ARNOLD PALMER HOSPITAL
For Children
Supported by Arnold Palmer Medical Center Foundation

Hewell Kids' Kidney Center
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Welcome to the Hewell Kids' Kidney Center

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Special thanks and recognition go to Barbara M. Cometti, Jennifer P. McDonald and Michael D. Schwing for their contributions and dedication in compiling this handbook.

SECTION 1

INTRODUCTIONS TO STAFF

This handbook is designed to assist you, the patient/family, by enhancing your understanding of the diagnosis, by knowing what you can expect from your healthcare team at the Hewell Kids' Kidney Center at Arnold Palmer Hospital for Children, and by clarifying what your healthcare team expects from you as a participant in your treatment.

OUR TEAM

Physicians

Jorge A. Ramirez, MD

Jorge A. Ramirez, MD, is board certified in pediatrics and pediatric nephrology and currently serves as the medical director of pediatric nephrology. Dr. Ramirez was born in Cuba and moved to the United States as a child. He is a graduate of the University of Monterrey in Mexico and completed his pediatric residency training at the Women & Children's Hospital of Buffalo in New York in 1989, where he was the pediatric chief resident in 1989 and 1990. Dr. Ramirez completed a pediatric nephrology fellowship at UCLA Medical Center in 1993. Dr. Ramirez is married with three children and enjoys golfing in his spare time. He is fluent in Spanish. He has received Orlando's Best Doctor award in 2006, 2007, 2008, 2010 and 2011.

Maricor Grio, MD, MS

Maricor Grio, MD, MS, joined Orlando Health Pediatric Nephrology Specialty Practice in 2007. Dr. Grio completed her medical degree from the University of Miami Miller School of Medicine in 2001 and her pediatric residency at Orlando Health in 2004. She served as a fellow in pediatric nephrology at the University of Michigan and was awarded the K30 scholarship from the National Institute of Health during her fellowship training. Dr. Grio achieved a master's degree in clinical research design and statistical analysis from the University of Michigan School of Public Health in 2007, with successful research in pharmacokinetics and continuous renal replacement therapy. Dr Grio was awarded "Leading Physician of the World and Top Pediatric Nephrologist in Orlando" by the International Association of Healthcare Professionals in 2011. She enjoys reading, hiking and traveling in her spare time; and advocates UNICEF and child literacy. Dr Grio is board certified in general pediatrics and pediatric nephrology, and she is committed to providing her patients with the best care possible.

Pharmacist

Jennifer Shenk, PharmD

Jennifer Shenk is a pediatric pharmacy clinical specialist. She graduated from West Virginia University with her Doctor of Pharmacy in 2008. She completed her PGY1 pharmacy practice residency at West Virginia University Hospitals in 2009. Since she took a strong interest in pediatric pharmacy, she moved to Orlando to complete her PGY2 pediatric specialty pharmacy residency at Arnold Palmer Medical Center in 2010. Jennifer works primarily in the Pediatric Special Care Unit of Arnold Palmer Hospital, but also serves as the pharmacy liaison to the Hewell Kids' Kidney Center. She is committed to helping patients and caregivers understand their medications to improve compliance. Jennifer enjoys spending time with her family and friends, traveling, swimming, reading and shopping.

Registered Dietitian

Jennifer McDonald, RD, LD/N, CDE

Jennifer McDonald is a registered and licensed dietitian. She graduated from Michigan State University with a bachelor's degree in nutrition with a specialization in health promotion. She completed an internship at Henry Ford Hospital in Detroit. Jennifer is a nationally board-certified diabetes educator working in pediatrics since the start of her career. She has years of experience covering multiple specialty areas such as gastroenterology, endocrinology and nephrology. She is committed to helping children and families with lifestyle modifications for their illness to make their lives easier. Jennifer enjoys traveling with her husband, along with nature, family and making jewelry.

Clinical Social Worker / Mental Health Therapist

Michael D. Schwing, MSW, LCSW

Michael Schwing is a licensed clinical social worker certified in children's services. With a Master of Social Work degree from the University of Central Florida's (UCF) School of Social Work, Michael has practiced as a clinical social worker since 2003. Michael completed his clinical internship at UCF's on-campus Student Mental Health Clinic, and his generalist internship with the Florida Department of Children & Families. Prior to joining Orlando Health, Michael served for over six years as a child and family therapist at a children's group home in central Florida. He has extensive experience working with diverse populations of children and families in a multidisciplinary team approach. Michael practices with a commitment to enhancing the quality of life of clients in the community and engages clients through unconditional positive regard and sensitivity to cultural and socio-economic characteristics. Michael and his wife enjoy traveling, kickboxing and family genealogy

Nurse Practitioner

Patricia Butterbaugh, ARNP

Trisha Butterbaugh is a certified advanced registered nurse practitioner. She graduated from the University of Mississippi with a bachelor's degree in nursing and from Northwestern State University with a master's degree in nursing in the Family Nurse Practitioner program. Trisha has worked in various fields of nursing since starting her career in 1983, with an emphasis in critical care nursing. Since graduating from nurse practitioner school in 1999, she has primarily worked with children. She worked at the Louisiana State University Outpatient Pediatric Clinic before relocating to the Orlando area in 2002. Prior to joining the Orlando Health Pediatric Nephrology Specialty Practice, she worked with a local pediatrician in the Baldwin Park area. She has been with Arnold Palmer Hospital since January of 2009. Trisha has experience with managing patients, not only in the inpatient setting, but also in the outpatient clinic. She works daily with patients that have chronic kidney disease, patients that require dialysis and those who have undergone kidney transplant. She is devoted to giving the best care possible to all her patients. Trisha enjoys gardening, walking her dog and swimming. She enjoys traveling with her husband and daughter, exploring new places, hiking in the mountains and walking the beaches.

Nursing Operations Manager
Pediatric Special Care Unit and Hewell Kids' Kidney Center

Lourdes Rosario, RN, BSN, CPN

Lourdes Rosario is a native New Yorker but has lived in Florida for the past 28 years. She graduated from Bronx Community College in New York with an associate of applied science degree and later obtained her Bachelor of Science in Nursing from Florida Southern College. She has worked with pediatric patients and their families her entire career in a variety of different areas including the Pediatric Intensive Care Unit, Pediatric Step-Down Unit, and Infants, Children, and Adolescent Units. Her love for kidney patients began about 21 years ago while personally caring for a renal baby and becoming a part-time caregiver for him.

Assistant Nurse Manager

Barbara Cometti, BA, RN, CDN

Barbara Cometti is a certified dialysis nurse. She graduated from Hofstra University in New York with a dual bachelor's degree in communications and psychology and from Columbia College with a degree in nursing. Barbara started working in nephrology nursing in 1997 in Colorado with the adult nephrology population, then in pediatric nephrology at Colorado Children's Hospital in Denver for the last five and a half years before coming to Orlando Health and the Hewell Kids' Kidney Center in July 2011. She is currently working toward her master's degree in healthcare administration through the University of Northern Colorado. She is fluent in Italian and enjoys spending time with her family, traveling and the great outdoors.

Clinical Care Coordinator

Melinda Rivera, AA, ASN, RN

Melinda Rivera began working in the Acute Pediatrics Department at Arnold Palmer Hospital in January 1999 as a clinical technician while she attended Valencia Community College's (VCC) nursing program. She graduated from VCC with an associate in arts and associate of science in nursing in 2002. She then transitioned within the registered nurse role in July 2002, and continued to work in the Acute Pediatrics Department for a total of five and a half years. In October of 2005 she began working in the outpatient setting at the Pediatric Nephrology Specialty Practice as a registered nurse and was promoted to outpatient clinical specialty coordinator in March of 2010. She currently holds this position in the Hewell Kids' Kidney Center. Melinda is proud to say that she has worked at Arnold Palmer Hospital for more than 10 years as an outpatient clinical specialty coordinator ensuring that the department delivers quality service and optimization of patient flow. In her spare time she likes to scrapbook — mainly of her two beautiful children.

Staff Registered Nurse/Preceptor

Amy Martinez, RN, ASN, PALS

Amy Martinez is a registered nurse with six years of experience in the medical field. Amy obtained her associate's degree in nursing at Florida Hospital College of Health Sciences, where she specialized in adult cardiology for three years at Florida Hospital. Amy became part of the Arnold Palmer Hospital Pediatric Nephrology Department in 2008, where she began to specialize in pediatric nephrology. At the Hewell Kids' Kidney Center, Amy is responsible for triaging patient calls and managing patient care. Amy enjoys working with kids and being involved in her patients' care as much as she can. Amy's hobbies are arts and crafts, singing (in the shower), interior decorating and spending time with her husband and two kids.

Lynda K. Haskett, LPN II

Lynda Haskett has been a LPN II at Orlando Health for 20 years, working in Adult Cardiac for one year, then the Mother Baby Unit, NICU/Extended Care, Acute Pediatrics and Radiology/Anesthesia, before joining the Hewell Kids' Kidney Center. Lynda states that she knew as a child that she wanted to be a nurse. Her grandmother, mother and she were pink ladies for Orlando Regional Medical Center all at the same time 25 years ago. Lynda has lived in Central Florida for the past 50 years. She is happily married, has three grown children, and six grandchildren. Her family is the love of her life. She enjoys cooking, horseback riding, motorcycling with her husband, and having her family and friends over to visit.

Francisca Paler, RMA/Phlebotomist Technician, AAMA, NPA

Francisca Paler worked for 17 years in New York as a registered medical assistant. She relocated to Florida in 2004 and worked at Florida Hospital as a nurse technician. In December 2010, she joined Orlando Health to work at the Hewell Kids' Kidney Center, where she enjoys working with children. Francisca's favorite quote is "There is only one person that can make you happy, and that person is yourself!" by David Burns.

Front Office Assistant

Venessa Nieves

Venessa Nieves was born and raised in Chicago, in Humboldt Park. She is the youngest of five children. After graduating from high school, she attended Harold Washington College and obtained an associate's degree. She worked at Northwestern Medical Faculty Foundation in an OB/GYN practice for five years at which time she decided to join her family in Orlando in May 2010. In February of 2011, she joined the team at Hewell Kids' Kidney Center. She is currently the front office assistant / department secretary. She greets and receives patients and their families; answers, screens and routes incoming calls and takes messages as needed; types memos, correspondence, reports and other documents; assists patients and staff with questions and information; issues visitors' passes and assists scheduler in making future appointments.

Financial Counselor II

Nancy Gutierrez-Rivera

Nancy Gutierrez-Rivera has been working at Orlando Health for 10 years in the Business Office. In April 2011, she had the opportunity to move to the Hewell Kids' Kidney Center to handle registration and scheduling for the Orlando office. As a financial counselor, Nancy uses the registration process to make sure that all the information from the patient, which includes address, contact phone numbers, the PCP (primary care physician) and insurance information, are current and accurate. She loves traveling in her RV, riding her motorcycle and planting.

SECTION 2

WHAT YOU NEED TO KNOW ABOUT YOUR KIDNEYS

Most people have two kidneys. You need at least one working kidney to live. The kidneys are located under the ribs in the back of the body, just above your waist. They are each about the size of your fist.

The kidneys do a lot of important jobs:

- Kidneys filter your blood. They keep what your body needs and get rid of what your body does not need.
- Kidneys keep the right amount of fluids in your body. Too little fluid, called dehydration, or too much fluid can cause many problems.
- Kidneys make three important hormones. Hormones are chemical messengers. They signal the need to make red blood cells, control blood pressure and help the body use vitamin D.

HEALTHY KIDNEYS

A healthy kidney filters all the blood in the body every 30 minutes.

1. From the artery, blood flows into the kidneys and passes through millions of tiny filtering units called glomeruli.
2. These tiny glomeruli filters can tell the difference between something you need and something you do not need. They can filter out the waste and extra fluid from your blood to make urine.
3. Tubes called ureters carry the urine to the bladder. Urine is then removed when you urinate (pee).
4. The cleaned, filtered blood then goes into the vein and back into your body's circulation.

SECTION 3

KIDNEY PROBLEMS

Kidneys can get damaged, and when they are damaged they cannot do all the things they should. When this happens it is called chronic kidney disease, or CKD. Chronic kidney disease can affect anyone, young or old.

Chronic kidney disease does not happen overnight. It happens slowly, and in stages. People with early kidney disease may not know that anything is wrong. They cannot feel the damage before some kidney function has gone.

What can damage the kidneys?

- Injury from an accident or trauma.
- Severe or chronic infections such as Hepatitis C, HIV or other severe viral and bacterial infections.
- Certain medications that are used too often for pain or fever, like those that are called non-steroidal such as ibuprofen and naproxen. Also, certain contrast drugs/dyes used in X-rays and scans. Always ask your doctor or pharmacist.
- Diabetes is the most common cause of kidney disease. Diabetes is a chronic disease where the body cannot control sugar. A high sugar level in the blood damages the small filters (glomeruli) in the kidneys.
- High blood pressure is the second most common cause of chronic kidney disease. High blood pressure makes the kidneys work much harder. This can damage the filters. People with high blood pressure can also have protein in the urine. Protein can mean the kidneys are damaged.
- **Kidney conditions:**
  - Glomerulonephritis is the third most common cause of kidney disease. It is usually caused by an infection that affects the glomeruli. They are the very small filtering parts of the kidneys.
  - Polycystic kidney disease (PKD) is an inherited kidney problem. People with PKD have many cysts in their kidneys. These cysts can take over the normal tissue in the kidney, making it harder for the kidneys to do their job.
  - Obstructions such as kidney stones can cause kidney damage if not treated quickly.
- Kidney disease also has other causes, which can include collagen-vascular diseases such as lupus, cancer, congenital defects and sickle cell disease.

SECTION 4

COMPLICATIONS OF CHRONIC KIDNEY DISEASE

Once a person has developed chronic renal failure, therapy options are basically the same regardless of the cause. However, some primary diseases may complicate the treatment.

Uremia

Patients whose kidneys are failing may have severe uremia, which is urine in the blood. Patients with uremia have many symptoms, including skin that appears yellow-gray, edema (swelling), high blood pressure, loss of appetite, nausea and vomiting, itchiness, shortness of breath, fatigue and weakness.

Anemia

Anemia is a shortage of red blood cells. Red blood cells carry oxygen throughout the body. Anemia in kidney disease is caused by the lack of erythropoietin, a hormone that is produced by healthy kidneys. Anemia may lead to fatigue, dizziness, shortness of breath and heart problems. With regular treatment with a medication called epogen (a genetically engineered form of erythropoietin), your red blood cells can be increased to normal values.

Renal Osteodystrophy

Renal osteodystrophy is a type of bone disease that occurs in patients with renal failure. This common disorder is caused by loss of calcium and excess phosphorus, which can cause weakened bones. Calcium regulates muscle function, aids nerve conduction (making you be able to move your nerves/muscles), helps blood clot and forms the major parts of your bones. Calcium and phosphorus levels are normally kept in good balance. With normal kidney function, calcium from your diet is absorbed in the gut with the help of calcitriol (an activated form of vitamin D produced by the kidneys). Calcitriol also helps the body absorb phosphorus, which is found in most foods. Some calcium and phosphorus is used in the blood, most is stored in the bones, and the kidney excretes the rest. When the kidneys fail they stop making calcitriol, and they stop excreting excess phosphorus in the urine. Without calcitriol, the body does not absorb calcium from food like it should. After awhile, the calcium loss and phosphorus excess causes your bones to become weak and at risk of fractures. It can also interfere with the making of new red blood cells and can add to your anemia problems. Treatments are available to help patients prevent bone fractures by limiting foods that contain phosphorus and taking phosphate binders (Tums, Renagel).

Electrolyte Imbalances

Electrolytes are substances that break apart into ions, which are electrically charged particles. They are found in body fluids and inside your cells. They are involved in many basic cell functions, including the sending of important signals between different types of cells, such as nerve impulse transmissions. Electrolyte levels in the body are normally controlled by the kidneys. Renal failure can upset the normal balance between the eliminating and reabsorbing of electrolytes in the kidneys and can lead to electrolyte imbalances. When the concentration of electrolytes in the blood is too high or too low, there can be serious effects on many body functions. The most important electrolytes to consider are sodium, potassium, calcium, phosphate, magnesium and bicarbonate.

Sodium

Sodium is important for maintaining your body's fluid balance. Having too much sodium/salt in your blood is called hypernatremia. It can cause swelling, called edema, which is the buildup of water in some of the tissues in your body. It can also cause shriveling of your red blood cells. Some signs of high sodium are excessive thirst, high blood pressure, headaches, confusion, seizures and coma. Low sodium, called hyponatremia, can also occur in renal failure patients. With hyponatremia, water moves into the cells. Red blood cells may swell to the point of bursting, which is called hemolysis. Other symptoms may include low blood pressure, muscle cramping, headaches, nausea, vomiting, tremors and seizures.

Potassium

Potassium has a major role in the function of the nerves and muscles, which includes heart muscle contraction. Most of the body's potassium is found within the muscle cells. A higher than normal potassium level, called hyperkalemia, can cause serious or even fatal changes in your heart rhythm. Symptoms include muscle weakness and abnormal heart rhythm. It can cause sudden cardiac arrest (make your heart stop beating). Hypokalemia is a lower than normal blood potassium level. It is unusual in dialysis patients but can occur, especially if you have been vomiting, had diarrhea, have a diet that is low in potassium, or too much potassium is removed by dialysis. The symptoms include fatigue (being really tired), muscle weakness, paralysis, respiratory failure, abnormal heart rhythms and cardiac arrest.

Calcium

Calcium is found mostly within the bones and teeth. Small amounts of calcium are vital for controlling many cell activities, including clotting, enzyme regulation, hormone actions, and function of nerves and muscles. Too much calcium is called hypercalcaemia. Higher than normal calcium in the blood can cause poor appetite, nausea, vomiting, abdominal pain as well as central nervous system problems where a patient can experience confusion, delirium, irritability and even coma. Long-term hypercalcaemia can lead to calcium deposits in joints, soft tissues, eyes and blood vessels. Hypocalcaemia, which is low calcium levels, primarily affects the nervous system. Symptoms include dementia, depression, numbness, seizures and tetany (muscle spasms and pain). Long-term hypocalcaemia can raise the parathyroid hormone level, which contributes to bone disease in renal failure patients.

Phosphate

Phosphate is an important structural component of cell membranes and bones and is essential for energy metabolism. Hyperphosphatemia is high blood phosphorus levels, which can lead to itching, bone damage and secondary hyperparathyroidism. Hypophosphatemia, which is below-normal levels of phosphate, may not be seen until late in the disease. It can cause muscle weakness and osteomalacia (softening of the bones).

SECTION 5

TREATING KIDNEY FAILURE

Choosing a Treatment

The most important thing in picking a type of renal replacement therapy is choice. The availability, location and convenience of treatment are factors that can influence your choice of treatment.

In acute kidney failure, hemodialysis is usually the treatment of choice until the injured kidneys can recover. In chronic kidney failure, there are a number of choices, based on your preferences and medical condition. Certain medical conditions may limit your choice of treatments.

Transplantation

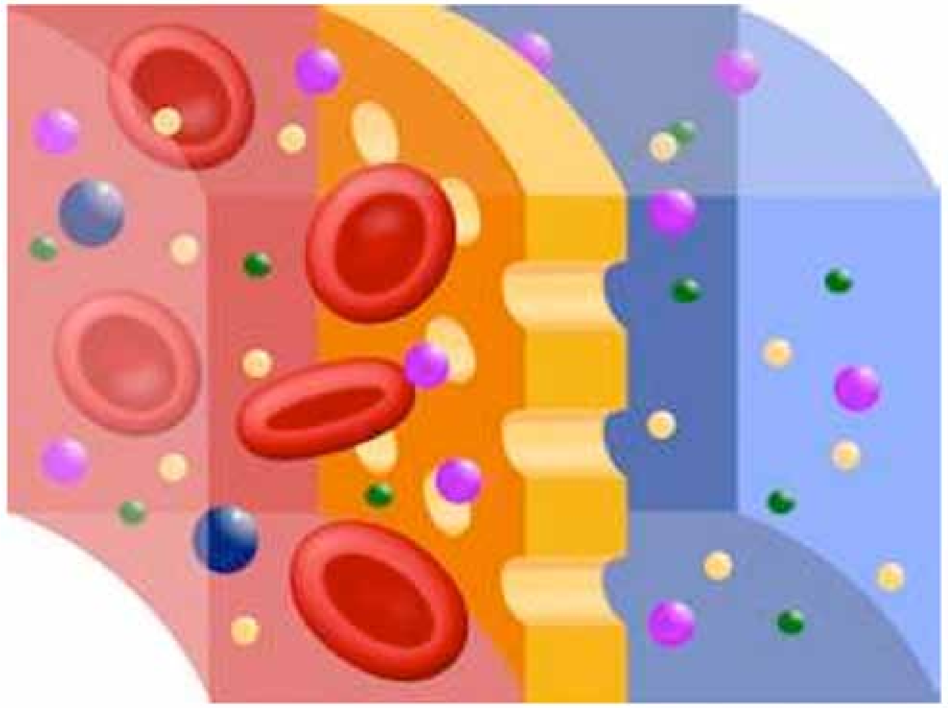
A kidney transplant provides the patient with one healthy kidney from a donor. Not all people with kidney failure are medically able to receive a transplant. If a patient wants a kidney transplant, they need to have a thorough medical workup to see if they are a good surgical risk. If they are a good candidate for a transplant, they can next decide if they want to receive a kidney from a blood relative, friend or other living donor, or they can be placed on a transplant list for a deceased donor called a cadaveric. Family members and friends in good health can volunteer to donate a kidney, but they must also be suitable for surgery. They will need to be tested to check their blood type and tissue to see if it matches the patient's.

Once transplanted, a patient will need to take immunosuppressant drugs. This prevents their bodies from rejecting, fighting and destroying the transplanted organ for the life of that organ.

A transplant is not a cure; however, a transplanted organ may last several years. The shortage of matching cadaver organs available for transplant means that some patients may have to wait longer. Patients are usually treated with dialysis while they wait, and if the transplant does not work they may go back on dialysis again. Most people have to start out on dialysis, even if they want a transplanted kidney.

DIALYSIS

Dialysis is the medical term for removing the wastes and extra fluid from your blood that your kidneys can no longer remove themselves. Dialysis works on the principles of the diffusion of solutes and ultra-filtration of fluid across a semipermeable membrane. Diffusion describes how substances react in water. Substances in water tend to move from an area of high concentration to an area of low concentration. In dialysis, the blood flows by one side of a semipermeable membrane, and a dialysate, or special dialysis fluid, flows by the opposite side. A semipermeable membrane is a thin layer of material that contains various sized holes, or pores. Smaller dissolved substances and fluids can pass through the membrane, but the membrane blocks the larger substances (for example, red blood cells, large proteins) from going through.

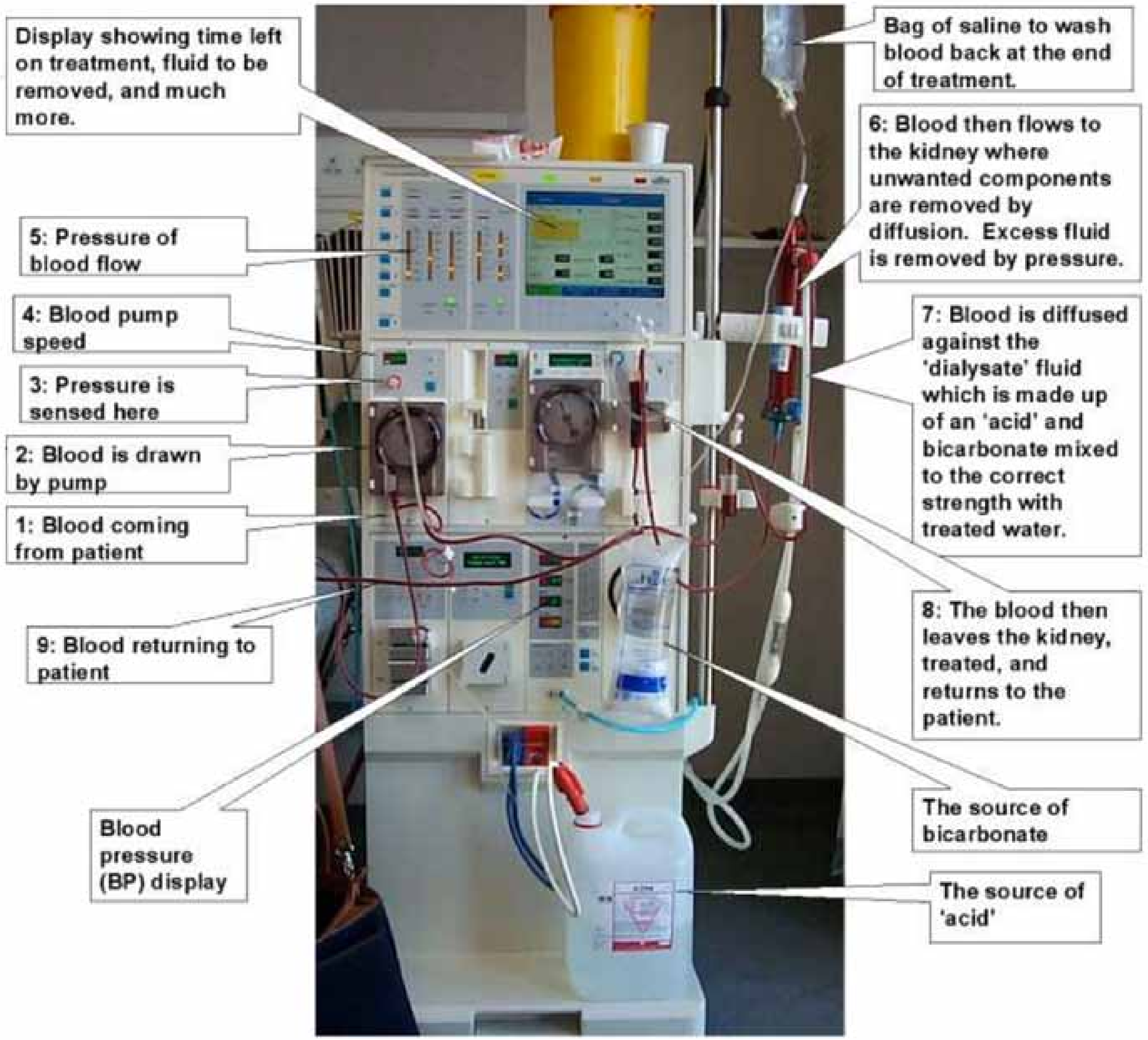


There are basically two types of dialysis: peritoneal dialysis and hemodialysis. Both types of dialysis work well. There may be medical reasons why one therapy is better for you than another. It is not uncommon to start with one type of treatment and then change to another.

Hemodialysis

Hemodialysis is performed in hospitals, clinics and homes all over the world. In hemodialysis, blood is pumped out of a patient's vascular access through an artificial kidney or hemodialyzer, and then is pumped back into the vascular access. About one cup of blood is outside the body at any one time.

On the next page is a picture of some of the things you will see if you go on hemodialysis.



Most dialysis treatments today take 3-5 hours 1, 2 or 3 times a week. The treatment time depends on the size, activity level, diet and how much kidney function is left with each individual patient.

Patients who do not receive their prescribed dialysis treatments become more ill. It is very important that you receive your full treatments as prescribed by your doctor. Please call the dialysis facility when you are unable to keep your appointment. ***We may be able*** to reschedule your treatment.

Missing Dialysis
Skipping treatments and shortening dialysis time can cause many complications:

- Fluid overload — you can have shortness of breath from all the excess fluid. The excess fluid can go to your lungs making it hard to breathe.
- Heart complications — cardiac arrhythmias, cardiac arrest due to high potassium levels.
- Worsening of anemia and bone disease — due to missed medications from missed dialysis treatments.

While you are having your treatment, you will be sitting or lying next to a hemodialysis machine. A nurse or technician will place you on dialysis using a vascular access that was put in specially for you to receive dialysis. There are several types of accesses. To put in an access to get your blood, a surgeon will do an operation to strengthen one of your veins inside your arm or thigh. This is called a fistula. If your veins are small or weak, the surgeon puts in a graft. A graft is a soft tube connected to an artery on one end and a vein on the other. Blood then runs through the graft and/or fistula. Both a fistula and a graft are underneath the skin. A permanent access can take up to a few months to heal correctly and may not be used right away. The surgery is done in the hospital, and the patient may have an overnight stay.

Most of the time, hemodialysis treatments are done in a hospital or dialysis unit. Appointments must be scheduled in advance and are usually at the same time on the same days or as your physician orders.

If you need dialysis before a permanent access is in place, the doctor will make a temporary access. This is done by placing a special tube called a HD catheter in a large blood vessel in your neck or groin area.

Fistula / Graft / HD Catheter
Arteriovenous fistulas generally last many years, have less infection and fewer complications, and can use higher blood flows during dialysis. They are named AV fistulas because they connect an (A) artery to a (V) vein. After they are connected, the stronger arterial blood passing through the vein makes the vein larger and stronger. It takes about 6 weeks for the fistula to get large enough and the walls thick enough to deliver blood flow and be used for hemodialysis.

A fistula may not work for everyone, but new surgical techniques and vein mapping can make it possible for more and more people to have a working fistula. Vein or vessel mapping tells your surgeon where your blood vessels are located, how large they are and if they are healthy enough to be used for a fistula.

A graft is when a small soft tube is placed under the skin during the surgery, and one end is attached to an artery and the other end to a vein. They can be used within 2 to 3 weeks.

A HD catheter is a small Y-shaped plastic tube that is put into a large vein in the neck. The top part of the catheter is outside the body, and the bottom part sits in the heart. Catheters can be used right away.

You owe it to yourself to make sure you have the best possible vascular access. To find out which access will best work for you, read this information and visit www.fistulafirst.org, then talk to your nephrologist and surgeon.

Peritoneal Dialysis
Peritoneal dialysis (PD) cleans your blood and removes extra fluids using your own body's membranes, the peritoneal membrane. The peritoneal membrane is the lining that surrounds the peritoneal abdominal cavity. This cavity contains your stomach, liver, spleen and intestines. In this type of dialysis, your blood is cleaned inside your body.

A nurse experienced in PD will train you to perform the dialysis in the dialysis unit for about a week or two as an outpatient. To perform peritoneal dialysis, a small soft tube called a catheter is put through the wall of your abdomen into the peritoneal cavity. The PD solution flows in and out of the peritoneal cavity through this catheter. These ins and outs are called exchanges.

Continuous cycling peritoneal dialysis is done overnight, with a machine called a cycler. This machine does the exchanges automatically, usually when you are sleeping.

YOUR MEDICATIONS

- Know and carry a current list of ALL your medications (name, dose and frequency) with you at ALL times.
- Update your medication list when changes are made.
- Know why you take each medication.
- If you have trouble remembering to take or give the medications, keep a calendar or notebook and check off when the medication was given. Try to associate taking your medication with things you do each day, such as brushing your teeth or eating meals.
- Keep all medications stored securely and out of the reach of children. Store all medications in a dry and cool place (not the bathroom or kitchen), unless they must be refrigerated. Make sure your medications are not expired, which can be found on the prescription bottle.
- Don’t wait until you are out of medications to get them refilled. Always call in and pick up medication refills when you have a 1-week supply of your medicines. This will always give you a 1-week supply in case of emergencies.
- If you don’t understand or have trouble getting your medication, ask your pharmacist or your doctor.
- Try to get all your medications filled at the same pharmacy. This will allow the pharmacist to make sure all of your medications are safe for you.

Information above provided by Jennifer Shenk, PharmD, pediatric pharmacy clinical specialist at Arnold Palmer Hospital.

SECTION 6

NUTRITION WITH CHRONIC KIDNEY DISEASE

Role of the Nutritionist:

- To help you learn the self-management techniques to create an overall healthy diet with adjustments made for your lab results. Your dietary limitations will depend on your blood work.
- To provide you with a renal diet that will help control buildup of waste products and fluid in your blood.

What is a Renal Diet?

Adequate Protein

- Need enough protein for nourishment, growth and tissue repair.
- Rich sources of protein are lean beef, poultry, fish, eggs and seafood.
- Ask your nutritionist how much protein is right for your diet because this may vary with the type of dialysis you are on.

Low Sodium

- High sodium intake can increase blood pressure and cause fluid to stay in your body. Excess fluid in the body can cause difficulty breathing, chest pain, edema and high blood pressure.
- High sodium foods are salt, canned soups, frozen dinners, processed cheese, fast food, pickles, olives, and smoked and cured foods such as bacon, ham and luncheon meats.
- Read labels. Choose products with less than 140 mg sodium per serving and less than 600 mg sodium for a meal.

Fluids

- If you are retaining fluids or have little or no urine output, you may need to limit liquid intake to 4 cups (1 liter) of fluid per day.
- You must measure any liquid or any food that melts in your mouth, like ice cream, ice, Jell-O, pudding, broth, coffee, tea and milk.
- Excess fluid in the body can cause difficulty breathing, chest pain, edema, high blood pressure.
- Your nutritionist can share tips on how to control thirst and dry mouth.

Phosphorus

- High levels of phosphorus can weaken your bones.
- Control phosphorus by avoiding high-phosphorus foods, such as dried beans and peas, nuts, liver and other organ meats, cola, canned salmon. Limit your milk intake to ½ cup and cheese to 1 ounce per day. Take phosphate binders as prescribed by your doctor. Examples of phosphorus binders are calcium carbonate, "Tums," Phoslo, Renagel and Renvela.

Potassium

- Both high and low potassium levels are dangerous to your heart. We need to watch your potassium closely in your blood.
- Foods high in potassium content are bananas, oranges, kiwi, dark green leafy vegetables, broccoli, dried beans, salt substitutes, nuts, potatoes and tomatoes.
- Your nutritionist can help you with diet modifications.

Vitamins and Minerals

- Vitamins made for patients with kidney disease have extra B-vitamins, no vitamin A and some vitamin C. Your nutritionist will start you on a renal multivitamin.
- Most patients need extra vitamin D, which is checked in your blood work and will be given as needed depending on your level.
- Iron supplementation is needed to help increase red blood cells. Do not take your iron supplement at the same time as your calcium because it affects absorption.

SECTION 7

COPING WITH KIDNEY DISEASE

CHILDREN WITH CHRONIC KIDNEY DISEASE: TIPS FOR PARENTS

If your child has been diagnosed with chronic kidney disease, you are no doubt feeling distressed and bewildered. These feelings are normal. And once you realize that your child's illness is a reality the family must accept, you can develop some practical ways to cope with the day-to-day aspects of it. Here are some things others have found helpful.

Learn about the disease and its treatments

- Learn as much about your child's disease and its treatment as you possibly can, and pass this information on to your child. You would be surprised at how much even very young children can understand. Many times, they will accept information more easily than an adult.
- Encourage your child to ask questions, not only of you but of doctors, nurses and other health professionals. Many times, your child will ask questions you had not thought about or were afraid to ask because you thought they sounded "dumb."
- Don't try to explain more than your child can understand, but don't lie and don't apologize for any treatments or procedures that have to be followed.
- Help your child understand that the doctors, nurses, social workers, dietitians, laboratory personnel and everyone else is on his or her side. They all want to help your child feel better, even if that means they have to do things that will cause some temporary pain or discomfort.

Actively participate in your child's care

- Develop a spirit of mutual respect and cooperation with health professionals.
- Write out all the details of your child's medical history, including dates. This will make it easier for you each time you come in contact with a new doctor.
- Try to be with your child as much as possible during treatments and any hospitalization that might be necessary. If you cannot be there, arrange for someone else to be present, such as a grandparent, other relative or close family friend. And make sure a favorite book, stuffed animal or special blanket is taken along.
- If your child is not talking yet, it's a good idea to tape a note to his or her hospital bed or crib with helpful information for the healthcare team, such as favorite foods, special toys or blankets, preferred time and method of taking medicines.

Help your child take control of the illness

- Try to maintain a normal daily routine, even during hospitalization.
- Help your child understand about doctor's offices, hospitals, dialysis units and laboratories and how they are used. By helping your child understand the places that are filled with strange and frightening instruments and machines, you can help eliminate a lot of your child's fear.
- Be creative in finding ways for your child to participate in his or her own care. Your child will feel much more in control if you provide as many opportunities to do so as you can.

Help your child to understand and accept diet restrictions

- Even a child as young as 2 or 3 can understand about "diet" if it is explained simply. Often, the child will be more compliant with dietary restrictions than an adult will.
- Have your child make a list of favorite foods and take him or her with you when you talk to the dietitian to see if these foods can be incorporated into the diet plan.
- Whatever you do, don't ever use bribes or force your child to eat. These tactics rarely work and more often turn mealtime into a very unpleasant experience.

Don't let medicine time ruin your day

- A matter-of-fact attitude is your best weapon in getting your child to take medication. Even very small children will swallow anything, no matter how distasteful, if they know they have no choice.
- A good trick with babies and small children is to use syringes (minus the needles) to dispense the medication. Not only can you measure the medicine more accurately, but you can squirt the liquid directly in the child's mouth instead of having to deal with a teaspoon (associated with food) or a medicine cup. The benefit to your child is in not having to smell the medicine as well as taste it.
- Your child has no choice about whether or not to take prescribed medication, but you can offer a choice of when and where. And once the choice is made, make a schedule and stick to it. Unpleasantness is a lot easier to cope with if you know exactly when it is coming and do not put it off.
- Sometimes medication must be given with meals, but don't give it at the table where your child eats. Find someplace not associated with food and eating, such as the living or family room while your child is distracted by a favorite TV show.
- Another weapon you have at medicine time is plain, ordinary water. If your child is on a fluid-restricted diet, water may be one of the things he or she would like to have most, so reserve part of the day's fluid intake for a couple of swallows after medicine time.

Share your experience with others

- Don't let yourself become isolated. Talk with the renal staff and with other families of children with kidney disease.
- Don't hesitate to ask relatives and friends for help. Chances are they want to help but don't know how, and are just waiting for you to ask.
- Sharing your experience will help you find ways to grow with it.

HOW CAN THE FAMILY DEAL WITH THE STRESS OF CHRONIC KIDNEY DISEASE?

It is important to realize that the stresses and frustrations of kidney failure are real, and at times, very difficult. Family members may feel as though their world is caving in, especially if they have not faced a major health crisis before, and the diagnosis was unexpected. They may feel helpless because they cannot do anything about the child's illness. They may be angry that kidney disease has happened to "their" family. They may fear that the child could die. They may feel guilty if they did not realize the seriousness of the child's illness, thinking they should have or could have done something to prevent it.

A period of confusion and tension may occur as everyone tries to cope with the demands of the illness, the anxiety of treatment, the disruption of everyday life and the sudden presence of the healthcare team in your family's lives. Kidney failure requires changes in lifestyle. Routine chores and activities that demand some physical strength may be difficult for the child to perform now. Family members or friends may have to take on added responsibilities. Eventually, family life may return to nearly normal, with treatment becoming more or less routine. The following steps can help decrease stress:

- Talk to the healthcare team at the dialysis center or transplant clinic.
- Write down questions ahead of time and inform family members about changes in treatment.
- Find out as much as possible about the illness through the National Kidney Foundation (NKF), local or national support groups, written materials and educational classes.
- Help the child stay involved in the joys, activities and responsibilities of daily living.
- Find time to be active/exercise at a level to suit your child's abilities.
- Help the child share feelings with family or close friends.
- Help the child share feelings with other patients.
- Seek help from the clinical social worker at the dialysis center or transplant clinic, or from an outside counselor, if family or personal problems need further attention.
- Find time to enjoy the outdoors.
- Arrange your child's treatments around your previous activities.
- Be patient and set realistic goals in adjusting to all lifestyle changes.

WHEN YOUNG ADULTS HAVE KIDNEY DISEASE

How can teenagers with kidney failure handle fears about what friends and schoolmates will think of them?
Teenagers are concerned about how to tell their friends about their condition and how their friends will react. Often, schoolmates will notice the graft or fistula in the patient's arm and ask about it. Friends may wonder why the teen patient has to go to the hospital or clinic several times a week. Sometimes teenagers may have some knowledge about dialysis and transplants; they may have seen TV programs about kidney failure or transplants and be aware and supportive. Teenagers who have trouble telling others about their medical problem may not have worked out their own feelings about the illness. Talking with the school counselor or clinical social worker in the dialysis center or transplant clinic may help them work through these feelings. Also, talking to other teenagers with kidney disease about how they deal with things may help. The key is feeling secure and comfortable with themselves; then telling other people becomes easier.

Do many teenagers with chronic kidney disease feel that their plans for the future are over?
Yes. Most teenagers (and even adults) who have kidney failure feel this way. Having kidney disease affects an individual's life, but the future is far from over. Starting dialysis treatments or having a transplant, following a special diet and taking medicines are big changes. A kidney transplant may make extra medical visits necessary. Most young people worry about being able to continue with school, earn a living, get married or have meaningful relationships. However, many teenagers with kidney failure have gone on to complete school and start successful careers. Talking to the clinical social worker at the dialysis center or transplant clinic about these concerns may be helpful. Other teenagers with kidney failure may be willing to talk about how they cope with setbacks. Summer camp is a great place to meet other young people with kidney failure. The NKF or a social worker can provide information about the many summer camps throughout the country available for teenagers with kidney disease. The NKF also has a publication that is written especially for teenagers called: *It's Just a Part of My Life: A Guide for Young Adults with Chronic Kidney Disease.*

Can a youngster with kidney failure safely take part in active sports?
A youngster who is feeling well and enjoys active sports does not want to feel overprotected. Parents may find it hard to know how far to let their child venture. Talking this over with the doctor will help parents learn whether they are making a decision from a medical or emotional position. Often a doctor's advice will be based on the type of physical activity (e.g., horseback riding, football). Controlling a child too much may make the child angry, rebellious and resentful. It is important to try to keep a healthy balance between common sense and concern over the child's health and well-being. As time passes and the parents see that their child continues to feel better, they may feel more comfortable with their decisions.

How can a parent handle having to make difficult medical decisions for a child who has chronic kidney disease?
Parents do not have to make decisions about medical care alone. A team of healthcare professionals is there to help make these decisions based on the most up-to-date information. The choices are not always easy, and no one can predict the future. Parents always wonder whether they are doing the right thing. Parents must take comfort in trying to make the best decisions possible along with the healthcare team members. It may be helpful to talk issues over with other parents of children with chronic kidney disease.

What should the family do if the patient is not following medication and diet guidelines?
Families often confuse love with taking care of the patient. Even with the best of intentions, they can keep the patient in the "sick/dependent" role by taking too much responsibility for the patient's behavior. Generally, patients have a greater feeling of self-worth when they take control of their own behavior. The following suggestions can help avoid this problem:

- Family and staff need to realize that the patient has the illness as well as control over intake of food, fluids and medication. No one else can take on this control. In many cases, the patient will begin to follow the treatment plan if the family clearly states their concerns and limits of responsibility, then "backs off."
- A good caregiver is a loving, open person. However, struggles with the patient over diet, fluids and medicines are often mixed with needs for power and control, and feeling responsible and "better than" the patient. This, in turn, makes the patient angry and even less cooperative.
- Family members need to make sure that they are not making it more difficult for the patient to stick to the treatment by offering food or fluids not included in the diet.

THE ROLE OF THE CLINICAL SOCIAL WORKER

The clinical social worker serves as a support system for the patient and family in adjusting to and understanding end-stage renal disease (ESRD). Your social worker is the patient advocate, and serves as a bridge in communicating patient and family needs to the healthcare team, which consists of the nephrologists, nurses, dietitians, clinical social workers and of course, most importantly, the patient.

The clinical social worker must complete an initial assessment with the patient within the first 30 days of admission to the dialysis unit. During this assessment, the patient will be asked numerous questions. Topics include:

- Family and other support systems
- Current activities and limitations
- Financial and insurance information
- Medical history
- Emotional health
- Mental health or substance abuse concerns
- Physical abilities
- Preference in treatment modality
- Legal documentation, such as advanced directives
- Education and work history

In addition to helping patients with learning how to cope with kidney disease and adjusting to the life changes of dialysis, other clinical social worker responsibilities include:

- Evaluating for vocational rehabilitation services, which include employment, going to school, volunteering in the community or returning to previously enjoyed activities.
- Providing education and referrals to appropriate resources.
- Assisting with getting or keeping insurance coverage.
- Assisting patients with understanding their rights and responsibilities.
- Providing supportive counseling.
- Assisting in telling patients the importance of treatment participation.
- Advanced directives education.

For further assistance and concerns please contact the Hewell Kids' Kidney Center's clinical social worker, **Michael Schwing, LCSW, at 321.841.7970**.

For more information and publications, visit the National Kidney Foundation website at kidney.org.

Citations: kidney.org

SECTION 8

UNDERSTANDING INSURANCE COVERAGE

MEDICARE FOR CHILDREN WITH CHRONIC KIDNEY DISEASE

Finding out that your son or daughter has chronic kidney disease (CKD) is difficult. Your child may have permanent kidney failure and need dialysis or a kidney transplant. This is known as end-stage renal disease (ESRD). Besides your many questions about your child's health condition and treatment options, you will most likely be concerned about paying for healthcare costs that come with CKD. The cost of kidney dialysis, kidney transplants and other related services are expensive. These costs can create a financial hardship for any family caring for a child with CKD. The information below can help parents understand how Medicare works to cover your child's healthcare costs. For more information and to enroll, go to: www.medicare.gov/default.aspx or socialsecurity.gov/pubs/10043.html#partC or call 800.MEDICARE (800.633.4227) or TTY/TDD 877.486.2048 (for the hearing and speech impaired).

MEDICARE BASICS

What is Medicare?

Medicare is a health insurance program for

- People of all ages with ESRD
- People age 65 or older
- People under 65 with certain disabilities

Patients with ESRD have access to limited health insurance coverage through Medicare. Medicare is a federal program, and ESRD patients are eligible by diagnosis. There is no income qualifier. Patients do not need to be documented citizens with social security numbers. Parents need to have paid into the Medicare system through income tax for a sufficient number of quarters.

Peritoneal dialysis (PD) patients are eligible from the date of the first PD treatment for the duration of time on dialysis. Hemodialysis (HD) patients are eligible starting three months following the first HD session for the duration of time on dialysis. Transplant patients will be eligible from the date of transplant for 36 calendar months.

Medicare will be the secondary payer for the first 30 months on dialysis and for all transplant coverage time unless the patient also has Medicaid coverage. For Medicaid patients, Medicare will be the primary payer for the duration of dual Medicaid/ Medicare enrollment.

Medicare Part A
All ESRD patients who enroll in Medicare will get Part A coverage at no cost. Part A covers inpatient costs associated with ESRD treatment as well as any other inpatient costs.

Medicare Part B
Patients will need to sign up for Part B separately. Part B covers certain outpatient costs associated with ESRD treatment and certain medications (EPO, post-transplant immunosuppressant medications). Part B is free of cost for people on Medicaid. There is a tiered quarterly premium for those patients without Medicaid coverage.

Medicare Part C
Medicare Advantage plans are available in many areas. People with Medicare Parts A and B can choose to receive all of their healthcare services through one of these provider organizations under Part C.

Medicare Part D
A prescription drug plan for Medicare patients. There are multiple plans to choose from and plan availability. ESRD patients with Medicaid coverage must have a Part D plan. Patients will be auto-enrolled, but may opt to change Part D plans at any time. There are co-pays associated with Part D plans. Part D plans are also available for patients without secondary Medicaid coverage. However, patients should be careful to assess out-of-pocket costs and to determine whether the Part D plan will interfere with coverage from an existing prescription drug benefit through private insurance. Patients without secondary Medicaid coverage will have co-pays, monthly premiums and a coverage gap. In general, pediatric patients with private insurance do better without a Part D plan.

MEDICARE AND GROUP HEALTH COVERAGE FOR PEOPLE WITH ESRD

Question:
I have ESRD and group health coverage. Who pays first?

Answer:
If your child is eligible to enroll in Medicare because of ESRD and is enrolled in your group health plan, that plan will pay first on your hospital and medical bills for 30 months, whether or not your child is enrolled in Medicare and has a Medicare card. During this time, Medicare is the secondary payer. The group health plan pays first during this period, no matter how many employees work for your employer, or whether you or a family member are currently employed. At the end of the 30 months, Medicare becomes the primary payer. This rule applies to all people with ESRD, whether you have your own group health coverage or you are covered as a family member.

Example:
Bill's child has Medicare coverage because of permanent kidney failure. He also has group health coverage through the company he works for, and his child is on this plan. His group health coverage will be the primary payer for the first 30 months after Bill's child becomes eligible for Medicare. After 30 months, Medicare becomes the primary payer.

Question:
Can a group health plan deny me coverage if my child has permanent kidney failure?

Answer:
No. Group health plans cannot deny you coverage, reduce your coverage or charge you a higher premium because your child has ESRD and Medicare. Group health plans cannot treat any of their plan members who have ESRD differently because they have Medicare.

Question:
If I have additional questions on my Medicare coverage, whom do I call?

Answer:
800.MEDICARE (800.633.4227) or TTY/TDD 877.486.2048 (for the hearing and speech impaired).

MEDIGAP POLICIES FOR PEOPLE UNDER AGE 65 WITH A DISABILITY OR END-STAGE RENAL DISEASE

A Medigap policy is a health insurance policy sold by private insurance companies to help you pay the medical costs the Original Medicare Plan does not cover.

Question:
If I have Medicare and I want to enroll in my or my spouse's employer group health plan, can I stop my Medigap policy?

Answer:
The Ticket to Work and Work Incentives Improvement Act of 1999 gives you the right to suspend a Medigap policy. If you are under 65, have Medicare, and have a Medigap policy, you have the right to suspend your Medigap policy. This lets you suspend your Medigap policy benefits and premiums, without penalty, while you are enrolled in your or your spouse's employer group health plan.

If, for any reason, you lose your employer group health plan coverage, you can get your Medigap policy back. You must notify your Medigap insurance company that you want your Medigap policy back within 90 days of losing your employer group health plan coverage.

Your Medigap benefits and premiums will start again on the day your employer group health plan coverage stopped. The Medigap policy must have the same benefits and premiums it would have had if you had never suspended your coverage. Your Medigap insurance company cannot refuse to cover care for any preexisting conditions you have. So, if you are disabled and working, you can enjoy the benefits of your employer's insurance without giving up your Medigap policy.

MEDICAID BASICS

What is Medicaid?
Medicaid is generally available for lower-income individuals. Florida has multiple Medicaid programs that are available for individuals in different situations at different income levels. Programs typically determine eligibility based on age, income, citizenship, disability or state dependency.

Children will age out of their Medicaid program on their 19th birthday. Patients will need to reapply for a different Medicaid program or reapply for the same program as an independent adult.

To enroll, Florida residents should go to: medicaidoptions.net/ or cms-kids.com/families/health_services/eligibility.html

Medicaid Options is Florida's Medicaid managed care enrollment program. Qualified beneficiaries enroll through the toll-free Medicaid Options Help Line to receive their healthcare services.

To enroll, call the toll-free Medicaid Options Help Line:

- 888.367.6554: available 8:00 am to 7:00 pm EST, Monday through Friday
- 800.653.9803: TDD users ONLY

Disability
Supplemental Security Income (SSI) is available for low-income children with disabilities. Patients need to qualify both medically and financially. Patients will qualify from a medical standpoint at some point during their progression to ESRD, at all times that they are receiving dialysis treatment, and for at least the first year post-transplant. Co-morbid diagnosis may extend eligibility periods beyond the timeframe. SSI is beneficial in two important ways. First, there is a monthly cash benefit dependent upon family size and income. Second, patients receiving SSI are automatically eligible for Medicaid coverage. Patients enrolled in Medicaid through SSI eligibility may need to reapply for Medicaid benefits if there is a change in SSI eligibility.

OTHER COVERAGE OPTIONS

Group Coverage
Group insurance coverage is offered to a particular group of people — typically through an employer or an organization. There is no government sponsorship and enrollment in the group determines eligibility for the coverage. Following are some examples of ways to get group insurance coverage:

- *Student Healthcare*: Most colleges and universities offer student health insurance plans to part-time and full-time students. These plans are typically inexpensive, but also provide less extensive coverage.
- *Employer Healthcare*: Many employers are able to offer group insurance plans to full-time employees and sometimes to part-time employees. These plans tend to be more comprehensive, but are sometimes more expensive.
- *Consortium Healthcare*: Some religious, fraternal and business associations offer health insurance plans for members of the organization. Some national disability organizations offer health insurance options as well.

Individual Coverage
It is possible to purchase individual coverage directly from commercial health plans. Individual coverage can be more costly than group coverage plans. There may also be more restrictions regarding initial health screenings or waiting periods for preexisting conditions.

COBRA Coverage
COBRA stands for Consolidated Omnibus Reconciliation Act. This is a federal law and will be applicable in all states. COBRA offers a way for individuals to extend insurance coverage for up to 36 months following the end of their eligibility in a group care plan. If a parent leaves a job that had employee healthcare benefits, the parent may use COBRA to pay the full cost of the plan for continued enrollment. If a child ages out of a parent's employer-based plan, the parent can use COBRA to pay the full cost of the plan for continued enrollment of their child.

You must notify the employer (or other enrollment group) within 60 days of the eligibility change in order to access COBRA benefits. COBRA has a maximum coverage period of 36 months. The full cost of a group plan may be quite expensive, but will usually be cheaper than purchasing an equivalent individual plan, and will eliminate waiting periods for preexisting conditions.

Student Status
Many group healthcare plans allow an extension of coverage for adult children who remain in school. The plan may determine the age of independence to be 18, but as long as the son or daughter remains a full-time student in high school, college or vocational school, the plan may allow them to remain fully enrolled in coverage through age 22 to 24. Some plans may even provide coverage for part-time students.

Waiting Periods
Many insurance plans include waiting periods for preexisting conditions. This means that the health insurance plan will not cover any treatment related to a condition that existed before enrollment in that plan for a certain waiting period. Other care will be covered according to the healthcare plan.

Often, waiting periods are waived as long as the patient has had "equivalent" healthcare coverage previously and there is no gap in coverage. This allows people to change jobs and change insurance providers without concern for lack of coverage, as long as there is no day without coverage.

Lifetime Maximum Benefits
Many health insurance plans have a lifetime maximum benefit. This means that the insurance company will not pay any more than $1 million (for example) in total healthcare expenses for an individual. Pediatric ESRD patients are likely to hit that lifetime maximum benefit at some point in their treatment. Parents should be aware of their insurance policies.

Some plans offer a renewable lifetime maximum. The dollar amount varies from plan to plan. Lifetime maximum benefits do not transfer with the patient, so that changing healthcare plans allows a patient to start over. Parents may need to advocate with employers to offer multiple healthcare plan options, allowing a change in plan to happen if the lifetime maximum benefit is exceeded.

Healthcare Trusts
There are a number of ways for parents to set up healthcare trusts for children with intensive medical needs. These trusts do not offer insurance coverage, but a way for parents to save money for their children to use specifically for out-of-pocket healthcare expenses. Many states offer programs to help parents set up such accounts for disabled children. Any financial advisor can assist a parent in investigating these options.

Assistance for Out-of-Pocket Expenses
Despite the many options described above, it is still very difficult for many children and young adults to keep adequate healthcare coverage.

When patients are uninsured, please look to the following resources for assistance with out-of-pocket expenses:

- *Charity care*: Parents can contact the social worker about applying to foundations available through this hospital and other community-based foundations that offer charity care for uninsured individuals.
- *Drug manufacturers*: Most prescription drug companies offer financial assistance for 1–3 month supplies of the medications they manufacture. There is often a lot of paperwork, and the supplies are usually limited to a short time.
- *Local and national organizations*: The American Kidney Fund offers pharmacy assistance. Many local community organizations offer emergency fund assistance that can help with co-pays and other out-of-pocket expenses for healthcare.

CONCLUSION

Given the high cost of medical care and the need for significant interventions that all chronic kidney disease patients face, it is critical that parents work with clinical social workers to attend to insurance issues in assessments and ongoing work with this patient population. The clinical social worker can assess the insurance status and direct patients and families to existing resources as necessary.

For further assistance with assessing your insurance coverage and needs, please contact the Hewell Kids' Kidney Center's clinical social worker, **Michael Schwing, LCSW, at 321.841.7970.**

Citations:

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Abridged for Florida standards by:
Michael Schwing, LCSW at Arnold Palmer Hospital for Children, Orlando, FL, 2011

socialsecurity.gov/disabilityresearch/wi/medicare.htm

medicare.gov/Publications/Pubs/pdf/10050.pdf

medicaidoptions.net/

kidney.org/

SECTION 9

WHAT TO DO IN CASE OF EMERGENCY OR DISASTER

THREE-DAY EMERGENCY DIET PLAN

This diet is to be used in the event of an emergency situation where the power may not be available to work your dialysis machines or roads may be closed, blocking access to your dialysis center. Hospitals may be unable to provide dialysis right away and you may not have access to treatment for a couple of days. The 3-day emergency diet will provide you with adequate nutrition in the event of an emergency as well as limit the amount of fluid and waste your body accumulates until you can get the necessary treatment. Please note: this diet is not a substitute for dialysis or your renal diet; it is only intended to be followed for 3 days or fewer in an emergency situation.

PATIENTS AGES:

0-23 months:

Bottled water is the most important for mixing of formulas. Make sure you have plenty of bottled water for 3 days worth of formula. You should also have about 9 jars of low potassium baby foods on hand. Some choices may include: carrots, peas, green beans, peaches, pears, and apples with cherries or berries. Make sure if you usually put formula in the refrigerator, you throw it out after 4 hours of no refrigeration. You will need to mix one bottle at a time or smaller quantities to limit some waste. Make sure that in the event of a hurricane or emergency without power, you will have enough formula to get through 3-5 days without a problem.

2-25 years old:

It is best to use the food stored in your refrigerator first, as this will spoil when the power is off.

The following food items will be needed for the 3-day emergency diet and should be stored in your emergency kit:

- 3 packages of dry milk or four 8-ounce cans of evaporated milk
- 2 to 3 gallons of distilled or bottled water, 2 packages of powdered fruit flavored drink or one large bottle of pre-mixed fruit flavored drink (read label to make sure it does not contain phosphate additive)
- 1 to 2 cans or bottles of clear soda (no dark sodas)
- A 6-pack or 2 large bottles of low-potassium fruit juice: apple, grape, cranberry or lemonade
- 6 boxes of single-serving cereal: frosted flakes, fruit loops, corn pops or rice chex
- 1 box of sugar or sugar packets
- Twelve 4-ounce cans of low-potassium fruit or fruit bowls: peaches, pineapple, mixed fruit, applesauce or pears
- 8 small cans of unsalted tuna, salmon, chicken or turkey (low sodium)

- 1 jar of peanut butter
- 1 small jar of grape or strawberry jelly
- 1 small jar of honey
- 3 small jars of mayonnaise (you must open a new jar each day) or 8-12 single-serving foil-wrapped packets
- 1 loaf of white bread (this can be stored in the freezer and replaced every 3 months or as needed)
- 1 box of vanilla wafers or graham crackers
- 1 box of unsalted crackers
- 4 to 6 bags of hard candy: jelly beans, mints, sourballs, lollipops, mike and ikes, gum drops, hard candies (Lifesavers, caramels)
- 1 package of marshmallows

On the 3-day emergency diet, you should only drink 2 cups or 500ml of fluid each day. This diet is stricter than your normal renal diet. It has been designed to limit the amount of waste and fluid buildup in your body if you are unable to receive dialysis.

You should begin your 3-day emergency diet right away in the event of an emergency. Please make sure you keep a copy of the diet with your emergency supplies to help guide you. The menu for the 3-day emergency diet is as follows:

DAY 1:

Breakfast
4 Ounces of Milk (dry powder mix) or 2 Ounces Evaporated Milk
with 2 Ounces Bottled Water
1 Bowl of Cereal
1 Tablespoon Sugar
½ Cup Drained, Canned Peaches

Snack
5 Vanilla Wafers or 1½ Graham Cracker Squares
Candy

Lunch
2 Slices of White Bread
2 Tablespoons Peanut Butter
2 Tablespoons Grape or Strawberry Jelly
½ Cup Drained, Canned Pears
4 Ounces of Juice or Drink

Snack
10 Marshmallows
½ Cup Applesauce

Dinner
2 Slices of White Bread
½ Can Unsalted, Canned Chicken
2 Tablespoons Mayonnaise
4 Ounces Cranberry Juice or Drink

Snack
10 Jelly Beans
5 Vanilla Wafers or 1½ Graham Cracker Squares

DAY 2:

Breakfast
4 Ounces Milk (powdered milk) or 2 Ounces of Evaporated Milk
with 2 Ounces Bottled Water
1 Bowl of Cereal
1 Tablespoon Sugar
½ Cup Drained, Canned Pears

Snack
5 Unsalted Crackers with Jelly
10 Jelly Beans

Lunch
2 Slices of White Bread
1 Ounce Unsalted, Canned Turkey
½ Cup Drained, Canned Pineapple
4 Ounces of Juice or Drink

Snack
Candy
½ Cup Applesauce

Dinner
2 Slices of White Bread
2 Ounces Unsalted, Canned Tuna
2 Tablespoons Mayonnaise
½ Cup of Cranberry Juice

Snack
5 Vanilla Wafers or 1½ Graham Crackers Squares
10 Gum Drops

DAY 3:

Breakfast
4 Ounces of Milk (powdered milk) or 2 Ounces of Evaporated Milk with 2 Ounces of Bottled Water
1 Bowl of Cereal
1 Tablespoon Sugar
½ Cup Drained, Canned Pears

Snack
10 Vanilla Wafers or 1½ Graham Cracker Squares
10 Hard Candies or other Candies from List

Lunch
2 Slices of White Bread
2 Tablespoons Peanut Butter
2 Tablespoons Honey or Jelly
½ Cup Drained, Canned Peaches
4 Ounces of Cranberry Juice

Snack
½ Cup Applesauce
Handful of Jelly Beans

Dinner
2 Slices of White Bread
½ Cup Unsalted, Canned Chicken
1 Tablespoon Mayonnaise
½ Cup of Clear Soda

Snack
5 Vanilla Wafers or 1½ Graham Cracker Squares
10 Marshmallows

Ask your renal dietitian if you have any questions about the emergency diet. Do not substitute any foods on this diet without talking with your dietitian first.

EMERGENCY PREPAREDNESS: YOUR MEDICATIONS

- Know and carry a current list of ALL your medications (name, dose and frequency) with you at ALL times.
- Keep a 1-week emergency supply of your medications on hand at ALL times.
    - To obtain these, always call in and pick up medication refills when you have a 1-week supply of your medicines.
    - Keep your emergency supply in the original container from the pharmacy.
    - Make sure your emergency supply of medications are not expired, which can be found on the prescription bottle.
- Keep a supply of as-needed (not every day) medications such as:
    - Diuretics (fluid pills)
    - Kayexalate and/or sorbitol (for high potassium)
    - Blood pressure medications (to take as needed for high blood pressure)
- If you check your blood pressure at home, make sure you have extra blood pressure monitor batteries.
- If you have diabetes, have a 1-week supply of insulin, syringes and glucose monitoring supplies (test strips, extra glucose meter batteries, lancets and alcohol wipes).
- If you are on peritoneal dialysis, have a 5-day supply of the antibiotic your doctor prescribes for peritonitis. Disasters create unclean environments and will make peritonitis much more likely.

Information above provided by Jennifer Shenk, PharmD, pediatric pharmacy clinical specialist at Arnold Palmer Hospital.

COMMUNITY – EMERGENCY CONTACT INFORMATION

ORGANIZATION	CONTACT NAME	PHONE NUMBER
Ambulance		
Fire Department		
Fire Department: Non-Emergency		
Police Department		
Police Department: Non-Emergency		
County Emergency Operations Center		
State Emergency Management Agency		
Hazardous Materials Handling/Information		
Local Electric Company		
Local Gas Company		
Local Water Department		
Nearest Hospital		
Nearest Trauma Center		
Poison Control		
Public Health Department		
Telephone Repair		
Transportation Company		

PATIENT INFORMATION FORM

Keep this information with you. It will assist the dialysis facility you may have to use in any case of emergency.

Name ______________________________

Address ______________________________

City ____________________ State _____ Zip Code ____________

Phone Numbers ______________________________

Emergency Contacts

Name(s) ______________________________

Relationship to you ______________________________

Address ______________________________

City ____________________ State _____ Zip Code ____________

Phone Numbers ______________________________

Your Medicare Number ______________________________

Other Insurance(s) ______________________________

Home Dialysis Center ______________________________

Address ______________________________

City ____________________ State _____ Zip Code ____________

Phone Numbers ______________________________

Charge Nurse ______________________________

Nephrologist ______________________________

TREATMENT INFORMATION FORM

This is your dialysis prescription in case of an emergency and you may need to receive dialysis at another facility. Your nephrologists and nurse at your facility can help fill in the data. You should update it as changes occur to the prescription.

Date Completed ______________________________

ESRD Diagnosis ______________________________

Allergies ______________________________

Medications ______________________________

____

____

Medical History ______________________________

____

____

Type of Treatment: Hemodialysis ______

Peritoneal ________ CCPD _____ CAPD _____

HEMODIALYSIS PRESCRIPTION

Dialyzer ____________ Dialysate ______________

Treatment Time __________ Times per week ____________

EDW ________ Average Weight Gain _______ BFR ________

Bath ______ Bicarb ______ Na ______ Tubing Size _____

Vascular Access Type __________ Location ___________

Needle Size if AVF _____ Lidocaine/EMLA ______________

Heparinization ______________________________

YOUR MEDICATION LIST

Last Updated ______________

MEDICATION NAME AND DOSE	TIMES TAKEN DAILY	TIMES OF DAY MEDICATION TAKEN	SPECIAL INSTRUCTIONS

COUNTY	NAME	ADDRESS	PHONE	FAX
Alachua	David Donnelly, Director	1100 SE 27th St. Gainesville 32641	352.264.6510	352.264.6565
Baker	Adam Faircloth, Director	1 Sheriff's Office Dr. Macclenny 32063	904.259.6111	904.259.6114
Bay	Mark Bowen, Director	700 Hwy. 2300 Southport 32409	850.784.4000	850.784.4010
Bradford	Brian K. Johns, Director	945-B N. Temple Ave. Starke 32091	904.966.6336 904.966.6337	904.966.6169
Brevard	Robert S. Lay, Director	1746 Cedar St. Rockledge 32955	321.637.6670	321.633.1738
Broward	Charles Lanza, Director	201 NW 84 Ave. Plantation 33324	954.831.3900	954.382.5805
Calhoun	Don A. O'Bryan, Director	20859 Central Ave. E. Room G-40 Blountstown 32424	850.674.8075	850.674.4667
Charlotte	Wayne Sallade, Director	26571 Airport Rd. Punta Gorda 33982	941.833.4000	941.833.4081
Citrus	Captain Joseph Eckstein, Director	3549 Saunders Way Lecanto 34461	352.746.6555	352.527.2100
Clay	Chief Lorin Mock, Director	P.O. Box 1366 Green Cove Springs 32043	904.284.8735	904.284.8015
Collier	Dan E. Summers, Director	8075 Lely Cultural Pkwy. Suite 445 Naples 34113	239.252.3600	239.252.3609
Columbia	Shayne Morgan, Director	263 NW Lake City Ave. Lake City 32056	386.758.1125	386.752.9644
DeSoto	Catherine Furr, Director	2200 NE Roan St. Arcadia 34266	863.993.4831	863.993.4840
Dixie	Tim Alexander, Director	17600 SE Hwy. US 19 Cross City 32628	352.498.1240 ext. 224	352.498.1244
Duval	Martin Senterfitt, Director	515 North Julia St. Jacksonville 32202	904.630.2472	904.630.0600

COUNTY	NAME	ADDRESS	PHONE	FAX
Escambia	John Dosh, Emergency Manager	6575 North W St. Pensacola 32505	850.471.6409	850.471.6455
Flagler	Troy Harper, Director	1769 E. Moody Blvd. Bunnell 32110	386.313.4240	386.313.4240
Franklin	Pamela Brownell, Director	28 Airport Rd. Apalachicola 32320	850.653.8977	850.653.3643
Gadsden	Shawn Wood, Director	339 E. Jefferson St. Quincy 32351	850.875.8642	850.875.8643
Gilchrist	Ron Mills, EM Director	3250 N. US Hwy. 129 Bell 32619	352.463.3198	352.463.3189
Glades	Angela R. Snow, Director	P.O. Box 68 Moore Haven 33471	863.946.6020	863.946.1091
Gulf	Marshall Nelson, Director	1000 Cecil G. Costin, Sr. Blvd., Bldg. 500 Port St. Joe 32456	850.229.9110	850.229.9115
Hamilton	Henry Land, Director	1133 US Hwy. 41 NW Jasper 32052	386.792.6647	386.792.6648
Hardee	Richard S. Shepard, Director	404 W. Orange St. Wauchula 33873	863.773.6373	863.773.9390
Hendry	M. Lupe Taylor, Director	P.O. Box 2340 LaBelle 33975	863.674.5400	863.674.4040
Hernando	Cecilia O. Patella, Director	18900 Cortez Blvd. Brooksville 34601	352.754.4083	352.754.4090
Highlands	Scott Canaday, Emergency Operations Director	6850 George Blvd. Sebring 33875	863.385.1112	863.402.7404
Hillsborough	Preston Cook, Director	2711 E. Hanna Ave. Tampa 33610	813.236.3800	813.272.6878
Holmes	Wanda Stafford, Director	1001 E. Hwy. 90 Bonifay 32425	850.547.1112	850.547.7002
Indian River	John King, Director	4225 43rd Ave. Vero Beach 32967	772.226.3859	772.567.9323

COUNTY	NAME	ADDRESS	PHONE	FAX
Jackson	Rodney Andreasen, Director	2819 Panhandle Rd. Marianna 32446	850.718.0007 850.482.9678	850.482.9683
Jefferson	Carol Ellerbe, Director	169 Industrial Park Blvd. Monticello 32344	850.342.0211	850.342.0214
Lafayette	Donnie E. Land, Director	164 NW Crawford St. Mayo 32066	386.294.4178	386.294.2846
Lake	Jerry Smith, Director	315 W. Main St. / P.O. Box 7800 Tavares 34778	352.343.9420	352.343.9728
Lee	John D. Wilson, Director	2665 Ortiz Ave. Fort Myers 33905	239.533.3911	239.482.2605
Leon	Richard Smith, Director	535 Appleyard Dr. Tallahassee 32304	850.488.5921	850.487.3770
Levy	Mark Johnson, Director	P.O. Box 221 Bronson 32621	352.486.5212	352.486.5152
Liberty	Rhonda Lewis, Director	10979 NW Spring St. Bristol 32321	850.643.2339	850.643.3499
Madison	Tom Cisco, Director	1083 SW Harvey Greene Dr. Madison 32340	850.973.3698	850.973.4026
Manatee	Laurie Feagans, Chief of Emergency Management	2101 47th Terrace East Bradenton 34206	941.749.3500	941.749.3576
Marion	Capt. Chip Wildy, Director	P.O. Box 1987 Ocala 34478	352.369.8100	352.427.3115
Martin	Keith Holman, Director	800 Monterey Rd. Stuart 34994	772.288.5694	772.286.7626
Miami-Dade	Curt Sommerhoff, Director	9300 NW 41st St. Miami 33178	305.468.5400	305.468.5401
Monroe	Irene Toner, Director	490 63d St., Ocean Suite 150 Marathon 33050	305.289.6065	305.289.6333
Nassau	Danny Hinson, Director	77150 Citizens Circle Yulee 32097	904.548.4980	904.491.3628
Okaloosa	Randy McDaniel, Division Chief	90 College Blvd. East Niceville 32578	850.651.7150	850.651.7170
Okeechobee	Mitch Smeykal, Director	499 NW Fifth Ave. Okeechobee 34972	863.763.3212	863.763.1569
Orange	David Freeman, Interim Emergency Manager	6590 Amory Court Winter Park 32792	407.836.9140	407.836.9147
Osceola	Richard Collins, Fire Chief / EM Director	2586 Partin Settlement Rd. Kissimmee 34744	407.742.9000	407.742.9021
Palm Beach	Bill Johnson, Director	20 South Military Trail West Palm Beach 33415	561.712.6321	561.656.7490
Pasco	Annette Doying, Interim Director	8744 Government Dr., Bldg. A New Port Richey 34654	727.847.8137	727.847.8004
Pinellas	Sally Bishop, Director	400 South Fort Harrison Ave. Clearwater 33756	727.464.5550	727.464.4024
Polk	Pete McNally, Director	1890 Jim Keene Blvd. Winter Haven 33880	863.534.5605	863.534.5647
Putnam	Quin Romay, Director	410 S. State Rd. 19 Palatka 32177	386.329.0379	386.329.0897
Santa Rosa	Sheryl Bracewell, Director	4499 Pine Forest Rd. Milton 32583	850.983.5360	850.983.5352
Sarasota	Edward J. McCrane, Chief of Emergency Management	1660 Ringling Blvd., 6th Floor Sarasota 34236	941.861.5495	941.861.5501
Seminole	Alan S. Harris, Manager	150 Bush Blvd. Sanford 32773	407.665.5017	407.665.5036

COUNTY	NAME	ADDRESS	PHONE	FAX
Seminole Tribe of Florida	Robert Tarrant, Director	6300 Stirling Rd. Hollywood 33024	863.983.2150	954.989.1597
St. Johns	E. R. Ashton, Director	100 EOC Dr. St. Augustine 32092	904.824.5550	904.824.9920
St. Lucie	Tom Daly, EM Director	15305 W. Midway Rd. Ft. Pierce 34945	772.462.8100	772.462.1774
Sumter	David Casto, Director	7375 Powell Rd. Wildwood 34785	352.569.1661	352.689.4401
Suwannee	Kimberly Thomas, Assistant Director	617 Ontario Ave. SW, Suite 200 Live Oak 32064	386.364.3405	386.362.0584
Taylor	Dustin Hinkel, Emergency Management Director	591 E. US Hwy. 27 Perry 32347	850.838.3575	850.838.1642
Union	John R. Walker, Director	58 Northwest 1st St. Lake Butler 32054	386.496.4300	386.496.3226
Volusia	Charlie Craig, Director	49 Keyton Ave. Daytona Beach 32124	386.254.1500 ext. 1505	386.248.1742
Wakulla	Scott Nelson, Director	15 Oak St. Crawfordville 32327	850.745.7200	850.926.8027
Walton	Capt. Joe Preston, Director of Emergency Management/ Public Safety Communications	752 Triple G Rd. DeFuniak Springs 32433	850.892.8065	850.892.8366
Washington	Roger Hagan, Director	2300 Pioneer Rd. Chipley 32428	850.638.6203	850.638.6316

Information above provided by:
The State of Florida's State Emergency Response Team and FloridaDisaster.org

SECTION 10

COLLABORATION AND EXPECTATIONS

(Otherwise known as "The Rules")

- Any movies you bring in to watch must be pediatric-appropriate — nothing above a PG13 rating please.
- Please wear earphones to reduce the overall noise level.
- Music is awesome — it can be soothing and calming … well, sometimes. So whether you like Hip Hop, Alternative, Rock, Christian, etc., please keep it low and pediatric-appropriate.
- When you are being placed on dialysis and taken off dialysis, please hold off from chatting and texting on your phones.
- No hide and seek allowed — we need to see your access (catheter and fistula) and your beautiful faces. No exceptions!
- If you are cold, we will provide you with toasty, warm blankets.
- If you eat here, you must follow your renal diet.
- We know that by the time you arrive at dialysis you are probably hungry, but we want you to follow the renal diet you were taught about from our dietitian. So if you do decide on eating while here, you *must* bring your binders.
- Please limit the number of visitors to 2. No visitors are allowed during the put on and take off parts of dialysis, except for parents and caregivers of patient. No unaccompanied minors allowed without adult supervision. Visitors without adult supervision must be 18 years of age.
- Only patients are allowed to eat in the dialysis area. All parents, caregivers and guests are not allowed to eat in the dialysis area; there is a high risk of contamination. We prefer you eat in the hospital cafeteria only.
- We will provide blankets and pillows to make you comfortable while on dialysis. Tell us what you need, and we will try to accommodate your needs. Always let us know if there is something we can do to make your treatment better for you. We are here to help you, and we care about your health.

SECTION 11

CONTACT INFORMATION

Jorge Ramirez, MD
Medical Director
Hewell Kids' Kidney Center
Arnold Palmer Hospital for Children
92 W. Miller St.
Orlando, FL 32806
321.841.7970
Fax 321.841.7978

Maricor Grio, MD
Nephrologist
Hewell Kids' Kidney Center
Arnold Palmer Hospital for Children
92 W. Miller St.
Orlando, FL 32806
321.841.7970
Fax 321.841.7978

Vascular Specialists of Central Florida
Fistula Placement Surgeons
80 W. Michigan St.
Orlando, FL 32806
407.648.4323

Children Surgical Associates of Orlando
Hemodialysis and Peritoneal Catheter Placement Surgeons
1814 Lucerne Terrace, Suite A
Orlando, FL 32806
407.540.1000

SECTION 12

ADDITIONAL RESOURCES

List of Websites and Links Related to Kidney Disease:

- Network 7 for Florida ESRD: *fmqai.com*
- National Kidney Foundation: *kidney.org*
- American Nephrology Nurses' Association: *annanurse.org*
- Fistula First: *fistulafirst.org*
- Medicaid Options: *medicaidoptions.net/*
- Children's Medical Services: *cms-kids.com/families/health_services/eligibility.html*
- Medicare: *medicare.gov/default.aspx*
- Medicare Advantage Plans: *socialsecurity.gov/pubs/10043.html#partC*

Hospital/Homebound
Hospital/Homebound offers a short term instructional program for eligible students who have been diagnosed with a medical or psychiatric condition that confines the students to the home, hospital or other restrictive setting for at least 15 school days. These students must be able to participate and benefit from an instructional program to be eligible for these services.

Teachers provide instruction designed to help the students continue progressing academically in the core curriculum while away from their regular school program. The curriculum at Hospital/Homebound is based upon the Next Generation Sunshine State Standards.

Hospital/Homebound Applications
For Orange, Osceola, Seminole, Polk and Volusia counties public schools.

https://www.ocps.net/cs/ese/programs/hh/Pages/default.aspx

http://www.scps.k12.fl.us/Portals/10/177.pdf

http://www.polk-fl.net/parents/generalinformation/studentwellness.htm

http://blackboard.volusia.k12.fl.us/webapps/portal/frameset.jsp?tab_tab_group_id=_16_1

http://www.osceola.k12.fl.us/depts/ESE/Pages/documents/HHB_English.pdf

http://www.osceola.k12.fl.us/depts/ESE/Pages/documents/HHB_Espanol.pdf

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