

CHOP Family News

Fall 2007

CHOP's Philosophy of Family-Centered Care

DIGNITY AND RESPECT, INFORMATION SHARING, PARTICIPATION, COLLABORATION

"Thank you very much for not only taking good care of the patient, but the family too. Your staff is great. From the housekeeping staff to the doctors, they show that they love their work and they are very helpful. The Connelly Family Resource Center is an additional plus to the care. We don't have to worry about our clothes, food and a place to send e-mail. You have provided it all."

In this issue of *CHOP Family News*, you will see how Children's Hospital's principles of family-centered care are a part of the work we do here on a daily basis — work that leads to satisfied families, like the ones who shared the quotes throughout this story.

Family-centered care emphasizes mutually beneficial partnerships among patients, families and healthcare providers. It acknowledges that you, as families, are essential to your children's health and well-being, and are allies for quality and patient safety within the healthcare system. The core concepts of patient- and family-centered care, which you will find throughout this issue and others, are:

- **Dignity and Respect:** Care providers listen to and honor patient and family perspectives and choices. Providers incorporate patient and family knowledge, values, beliefs and cultural backgrounds into care planning and delivery.
- **Information Sharing:** Care providers communicate and share complete and unbiased information with patients and families in affirming and useful ways. Patient and families receive timely and accurate information so they may effectively participate in care and decision-making.

- **Participation:** Care providers encourage patients and families to participate in care and decision-making at the level they choose.
 - **Collaboration:** Patients, families, care providers and Hospital leaders collaborate on policy and program development, execution and evaluation in healthcare facility design, and in professional education and care delivery.
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"Thank you to the Connelly Family Resource Center for helping me relax and giving me a place to come that's not stressful and providing me with access to information."

Sometimes these philosophies are seen in Hospital policies and procedures that have been thought out by a Hospital committee, and include family input. Other times you simply may find the philosophies embodied in the good judgment of a staff member. No matter where you find them, you should always feel that you are a true partner in care of your child or family member.

We'd love to hear from you about how you have experienced family-centered care at CHOP. E-mail loftus@email.chop.edu and we may share your story in an upcoming *CHOP Family News*.

"I hope that I never come here again, but if I do, I know my son will get the best treatment and care in the best hospital in the nation!"

New Healthy Choices Available at CHOP

It's 5:30 p.m. on a Monday night, and Children's Hospital's kitchen — where food is created for visitors, patients and staff alike — is filled with more people than usual.

That because families who are part of the Hospital's Healthy Changes Program (under the umbrella of CHOP's Healthy Weight Program), are acting as taste testers while CHOP chefs serve up new, healthy recipes. Recipes receiving positive reviews will be included in the Healthy Weight Program's *Nutrition in the Kitchen* cookbook, currently in the works. The recipes may also end up on the Hospital's Room Service menu or in the cafeterias.

Developing tasty, healthy recipes is just one example of how Children's Hospital is creating a healthier environment for patients, families and staff.

There are also new offerings in the Hospital's cafés, such as a reworking of value meals. Previously, diners could order grilled items with French fries and a fountain drink at a discounted price. Hospital leadership, the Healthy Weight Program, and the Food and Nutrition Department decided it was time to replace the former value meal with a new one that replaces French fries with vegetables or a side salad when matched with an entrée.

Lara M. Khouri, program director of the Healthy Weight Program, says the new deal really pushes the idea of pairing salads and vegetables with the main course. "It's a substantial savings, and gives exposure to side salad and cooked veggie offerings that are available every day," she says.

She says as far as the cafés are concerned, recent changes have been made so there is a vegetarian soup available daily, and now, when ordering a sandwich, there is the option of getting carrot sticks on the side instead of chips or pretzels.

The opportunity to make healthy choices is not just available in CHOP's cafés, either. When you visit the newly renovated McDonald's on the first floor of CHOP's Main Building and order a Happy Meal, the assumption won't be that you want fries with that. You will have the choice of apples. Customer representatives should be asking you if you would like milk with your Happy Meal, too.

"A small change in choice can eventually lead to new habits in healthy eating," Khouri says. "We hope that through these efforts and new ones in the works, CHOP's families and staff will make more healthy decisions regarding what they eat — both at home and school."

Ensuring Immunizations are Up-to-date

Vaccines keep your child safe and healthy by preventing infectious diseases. They not only protect your child but also protect those in the community who cannot be vaccinated. Vaccines are responsible for the control of many infectious diseases that were once common in this country, including polio, measles, pertussis (whooping cough), rubella (German measles), mumps, tetanus and Haemophilus influenzae type b (Hib) (a bacteria that could cause meningitis). We've listed two resources here to help provide you with more information about vaccines and give you ways in which you can record your child's vaccinations so they stay up-to-date. The Center for Disease Control (CDC) is the primary resource for vaccine information. The CDC has outlined some steps to make sure your child is protected from vaccine-preventable diseases:

1. Visit CDC's childhood scheduler online at http://www2a.cdc.gov/nip/kidstuff/newscheduler_le/ to find out what immunizations your child needs, or talk with your child's doctor, nurse or clinic.
2. Find out if your child is eligible for no-cost or low-cost vaccines through the Vaccines for Children (VFC) Program. Find a VFC provider in your area by contacting your local health department. A description of the VFC program can be found by visiting <http://www.cdc.gov/vaccines/programs/vfc/default.htm>.
3. Get an immunization card or record for your child, and bring it to every doctor's visit. One example can be found at <http://www.immunize.org/catg.d/p2022b.pdf>.
4. Ask at every visit if your child needs an immunization; sometimes a sick visit can still be used for immunization and save you an extra visit to the doctor — just ask your doctor or nurse.
5. Visit the CDC Web site at www.cdc.gov/vaccines, or call 1-800-CDC-INFO (800-232-4636) for more information.

Another resource is CHOP's Vaccine Education Center, which offers a variety of helpful information. The Center has two Web sites with information about vaccines and the diseases they prevent. You can also contact the Center for answers to your vaccine-related questions. On the Parents PACK site you can register to receive a monthly e-mail newsletter about vaccines. Please visit both sites at www.vaccine.chop.edu and www.vaccine.chop.edu/parents.

Developing tasty, healthy recipes is just one example of how Children's Hospital is creating a healthier environment for patients, families and staff.

Family-friendly Meets State-of-the-Art:

New PACU and Surgical Suite in CHOP's West Tower

The fourth floor of the West Tower, home of the PeriAnesthesia Care Unit (PACU) and Surgical Suite, is evidence of one of the latest construction projects at CHOP to incorporate plans that feature the best of both worlds: the technology and facilities to ensure patient safety and world-class care, enhanced by family-friendly touches to comfort and reduce stress.

The “perianesthesia” phase includes the time before and after anesthesia. More than 15,000 patients come through the PACU each year for a variety of procedures — examples include myringotomy with tube placements (ear tubes), tonsillectomies, bowel and urinary tract surgeries, arthroscopy, neurosurgery and transplantations.

The new PACU and OR suite are part of a broader redesign that will conclude in 2009. Patient capacity is expected to increase by 3 percent next year and to continue to grow.

The PACU is designed to make families comfortable and to minimize patient movement from room to room and staff to staff — reducing handoffs is an essential patient safety goal. Features include:

- a large reception desk staffed by Patient Access and Revenue Cycle for check-in and checkout
- two waiting areas. One is for families and patients before surgery and features televisions, a play area and a computer nook to surf the Web or play games. The other, for families during and after surgery, is separate, offering privacy and quiet.
- lockers for families
- a rocking chair at each bedside
- a computer in each room for staff
- 28 patient bays offering privacy before and after surgery. There is a double bay — the staff calls it the “twin room” — that can be used for siblings. The bays are a great improvement from the current PACU, which is basically a large room with curtains between beds.
- six consult rooms where doctors and nurses can talk to parents in private

From the PACU bays, patients will be taken to the operating rooms. The eight new rooms are large and designed to accommodate the technology of today and the future, including laparoscopic (minimally invasive) and robotic surgery. This year, nearly 900 patients have had their surgery done using laparoscopic techniques, 25 percent more than the previous year.

From the new rooms, surgeries can be broadcast to key Hospital locations, such as the pathology laboratory and conference rooms, as well as externally. With this technology, surgeons can guide procedures in distant locations — the staff has already broadcast to France, India and other countries.

Features of the operating rooms:

- multiple cameras, including in the wall at the foot of the room and in the lights that hang from ceiling booms “infield” (around the patient), as well as the surgical cameras used during laparoscopy
- four monitors/screens on ceiling booms, to show images from cameras inside and outside of the body. Surgeons can position the screens at various places to obtain a better view while performing surgery.
- a large monitor/screen at the foot of the room, for a bigger image of the surgery
- two equipment booms and four light booms, to minimize need for carts
- a touch-screen monitor at the foot of the room, from which a nurse will adjust lighting and what is showing on the monitors. The touch-screen feature is also available at the “infield” monitors.
- adjustable light patterns, including green lights for use during laparoscopic procedures. This allows the monitors to easily be seen while allowing the other members of the team the ability to work while lights are dimmed.
- built-in blanket warmer in each room
- alcoves outside each OR so stretchers or beds don't protrude into the hallway

While families wait during their children's surgeries, new tracking system screens allow them to know exactly where they are in the Surgical Suite so that they can be reunited as soon as possible, too.

Planning for the new complex began more than five years ago, with input from surgeons, nurses, anesthesiologists, support staff and patient families. Two current operating rooms (15 and 16) were used as prototypes.

“We've grown by leaps and bounds, and now the much-awaited new facility is here,” says Brenda McKonly, R.N., M.S.N., C.N.O.R., M.B.A., director, Perioperative Nursing. “We've met with so many people to hear their thoughts about what the future of surgery would look like at the Hospital. We're going to be able to do phenomenal things.”

When the entire project is complete, there will be 46 PACU patient bays, 20 operating rooms (all either renovated or completely new) and two “procedure rooms” for less complicated procedures such as setting fractures, placing central IV lines and some dental work.

The project also includes a new staff locker room and lounge for OR staff, including showers, on-call sleep rooms and cafeteria; that's slated to open in fall of 2008.

The Parent's Perspective

by Amy Craig-Martiner

When I learned that I was pregnant with my second child in spring 2001, I was thrilled. My “big girl” Abby was a joyful 2-year-old, and my husband and I were ready to expand our family. Aside from what seemed like a more difficult than usual case of morning sickness, we were excited about our new addition that was due to join us on Aug. 10.

On April 21, I awoke from a nap and was quickly in distress.

I was in labor and only 24 weeks into my pregnancy. After a trip to my local hospital, my husband and I were told that the baby's survival was out of the question. This labor couldn't be stopped and there was no sign of fetal heartbeat.

Time stood still.

We elected to have an emergency c-section.

I awoke from anesthesia to learn that my baby was alive. A neonatologist had arrived just in time and had resuscitated her three times. It was a girl, weighing 1 lb 6 oz — born 16 weeks prematurely. We named this miracle baby Grace Leigh and prepared for her immediate transport to CHOP.

It took a few days for us to fully understand the critical nature of her situation. Only 25 percent of “24-weekers” survive, and Grace was critically ill. Although no exact reason for my early delivery was ever determined, it was presumed there was an infection that had been making me feel so sick and had caused the early labor.

The Newborn/Infant Center (N/IC) on CHOP's second floor quickly became our second home as we joined the medical team in our fight to save “baby Grace.” The social worker, nurses and doctors held our hands, figuratively and literally, as we began to navigate the scary world of premature birth. They taught us how to parent a child who was too fragile to be touched; how to participate in her care and successfully partner with the clinical team. They were generous, understanding and skilled. They are family now.

Our journey in the N/IC can best be described by the cliché “roller coaster.” The highs were when we could hold her skin- to-skin. The lows were when she coded and we created a DNR (do not resuscitate) order. She is a fighter and the miracle baby Grace came home on Sept. 14, 2001, weighing 6 lbs.

Today, Grace is a gorgeous 6-year-old. She is perfectly physically healthy, but was diagnosed with autism when she was 2. No one who meets Grace ever forgets her laugh and beautiful smile. No matter how challenging things get as the parent of two active little girls, I am grateful every single day for the gift that is our Gracie.

My experience as the parent of a critically ill child at CHOP was life-changing. Not long after I got Grace home, I immediately wanted to find ways to give back. I wanted to make good come from the suffering that my family had endured.

In 2003, I began my second career at CHOP as a Family Consultant in the Social Work and Family Services Department. I work with three peers, all of whom have had special needs children treated here. It is our mission to

promote the practice of family- centered care throughout the institution. I talk to nurses, doctors and staff, tell our story and highlight all the things that went so well (as well as things that could've been better). I also work on planning committees and see families directly to provide parent-to-parent support. It's all about partnerships, and finding new ways to improve communication to improve outcomes and care.

This is my life's work and passion now — giving back to the institution that gave me and my family so much. CHOP is my children's hospital, and I am dedicated to insuring that every family who comes through our doors will have the same extraordinary experience we did.

Sometimes hearing the perspectives of other CHOP families can make coping with the Hospital experience easier. If you would like to share your story with other families through CHOP Family News, please contact Jennifer Loftus at loftus@email.chop.edu.



Abby and Grace Martiner

photo by Susan Pardys

Electronic Medical Record Replaces Paper Charts in Specialty Care

In an age of Blackberrys® and iPods®, it's hard to believe that the world of medicine's standard way of tracking a patient's progress is by pen and paper. It's a system with problems at hospitals everywhere — charts get lost, handwriting can be illegible, patients have to repeat information at multiple visits. One of the biggest issues is communication breakdown between the primary-care pediatrician and the specialty-care physician who see the same patient.

Children's Hospital is in the midst of implementing a new, more efficient way to track its specialty patients with EpicCare, an electronic medical-record system for patients that replaces paper charts. So far, the Otolaryngology (ear, nose and throat), Audiology, Allergy, Adolescent Medicine and General Surgery practices at CHOP have introduced Epic. Rheumatology will introduce the system at the end of November, and over the next few years, all specialty-care practices will begin using it.

Epic makes communication among patients and families, physicians and specialists more efficient. It also makes scheduling, registration and billing for patients and families easier, allows easier access to patient records by multiple providers and reduces the likelihood of medical errors.

"Epic will make things easier — everything is centralized, and it allows better communication," says Terri Brown-Whitehorn, M.D., the physician overseeing the use of

Epic in Allergy. "I can see what the primary care doctor in the Kids First practice does the same day he sees a patient. The goal, eventually, is for the whole Hospital to do this."

"Access is the biggest benefit," agrees Joy Peterson, Au.D., CCC-A, manager of Audiology. Her department provides care at seven sites in the CHOP network, and before Epic, they had paper charts at each location. Now, she's seen a vast improvement in the ability to share information with families, such as the ins and outs of programming a child's hearing aid. "In the old days, we'd have to put the phone down, go find the record and get back to them," she says. "Now, if a question comes up, whether you're on the phone or in the clinic, you're able to view the record."

Another important benefit for Audiology is that some of the department's clinical diagnostic equipment "talks" to Epic, so a clinician can dump data from a hearing test, for example, directly into a patient's electronic record without manually recording points on a paper graph.

The system has made it easier for specialists to record details of patient visits, says William Potsic, M.D., chief, Division of Otolaryngology. "We aren't depending upon handwriting and legibility — physicians five to 10 years later can't always decipher what they wrote themselves! With the electronic medical record, the accuracy is better and that's better for patient safety."

Epic also is improving the Hospital's relations with patients' primary-care physicians, Potsic says, by instantly updating the home doctor about any visits or procedures her patient had at CHOP.

Future plans for the Epic implementation include a "patient portal" that will allow patients and families to view portions of their own medical records through a password-protected Web site, including medication information and lab results.

continued on back

You've Got Questions. We've Got Answers.

Understanding how CHOP works can be tough. We're here to help.

Perhaps it's your child's grandparent who is visiting their grandchild or it's your wife who just delivered and wants to get to your child's isolette. Maybe it's your own child who needs help getting around CHOP. Whatever the reason, we want to make it easy for you to get a wheelchair.

When you arrive at CHOP and need to get a wheelchair, ask our Security personnel for assistance. They are located at every entrance to the Hospital and are available to assist you in a variety of ways.

If you arrive in the parking lot and find no wheelchairs in the elevator bays, simply ask the parking attendant to contact Security for you. Security will obtain a wheelchair and bring it to you in the parking garage as quickly as possible.

"Our security officers are not only dedicated to providing a safe environment for each and every patient, family member and staff member, but are equally dedicated to helping our patients and families with assistance such as securing a wheelchair," says Mike Brooke, director of Security, Parking and Transportation.

You may also talk to staff in the Welcome Centers or at the Information Desks, says Adrienne Meek, manager of Family Access Services. "Our staff may have direct access to wheelchairs," says Meek. "In the event that we don't, we'll immediately call other Hospital areas to obtain one."

If your child is an inpatient and requires a wheelchair to get around, simply ask your nurse or unit clerk for assistance. CHOP has a number of wheelchairs, wagons and coaches available for parents to use while their children are in the Hospital. These items are in high demand, so if you see one sitting in a hallway somewhere not being used and you have a free hand, please grab it and return it to one of the Security desks located throughout CHOP.

continued from previous page

This technology supports the Hospital's commitment to partnership between physicians and families, a partnership that increases the safety of the care our children receive. In addition, families also may be able to schedule appointments and pay bills through this portal.

"We're trying to facilitate a better patient experience," says Mark Newman, project director for Specialty Care. "We're in the planning stages to make the data available no matter where they're receiving care across the spectrum."

Involving Siblings in the Care Plan

by Children's Hospital mom Beth Lohne

As parents, we strive for the best in life for all of our children. When one of your children suffers with a disability, the "best life has to offer" takes on a different meaning. Instantaneously, their life and yours are forever changed. As the parent, play dates may become a thing that only the neighbors get to do, and time for the rest of your family is put on the back burner. Now you are inundated with doctors' visits, evaluations and stress beyond anything you can imagine. Where do you find the time to maintain your home, your marriage, and most of all, your other children?

As the mother of a disabled child, I have struggled with these very questions. It can be overwhelming enough to understand one child's special needs, and then turn to see the same concern in your older son. Suddenly you realize the impact this has on him as well. Someone once told me you will never truly know the feeling of guilt until you become a mother. What an understatement!

My older son has accompanied us for nearly every doctor appointment, hospitalization, early intervention session, as well as preschool evaluations, without any real complaints. He sits calmly and inquisitively listens to every word discussed, and sometimes asks questions on his own.

I had tried to shelter my older son by not including him in the discussion of his younger brother. But during an appointment, I realized it is just as important for my

PARTICIPATION

older son to understand his brother's condition as it was for me. While I am his mother, he is his brother, and friend. We are both constants in his life and value his needs.

Children's Hospital offers a number of resources for siblings of patients, including Sibshops, where children get to spend time with other children who have a brother or sister with a disability or special healthcare needs. At Sibshops, children ages 6 to 12, take part in activities that encourage them to talk about their family and realize that there are other children who have similar life experiences. Parents are invited to spend time in a discussion group focusing on sibling issues and the challenges of meeting the needs of all their children.

Sibshops will be occurring on the following Saturdays from 10 a.m. to 12:30 p.m.: Dec. 1, Jan. 26 and April 5. The group meets in the lobby of Children's Seashore House of The Children's Hospital of Philadelphia. If your child is interested in participating, contact Lenore Stern, M.S.S., L.S.W., at 215-590-7443. There is a \$5 nonrefundable donation requested to register.

We're Wireless Everywhere.

Patients and their families, as well as other visitors to the Hospital's Main Campus, can now connect to the Internet wirelessly at no cost in the Main Building, Richard D. Wood Ambulatory Care Center, Children's Seashore House and the Leonard and Madlyn Abramson Pediatric Research Center.

Patient-family Internet access was already available in several inpatient units via cable; this project expands the access throughout the Main Campus and will eliminate the need for plugging in.

For security reasons, this new wireless network is separate from the employee wireless network. Users of the guest wireless network are not able to reach the CHOP Employee Intranet or any clinical or business applications.

To connect, users must have a laptop computer with a wireless card, and choose "chopguest" as their wireless network. Before connecting to the Internet, they will be asked to agree to terms and conditions of use, and they will not be able to access sites deemed inappropriate, such as MySpace.

COLLABORATION

The Editorial Board of *CHOP Family News* includes family members and staff of The Children's Hospital of Philadelphia. Comments and suggestions are welcome and should be submitted to Jennifer Loftus at loftus@email.chop.edu.

The Promise *of* Partnership

Family-centered Care

at The Children's Hospital of Philadelphia

Founded in 1855, The Children's Hospital of Philadelphia is the birthplace of pediatric medicine in America. Throughout its history, a passionate spirit of innovation has driven this renowned institution to pursue scientific discovery, establish the highest standards of patient care and train future leaders in pediatrics.

For a century and a half, Children's Hospital has served as a haven of hope for children and families worldwide.

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