



Packard Children's NEWS

A Clean Start *New Dialysis Facility Will Boost Spirits as Well as Health*

BY JOAN THAR

In a contest for "Most Boring Experience a Kid Can Have," undergoing dialysis is clearly a contender.

You sit in a room with white walls and no windows, hooked to a machine that does what your kidneys used to do. Your blood is pumped out through a large catheter and sent to the dialyzer, a membrane that filters out toxins and excess substances such as salt and water. Then your cleansed blood streams back into your veins.

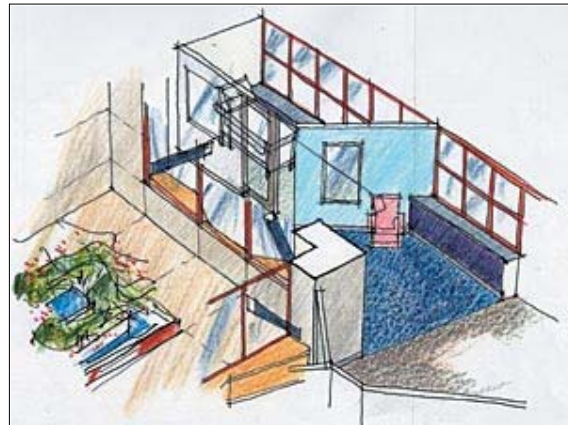
It's a three-days-a-week, four-hours-a-shot major bummer.

Plans to end this tedium for dialysis patients are under way at Lucile Packard Children's Hospital. Come this fall, construction will begin on a new facility that's designed to boost patient's spirits as well as their health.

Leading the drive for the new facility is Steven Alexander, M.D., medical director of dialysis and kidney transplantation, and director of pediatric nephrology. Alexander says the new facility will provide state-of-the-art dialysis treatment for children waiting for kidney transplants and those with temporary kidney failure; and do it in an environment that's welcoming and interesting to kids.

Kidneys can fail for many reasons, but when it happens to a child, it's usually because of a congenital abnormality, such as a blocked urethra or cysts in the kidneys. Certain health problems also can harm the kidneys, such as hypertension and frequent urinary tract infections.

By the time children need dialysis, they've lost nearly all kidney function. Most of them are candidates for transplants, and will need dialysis for anywhere from several months to several years, depending on how quickly a donor is found.



A new dialysis center will allow Packard to fully support its renowned kidney transplant program. The facility is being designed to create an inviting atmosphere for children who must spend months and even years undergoing dialysis. Each dialysis station will have a TV/DVD system, Internet access, and views of a sunny courtyard.

Waiting for Transplants

Packard has one of the largest, and the most successful, pediatric kidney transplant programs in the United States. Approximately 25 to 30 transplants are performed annually. The Hospital's expertise in kidney transplantation is bringing it more and tougher cases of kidney failure, and that means more demand for dialysis.

Currently the Hospital has only two dialysis machines, and it often must send some patients to other dialysis facilities in the San Francisco Bay Area. For example, in June of this year, nearly one-third of the Hospital's 19 dialysis patients received treatment elsewhere.

The new facility will have eight hemodialysis machines, tripling to 24 the number of patients who can be treated daily on site.

"Because of our successful kidney transplant program, we're seeing more kids with kidney disease," comments Harvey Cohen, M.D., Ph.D., Packard's chief of staff. "It's much more efficient, and I think the quality of care is better, if they can be treated in one place."

These state-of-the-art machines -- three of which already have been delivered -- come with sophisticated software that allows treatment to be customized for a patient's condition and adjusted on the spot. A nurse can check and immediately tweak a child's potassium levels and bloodflow rates, and Alexander can call up any dialysis machine and see what's happening, right from his office.

Alexander says the ability to tailor treatment especially helps children waiting for transplants.

"One of the reasons we have such good results with transplants is we send up healthy patients to our surgeons -- Dr. Salvatierra and Dr. Millan," says Alexander. "By being able to tailor dialysis, we can bring kids to transplant at the optimum time."

Being at Home

To help a child feel more at home during dialysis, every dialysis station will have a sophisticated audio/visual system that lets a patient access the Internet, watch TV and DVDs, and play games -- even interactive games with someone across the country or right there in the room.

Most of the machinery of dialysis will be hidden from view, and teens will have their own corner for treatment. From any point in the facility, patients can look out into a sunny, landscaped courtyard.

In addition, there will be a training room for parents who treat their children at home using portable dialysis machines.

Home dialysis uses the body's abdominal area, or peritoneal cavity, to filter wastes and excess fluids, and the patient's blood never leaves the body. It can be done on a patient of any age but it is the only kind of dialysis that works well on infants. That's because it is less invasive and much gentler on their small bodies.



In the new center, Steven Alexander, M.D., medical director of dialysis and kidney transplant, will be able to monitor and customize dialysis processes of patients like 2-year-old Bliss Williams, who is awaiting a kidney transplant.



It works like this: Before going to bed, the child is connected through a catheter in the belly to a small machine. Then, in continuous cycles throughout the night, the machine slowly fills the abdominal area with dialysis fluid; the fluid draws wastes from the blood vessels lining the abdomen; finally, the fluid and wastes are drained back into the machine.

Infant dialysis patients scheduled for transplants also are tube-fed highly nutritious food to get them plump and strong for their surgeries. That means before leaving Packard, their parents need to learn how to mix and give them their food at home. In addition, parents must understand how to give medications, as well as how to take their children's blood pressure and weight twice a day.

The new facility's training room, staffed by two highly experienced training nurses, will provide parents with a comfortable setting in which to gain confidence and skill in home treatment.

Child Friendly Features

Many of the facility's features came from the ideas of patients and their parents who were asked to help design it, says nephrologist Peter Yorgin, M.D., one of Alexander's team members.

"Most dialysis facilities are designed for adults, and the kids are really bored and uncomfortable while they're there," Yorgin says. "Here, we have a great opportunity to build from the ground up so that it works for kids."

Danielle Moyco, an 11-year-old from Hayward, California, knows how boring dialysis can be; she spent two years in treatment. Danielle was diagnosed in 2000 with glomerulonephritis -- an inflammation of the kidney that can ultimately destroy it. Both kidneys were removed in 2001, and she stayed on dialysis until her transplant in 2002.

Here's what Danielle says would make a dialysis facility nicer: "Color the walls with flowers and animals so it's more alive. The chairs are always cold, so maybe you could have something like electric blankets for seats. And you could have beads and coloring books."

"But first you have to do homework," she reminds future patients.

Promising New Therapies

On top of offering quality care for body and spirit, the new facility will allow Alexander and other doctors to try new therapies. One area ripe for research is using dialysis to treat other conditions caused by kidney failure, such as anemia, and weak or stunted bones.

All this will make Packard as well known for pediatric dialysis five years from now as it's known today for pediatric kidney transplantation, Alexander predicts. That means it can attract the best practitioners, researchers, and students in the field.

In research, Packard already is exploring, and using in the pediatric intensive care unit (PICU), a type of dialysis that appears to thwart a devastating and usually lethal respiratory complication commonly faced by patients who've had bone marrow transplants, chemotherapy, or radiation. The complication is called acute respiratory distress syndrome or ARDS. The method used to treat it is called hemofiltration, and it is a gentler form of dialysis. The nurses in the new dialysis facility will be trained to work closely with PICU staff to perform hemofiltration with portable equipment that they can take into the PICU.

Joseph DiCarlo, M.D., a PICU physician, initiated the use of hemofiltration on patients in the PICU in 1997. Its remarkable success over the years encouraged the PICU staff to use the technique more and more often, until today hemofiltration is considered standard practice at the Hospital for nearly all critically ill patients with ARDS.



Suzanne Springs of Redwood City, California, is convinced that her 10-year-old daughter, Zandalee, is alive today because of hemofiltration.

Cancer survivor Zandalee Springs (left) is alive today thanks to an experimental treatment involving hemofiltration, a type of dialysis used by Joseph DiCarlo, M.D. (right), in the pediatric intensive care unit.

When she was 8, Zandalee was diagnosed with stage-3 T-cell lymphoma, an advanced state of a cancer that affects the cells that fight infection and disease. She began chemotherapy and later radiation. A year later, she landed in the PICU with ARDS.

DiCarlo was on duty the day she arrived, and Suzanne recalls their conversation:

"He told me the chances were maybe 50/50 of someone like Zandalee making it, and then he started explaining about this experimental treatment. I'm listening to him give this long explanation of how it works and I'm thinking, 'Will you just be quiet and get started?'"

Zandalee rallied after two weeks of treatment. She stayed on the ventilator and continued hemofiltration for another two weeks, and then went home.

"I'll tell you this," says Suzanne. "If it wasn't for prayer, Dr. DiCarlo, and the dialysis machine, she would not have made it."

For whatever reason -- genes, accidents, disease, fate, bad luck -- kids like Danielle and Zandalee suddenly take a long and bumpy detour from a carefree childhood and arrive at Packard. From here, it will be a long time before they get to be what they so want to be -- just regular kids -- and they'll learn more about discomfort and discouragement than any kid ever should.

But part of this journey is about to get better. The new pediatric dialysis unit, built with young bodies and souls in mind, will greatly enhance Packard's use of dialysis -- the life line for children awaiting kidney transplants, and for many facing other life threatening diseases as well.

The Campaign

Within the [Transplant and Tissue Engineering Center](#), one of six Centers of Excellence in the [Campaign for Lucile Packard Children's Hospital](#), is a plan to significantly enhance the limited dialysis capabilities at Packard. The plan includes a new dialysis facility, sophisticated equipment, and additional dialysis specialists.

Gift Opportunities

Dialysis Facility: \$2 million

This naming gift for the construction of a new pediatric dialysis facility is a major commitment to the future of pediatric dialysis care at

Packard Children's Hospital. Packard plans to transform its current 400- square-foot hemodialysis unit with two machines into a 2,811-square-foot facility with six dialysis stations and two mobile units.

Endowed Director of Pediatric Dialysis: \$3 million

The Director will oversee Packard's dialysis program and will take part in the clinical care of nephrology and kidney transplant patients.

Endowed Dialysis Program Support: \$250,000 and up

This endowment will fund ancillary needs of the dialysis unit including the services of play therapists, psychologists, dieticians, and social workers. It also will help fund ongoing program needs, including catheters, child-sized equipment, and lab testing.

Dialysis Equipment: \$50,000

Through a general gift from the San Francisco Auxiliary, the Hospital has purchased six new dialysis machines to be used in the new facility. Additional equipment needs include five new "Critline" machines to monitor changes in blood volume, and a hemofiltration machine to treat oncology patients who have developed acute and life threatening respiratory conditions.

For more information about gift opportunities, please call (650) 498-7641 or e-mail campaign@lpfch.org.