment. That's where, in 2012, just months after moving into a new home with her federal Housing Choice Voucher (HCV), Lanice Walker's four-year-old daughter screened positive for lead poisoning.



ERIE FAMILY HEALTH CENTERS

Chicago, Illinois

<http://www.riefamilyhealth.org/>

Erie Family Health Centers is a Federally Qualified Health Center delivering care to more than 72,000 people.

The health center's **medical-legal partnership** with the Loyola University Chicago School of Law and Legal Assistance Foundation of Metropolitan Chicago has provided legal services to patients and their families since 2010.



POLICY CHANGE SNAPSHOT

After seeing many patients with lead poisoning who were prohibited from moving to a new home and still maintain their federal housing assistance, the medical-legal partnership at Erie Family Health Centers built a multi-state coalition that got the U.S. Department of Housing and Urban Development to update its federal lead regulations. Now, they are working to pass a federal bill that will require lead inspections of all federally assisted housing units before families move in.



Once a child ingests or inhales lead, it can be stored in the bones and continue to harm the child for years.

Dr. Sara Naureckas

U.S. Senator Richard Durbin (D-IL), Tolanda McMullen, lead poisoning prevention advocate and mom, and Emily Benfer, former Health Justice Project director, listen to Ethan Domsten, Health Justice Project student attorney, discuss the problem of lead poisoning in federally assisted housing. **Photo credit:** Scott Wills, Erie Family Health Centers.

Nurse practitioner Martha Glynn immediately called the Chicago Department of Public Health to report the elevated lead level, and to request an inspection. The city inspectors found lead-based paint hazards in the home, but the landlord — who was under a year-long contract with the Chicago Housing Authority (CHA) — refused to do anything about the hazards.

Ms. Walker repeatedly called CHA, asking them to intervene and force improvements to the unit. However, the problem was not an emergency by CHA standards. Even though her daughter's elevated blood lead level caused neurological problems, it didn't meet the level that would require the housing authority to take action. At the time, the Department of Housing and Urban Development's (HUD) definition of lead poisoning was *four times* the Centers for Disease Control and Prevention (CDC) reference value standard.

Moving wasn't an option for the Walkers either, or for other families in the HCV Program. Under federal law, families who live in federally assisted housing are not allowed to move out of a home with a lead hazard before the end of the lease term — even after their child has been poisoned and experiences health problems — and still maintain their housing assistance. So Ms. Walker faced an impossible choice: stay where her daughter was being poisoned, or become homeless.

During the time Ms. Walker was trying to get CHA to take action, all eight of her other children also tested positive for lead. It was then that Ms. Glynn referred Ms. Walker to the health center's medical-legal partnership with Loyola University Chicago School of Law and LAF Chicago. Attorneys contacted CHA and successfully obtained a reasonable accommodation under the Americans with Disabilities Act. This allowed the Walkers to move immediately, while retaining their housing assistance. The attorneys ensured that the family's new home was inspected for lead and hazards were abated before the family arrived. The children's lead levels went down, but ultimately, years of lead poisoning had resulted in permanent neurological damage.

"This is why prevention of lead poisoning is so important," said Dr. Sara Naureckas, Medical Director for Child and Adolescent Health at Erie Family Health Centers. "Once a child ingests or inhales lead, it can be stored in the bones and continue to harm the child for years."

To deal with the lasting effects of lead exposure, the MLP attorneys helped Ms. Walker obtain special education services for her daughter and public benefits to increase the family's income. In addition, they connected the family with a personal injury attorney to address the negligent harm caused to the family.

Having seen the devastating and permanent effect lead has had on so many kids, and motivated by the Walkers' experience and those of other families at Erie, the MLP focused their efforts on prevention. They knew this problem was not unique to Chicago, so they built a nationwide coalition of affected families, community organizations, renowned scientists, and public health practitioners to petition HUD to amend the antiquated *Lead Safe Housing Rule*, which had not been updated since the 1990s. They requested that HUD adopt the CDC's definition of lead poisoning, a change which would have forced housing authority interventions and a move to a safe home two years earlier for the Walkers, without needing the assistance of lawyers. Among other improvements, the petition also asked for mandated data sharing and reporting between housing authorities, public health departments, and HUD to help identify kids with elevated lead levels as soon as possible. Without this change, it was impossible to know the number of kids lead poisoned in federally assisted housing units each year.

After submitting the petition and engaging in a big media push that helped engage members of Congress, these proposed changes were successfully implemented in January 2017. Another critical change to the rule required that if a child in a federally assisted housing unit tests positive for lead poisoning, a lead hazard risk assessment must automatically be conducted on all other assisted units in the same building.

 **This is a very exciting step in moving HUD toward a primary prevention model for lead poisoning.** 

Emily Benfer
MLP ATTORNEY

“This is a very exciting step in moving HUD toward a primary prevention model for lead poisoning,” says Emily Benfer, founder and former director of the Health Justice Project and Clinical Professor of Law at Loyola University Chicago School of Law. “But unless all units are inspected and made lead safe before families move in, children will continue to be poisoned and suffer lifelong health and developmental repercussions.”

COALITION MEMBERS WHO PARTICIPATED IN PETITION FOR HUD RULEMAKING

- ChangeLab Solutions
- Childhood Lead Action Project
- Children's Defense Fund
- Civitas ChildLaw Center
- Coalition for Human Needs
- ColorofChange.org
- A Community Voice
- Emily Benfer, *Distinguished Visiting Scholar & Senior Fellow at Yale Law School in the Solomon Center for Health Law & Policy*
- Environmental Advocacy Center
- Erie Family Health Centers
- Farmworker Justice
- Green & Healthy Homes Initiative
- Healthy Homes Collaborative
- Improving Kids' Environment
- Dr. Bruce Lanphear, MD, MPH, *Professor, Faculty of Health Sciences, Simon Fraser University*
- Lawyers' Committee for Better Housing
- Lawyers' Committee for Civil Rights Under Law
- Louisiana Roundtable for the Environment
- Loyola University Chicago School of Law
- Dr. Howard W. Mielke, Ph.D, *Department of Pharmacology, Tulane University School of Medicine*
- National Alliance of HUD Tenants
- National Center for Medical-Legal Partnership
- National Housing Law Project
- National Low Income Housing Coalition
- Poverty & Race Research Action Council
- Professor Florence Wagman Roisman, LL.B, William F. Harvey Professor of Law, Indiana University Robert H. McKinney School of Law
- Dr. David Rosner, PhD, MPH, *Ronald H. Lauterstein Professor, Co-Director, Center for the History & Ethics of Public Health Sociomedical Sciences, Columbia University Mailman School of Public Health*
- Southern United Neighborhoods
- United Parents Against Lead
- Urban Justice Center

// Having medical, public health, science, and legal partners, as well as affected families at the table gave us so much credibility and broadened our perspective. //

Emily Benfer
MLP ATTORNEY

Sara Naureckas, MD, Director of Child and Adolescent Medicine, Martha Glynn, FNP, Site Medical Director, School-Based Health Centers, and Lee Francis, MD, MPH, President & CEO, all of Erie Family Health Centers, listen to Erie patient, mom, and advocate Lanice Walker, discuss the impact of lead contamination on her family during a meeting with U.S. Senator Richard Durbin (D-IL). **Photo credit:** Scott Wills, Erie Family Health Centers.



After the coalition's petition, HUD released *The Lead-Safe Homes, Lead-Free Kids Toolkit* that encouraged local public housing authorities to conduct pre-rental lead hazard assessments, and advised them on the funding streams they could use to pay for the inspections. However, federal regulations still do not yet require the pre-rental risk assessment, or give families a right to move and maintain public assistance when lead hazards are identified. Across the country there are only eight cities and five states that require any pre-rental lead hazard inspection before a family moves into a home. When enforced, those laws dramatically reduced lead poisoning rates among children.

Today, Ms. Walker and Erie Family Health Centers are part of a growing coalition to advocate for the *2017 Lead Safe Housing for Kids Act (S.1845)*, which would mandate both of these changes in public housing regulations, and protect millions of children from severe health and developmental problems. Senator Dick Durbin (D-IL) became a co-sponsor of the bill after meeting with Ms. Walker and the MLP team. Senators Tim Scott (R-SC), Bob Menendez (D-NJ), Todd Young (R-IN), Joe Donnelly (D-IN), Tammy Duckworth (D-IL), Tim McCain (D-VA), and Rob Portman (R-OH) are also co-sponsors. The Erie MLP has reached out to

colleagues at medical-legal partnerships in other states to find local groups and families willing to meet with Senators and Representatives and build support for the bill. In several cities, the coalition has secured support from landlords, inspection companies, and public housing authorities. And if they can get the bill passed, they have their eye toward supporting efforts that would improve lead standards in all housing types, not just federally assisted housing.

In reflecting on the HUD changes and the momentum for the bill, Ms. Benfer attributes success to the interprofessional, big tent nature of the coalition. "This is not just a legal issue," she said. "It isn't solely a housing issue or a health issue. Lead poisoning prevention is about protecting this generation of children, and all that follow. When it comes to our children, each of us has a role to play. Having medical, public health, science, and legal partners, as well as affected families at the table gave us so much credibility and broadened our perspective. As we learned from each other, the definition of the problem became more accurate, so the solution became more targeted and effective. We can advance social change so much more effectively, thoughtfully, and quickly working together."



**READ MORE STORIES IN THE
MLP PATIENTS-TO-POLICY SERIES AT:**
www.medical-legalpartnership.org/impact/stories

This story series is possible thanks to generous support from

THE KRESGE FOUNDATION

Increasing Nutritional Supports for Newborns

Story by Kate Marple & Erin Dexter

When Javana Bradford took her one-month old daughter, Augyst, for a checkup at Cincinnati Children's Hospital Medical Center, pediatrician Melissa Klein asked if she and her daughter were getting enough to eat. Ms. Bradford said she was having trouble adding Augyst to her Supplemental Nutrition Assistance Program (SNAP) benefits, commonly known as food stamps. Dr. Klein referred her to Deanna White, a paralegal at the hospital's medical-legal partnership (MLP) with the Legal Aid Society of Greater Cincinnati.



CINCINNATI CHILDREN'S HOSPITAL MEDICAL CENTER

Cincinnati, Ohio
<https://www.cincinnatichildrens.org/>

Cincinnati Children's is a nonprofit academic medical center, and one of the oldest pediatric hospitals in the country.

The hospital's **medical-legal partnership** with the Legal Aid Society of Greater Cincinnati has provided legal services to patients and their families since 2008.



POLICY CHANGE SNAPSHOT

Cincinnati Children's medical-legal partnership worked with the agency that administers food benefits in the county to eliminate administrative barriers to women enrolling newborns in benefits. New procedures allow hospital case managers to send birth records directly to the agency, and help hundreds of families enroll newborns months earlier than before, which translates to real money for child nutrition.

What \$154 Means for Bottle-Fed Newborns

\$154 can buy 48 – 60 days of formula for a newborn.



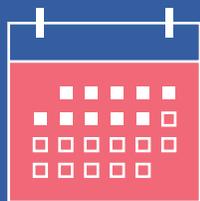
24 – 26
FLUID OZ



Amount of formula babies need per day.



of 2.13 lbs
formula powder*



Each can of this formula will feed a baby for

8 – 10 DAYS

\$154



6

CANS
of formula
powder



To add a newborn to a mother's SNAP benefits in Hamilton County, Ohio, the mother must call the Department of Job & Family Services (JFS) or go on their website to report the birth. A caseworker will then send mom a "baby packet" to complete and send back. Included in this packet is a new household verification form that mom's landlord must sign to confirm that the child lives with her. She also has to send back proof that she has applied for a social security number for her child.

"I've worked at Legal Aid for 12 years," said Ms. White. "I can't tell you how many times I've read in case worker notes that the baby wasn't added to SNAP benefits because mom failed to return the new baby packet. It's a very common barrier."

Even if a mom does get all the forms signed and returned, mail is not always reliable at JFS; not all paperwork that is received gets scanned properly, sometimes causing further delays. And if a mom clears all these hurdles and everything is in order, her SNAP benefits won't change until the month after the application is processed. So, a mom who reported the birth of a baby in mid-September may not get the baby packet returned until after October 1 and her benefits wouldn't increase until November 1. That delay means an average loss of \$154 in benefits for a family, and the resulting loss in nutrition during that time can be devastating.

This administrative delay means an average loss of \$154 in benefits for a family, and the resulting loss in nutrition during that time can be devastating.

"Having appropriate nutrition is critical throughout all stages of childhood," said Dr. Klein, who is also an Associate Professor of Pediatrics at Cincinnati Children's. "Proper nutrition may be the most critical during the first two years because that's a period of accelerated brain growth. Food insecurity is associated with many poor outcomes including micronutrient deficiencies, developmental and behavioral issues, increased rates of acute infections, hospitalizations, and complications due to chronic illnesses. In addition, when a mom cannot afford enough food, she will often attempt to spare the baby by eating less herself. This is especially an issue among breast feeding mothers who need an extra 500 calories a day. Thus, if the mom is not eating enough, it is not good for mom or baby."

*Based on the formula provided to families in clinic at Cincinnati Children's as needed.

What \$154 Means for Breastfeeding Moms

A nursing mother needs to consume an extra 500 calories per day. An additional \$154 dollars spread over 2 months might buy*:



**Food prices calculated based on most recent average nationwide estimates from the USDA.*

After receiving Ms. Bradford's referral, Legal Aid Society of Greater Cincinnati did some research and discovered three important things. One, the burdensome paperwork that was giving moms so much trouble wasn't required — all JFS legally needed to process and increase SNAP benefits was a medical record to verify the child's birth. Two, the delay in benefits post-application was technically legal, but JFS was waiting until the last moment allowable to make the increases; they could do it sooner. Third, and perhaps most significant, Ms. White learned that Medicaid Managed Care providers notify JFS — which also administers Medicaid in the county — weekly of all newborns born to mothers on Medicaid, and those babies are automatically enrolled in Medicaid. These same providers were not asking about SNAP, and the birth records sent to JFS were not being connected to SNAP records.

The MLP team raised these concerns with JFS, which then agreed to work with them to change the application requirements and processing procedure. Beginning in June 2016, JFS got rid of the baby packet. Instead, every day dedicated JFS staff now take the birth reports they receive from Medicaid Managed Care providers

and automatically run a check to see if any of the moms also receive SNAP. For anyone who does, her newborn is automatically added to her household; mom doesn't have to do anything. And since anyone who receives SNAP benefits is eligible for Medicaid, and most of those moms are already enrolled in Medicaid to cover prenatal and child birth expenses, this procedural change will catch most SNAP households with a newborn. JFS has taken the fix a step further and built a mechanism for Medicaid Managed Care providers to enter birth information directly into JFS' computer system, eliminating another administrative step, and enrolling babies in Medicaid, SNAP, and cash assistance even faster.

"This will impact people who would not ever have been referred to us," said Ms. White. "We tell health care providers to refer families if their food benefits had been denied or suddenly reduced without explanation. Here, the delay moms were experiencing, and the burden of the application packet itself, weren't traditional legal problems, but nonetheless they were a big reason why many children were never added to their mothers' accounts or were missing months of critical benefits."

Among the patients seen at the hospital-owned outpatient primary care centers, these changes are expected to help approximately 150 families per month enroll in and receive SNAP benefits faster, getting their infants the food needed in their first few months.

The MLP does not have data on the number of babies born per month in Hamilton County who are eligible for Medicaid or SNAP. However, the two primary care clinics in Hamilton County that the MLP serves, see about 180 newborns a month. From serial surveying, the hospital knows that one-third of these families are food insecure and ninety percent are on Medicaid. So among the patients seen at the hospital-owned outpatient primary care centers, these changes are expected to help approximately 150 families per month enroll in and receive SNAP benefits faster, getting their infants the food needed in their first few months.

The elimination of these administrative burdens didn't just benefit families; the elimination of the "new baby packet" also resulted in cost savings and efficiency improvement for JFS. And this whole process has changed how doctors at Cincinnati Children's screen families.

"Before, I didn't know anything about SNAP benefits or when they are implemented," said Dr. Klein. "From working with our MLP, my counseling has changed. Now I ask all moms with newborns about their SNAP benefits and whether the baby has been added to their case. Since we are a teaching site, this knowledge has been shared with many resident and attending providers, leading to more widespread practice change and greater advocacy for our patients and families."

This is really important, especially since inquiring about SNAP during a routine checkup is how this all got started.

"After this advocacy was over, I called Ms. Bradford, who had waited months for her daughter to receive food benefits," said Ms.

White. "We hadn't been able to help her — this change wasn't retroactive to the families impacted by the old policy — and by that time, she was back to work. But I told her about what the changes meant for other families, and that she was really the genesis of all of it. I told her how much I appreciated working with her, and that I would always think of the rule as her August's rule. She was just so proud."

"I'm so happy. I really am," said Ms. Bradford. "Any other time before that visit with Dr. Klein, I probably would have been too embarrassed to even admit during a routine check-up that I was hungry and not receiving enough food. But I was nursing at the time, and I was really afraid that I would start to have a milk shortage if I didn't get help fast. I did end up having to supplement, but the moms this may help in the future is tremendous."



Before, I didn't know anything about SNAP benefits or when they are implemented, from working with our MLP, my counseling has changed. Now I ask all moms with newborns about their SNAP benefits and whether the baby has been added to their case. Since we are a teaching site, this knowledge has been shared with many resident and attending providers, leading to more widespread practice change and greater advocacy for our patients and families.



Dr. Melissa Klein

ASSOCIATE PROFESSOR OF
PEDIATRICS AT CINCINNATI CHILDREN'S



**READ MORE STORIES IN THE
MLP PATIENTS-TO-POLICY SERIES AT:**
www.medical-legalpartnership.org/impact/stories

This story series is possible thanks to generous support from

THE KRESGE FOUNDATION

Ensuring People with Chronic Conditions Maintain Access to Care

Story by Kate Marple & Erin Dexter

When Whitman-Walker Health in Washington, D.C. hired its first in-house lawyer in 1986, it was to help HIV and AIDS patients write wills, secure disability benefits, and fight discrimination — all to ease suffering as they prepared for the end of life. Thankfully, advancements in medical treatment mean that people with HIV and AIDS are living longer, healthier lives. It also means that the health center's now 10 attorneys, two paralegals, and 15 insurance navigators play a very different role in patient care. Among other things, they lead Whitman-Walker's health insurance eligibility and enrollment efforts. And that's how in the Spring of 2016, attorney Erin Loubier came to receive a call from the head of the District's Health Benefits Exchange Authority (HBX) with news that CareFirst — one of the two biggest insurers in the D.C. Marketplace — intended to discontinue its platinum level plan widely used by Whitman-Walker's 3,600 HIV-positive patients.



WHITMAN-WALKER HEALTH

Washington, D.C.

<https://www.whitman-walker.org/>

Whitman-Walker Health is a Federally Qualified Health Center with a special expertise in Lesbian, Gay, Bisexual, Transgender, and Queer (LGBTQ) and HIV care.

The health center's **medical-legal partnership** is in-house; it has employed lawyers for its patients since 1986. Today, its legal department has 10 attorneys and two paralegals, along with 15 insurance navigators.



POLICY CHANGE SNAPSHOT

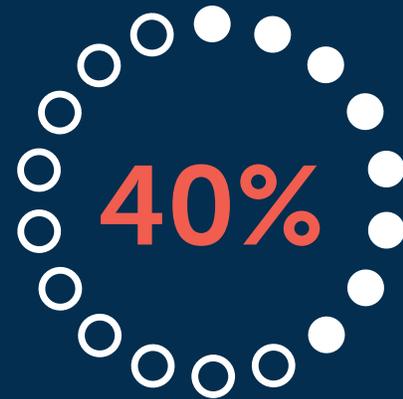
Whitman-Walker Health's medical-legal partnership helped prevent platinum insurance plans that were widely used by patients with chronic illnesses from being eliminated in the D.C. Marketplace. Through advocacy with the insurance commissioner and insurance companies, thousands of patients maintained access to care.



Medications that help
manage HIV can retail
for as much as

\$2,000
PER MONTH.

THAT'S



OF THE MEDIAN
HOUSEHOLD INCOME
IN THE U.S.



***Medications that were a mere
dream thirty years ago can now
help reduce a person's HIV viral
load to undetectable levels.***

Medications that were a mere dream thirty years ago can now help reduce a person's HIV viral load to undetectable levels, meaning they have fewer health complications and are also less likely to transmit the disease to their partners. But these drugs can retail for as much as \$2,000 per month, or 40 percent of the median household income in the U.S. So if you need this medicine, and particularly if you are low-income, your health insurance coverage likely determines whether you can afford it, and whether you are forced to make impossible choices between life-saving medications, food, and safe housing.

In May 2016, when the head of HBX Mila Kofman saw that CareFirst submitted its rates for the year and wanted to eliminate its platinum plan, she was immediately concerned and wanted to understand what effect this change would have on the accessibility and cost of care for D.C. residents. One of her first calls was to Loubier, Whitman-Walker's Senior Director for Health and Legal Integration and Payment Innovation.

CAREFIRST PLATINUM PLAN

offers the lowest out-of-pocket costs on medications for members. Prescription co-pays were a flat fee, often

\$20

PER MONTH.



IF THE PLAN HAD MOVED TO A CO-INSURANCE MODEL

Prescriptions for certain specialty medications could cost

\$400

PER MONTH
OR MORE.



Almost all of Whitman-Walker's HIV-positive patients insured through DC Health Link are on a platinum plan.

Almost all of Whitman-Walker's HIV-positive patients insured through DC Health Link are on a platinum plan. Loubier and her legal team encourage these patients to choose it because they have frequent health care needs and those plans offered the lowest out-of-pocket costs. Individuals on a platinum plan are responsible for 10 percent of their health care costs; the option with next highest level of coverage is the gold plan, which would make them responsible for 20 percent of costs out-of-pocket. Higher cost sharing can also have a significant impact on medication coverage. The change, Ms. Loubier noted, could price those who most frequently need health care services out of access to care.

HIGHER COST SHARING CAN PRICE PEOPLE WITH CHRONIC ILLNESSES OUT OF LIFE-SAVING MEDICATIONS

and lead to tradeoffs
between medication, food,
and stable housing.



After sharing their concerns with HBX, the health center's legal team and allies from the Multiple Sclerosis Society, patient advocacy groups, and the city's HIV/AIDS Hepatitis, STD and TB Administration explained to the insurance commissioner that the elimination of the platinum plan option would leave thousands of people without any options for similar coverage, which would be devastating to both access and cost of care. They also argued that the decision appeared to specifically target people with chronic conditions, and that there was a serious case to be made that this was discrimination. Together, they went to CareFirst, which ultimately agreed to maintain its platinum plan option.

For many patients, getting priced out of insurance is a life and death situation, and building relationships in the community that allow us to work with others in an upstream way is incredibly important.

Erin Loubier

SENIOR DIRECTOR FOR HEALTH AND
LEGAL INTEGRATION AND PAYMENT INNOVATION

Several months after the initial advocacy, CareFirst wanted to move certain high-cost specialty medications—many used to treat HIV and Multiple Sclerosis—to a percent co-insurance model, meaning that some prescriptions that currently had a flat co-pay of \$20, could suddenly skyrocket to as much as \$400 per month per medication. Staying connected to HBX and the other partner organizations, Whitman-Walker helped ensure this change was not made, once again ensuring access to lower out-of-pocket costs.

“The early alert from Mila Kofman and her staff was critical because it enabled us all to mobilize early and quickly,” said Ms. Loubier. “For many patients, getting priced out of insurance is a life and death situation, and building relationships in the community that allow us to work with others in an upstream way is incredibly important. And in this case, it meant that there was not any disruption in coverage or care for our patients. That’s the most important thing.”



**READ MORE STORIES IN THE
MLP PATIENTS-TO-POLICY SERIES AT:**

www.medical-legalpartnership.org/impact/stories

This story series is possible thanks to generous support from

THE KRESGE FOUNDATION