Kidney Failure in Children
Treatment Methods

Kidneys play an important part in a child's growth and health. They:

- Remove wastes and extra water from the blood.
- Regulate blood pressure.
- Balance chemicals like sodium and potassium.
- Make a hormone that signals bone marrow to make red blood cells.
- Make a hormone to help bones grow and keep them strong.

PROBLEMS SPECIFIC TO CHILDREN

- Extreme fatigue.
- Not able to focus.
- Weak bones.
- Nerve damage.
- Depression.
- Sleep problems.
- Additional problems for children can include effects on their growth and development. Children may fall behind on the growth chart and in school.

Finding the best treatment for a child takes on special significance to ensure that the child with kidney failure can become an active, productive, well-adjusted adult.

TREATMENT CHOICES FOR KIDNEY FAILURE IN CHILDREN

- Children usually have a range of treatment options for kidney failure.
- Many children begin with dialysis to stay healthy until a suitable kidney is available
- In most cases, the goal is to have a successful transplant that allows your child to lead the most normal life possible. But kidneys are not always readily available, and not all children can have a transplant. Sometimes, a transplant itself may stop working, and the child may need to return to dialysis.

TRANSPLANTATION

Once kidneys fail because of chronic kidney disease, function cannot be restored, so transplantation is the closest thing to a cure we have. Transplantation means that a healthy kidney from a donor is placed inside a child's body to take over the job of filtering wastes and extra fluid from the blood. A child with a transplant will still need to take medicines every day, follow a restricted diet, and get regular checkups to make sure the new kidney is accepted and functioning in the body. About half of the kidney transplants in children come from a living donor, usually a parent or other close family member.

DECEASED DONOR KIDNEYS

- To receive a deceased donor kidney, your child will be placed on a waiting list. Every person who needs an organ from a deceased donor is registered with the United Network for Organ Sharing (UNOS), which maintains a centralized computer network linking all regional organ gathering organizations and transplant centers.
- How long your child will have to wait for a transplant depends on many things but is determined primarily by how good the match is between your child and a donor. When a kidney becomes available, the hospital that has obtained the kidney reports to UNOS, where the central computer generates a list of compatible recipients. Candidates' ages and length of time they have waited are factors in the point system. Children 18 and under get extra points compared with adults because they are likely to receive the greatest benefit from a donated kidney.
- While your child is on the waiting list, notify the transplant center of any changes in health status, address, or phone number. The center will need to find you immediately when a kidney becomes available.

LIVING DONOR KIDNEYS

- About half of the kidneys transplanted into children are donated by family members usually a parent or a family friend. Potential donors need to be tested for matching factors and to make sure that donating a kidney will not endanger their health. Most people can donate a kidney with little risk.
- A kidney from a living donor often has advantages over a kidney from a person who has just died.
- A kidney from a parent is guaranteed to match on at least 3 of 6 proteins; mismatched proteins may cause rejection.
- Living donation allows for greater preparation and for the operation to be scheduled.
- A kidney from a living donor may be in better condition because it does not have to be transported from one site to another.

PREEMPTIVE TRANSPLANTATION

Preemptive transplantation means that the child receives a donated kidney before dialysis is needed. Some studies indicate that preemptive transplantation reduces the chances of rejecting the new kidney and improves the chances that it will function for a long time. Other studies show little or no survival advantage in preemptive transplants, although some families may feel that avoiding dialysis is an advantage in itself.

KEEPING A HEALTHY KIDNEY

Health professionals use the term "noncompliance" or "non-adherence" to describe a patient's failure or refusal to take prescribed medicines or follow a doctor's directions. Teenagers with transplanted organs are often noncompliant because the immunosuppressive drugs they must take change their appearance in unflattering ways. A child psychologist may be able to suggest techniques that reinforce desired behaviors. But communicating clearly about the reasons for treatment and the importance of following the regimen is an important part of helping all patients, including children. Children who understand that their decisions can affect their health are more likely to take responsibility for their actions.

DIALYSIS

The kidneys remove waste products and extra water from the blood. If the kidneys fail before transplantation is possible, your child may need some form of dialysis to do this job. Each type of dialysis will affect your family's lifestyle. Your caregiver will help you choose the one that is best for your child. Each situation is different.

PERITONEAL DIALYSIS

- Peritoneal dialysis uses the lining of your child's abdomen (*peritoneal membrane*) to filter blood. A mixture of minerals and sugar dissolved in water, called dialysis solution, is inserted into your child's abdomen through a soft tube. The sugar, called dextrose, draws wastes, chemicals, and extra water from the tiny blood vessels in the peritoneal membrane into the dialysis solution. After some time, the used solution now loaded with the wastes and extra fluid that the kidneys would have filtered out is drained from your child's abdomen through the tube. The period that dialysis solution is in the abdomen is called the dwell time. The abdomen is filled again with fresh dialysis solution, and the cycle repeats. The process of emptying and refilling the abdomen is called an exchange and takes about 30 to 40 minutes.
- Before the first treatment, a surgeon will place a small, soft tube called a catheter into your child's abdomen. The catheter tends to work better if the insertion site has time usually from 10 days to 3 weeks to heal. The catheter stays there to help transport dialysis solution to and from the abdomen and is removed only after a successful transplant is in place.
- Peritoneal dialysis can be done with or without a cycling machine
  - **Continuous ambulatory peritoneal dialysis (CAPD)**. CAPD requires no machine and can be done in any clean, well-lit place. With CAPD, your child's blood is always being cleaned. The dialysis solution passes from a plastic bag through the catheter and into the abdomen, where it stays for several hours with the catheter sealed. After the dwell time, the child drains the dialysis solution into a drain bag for disposal. Then the same catheter is used to refill the abdomen with fresh solution so the cleaning process can begin again. With CAPD, the dialysis solution stays in the abdomen for 4 to 6 hours or more. Most

people change the dialysis solution at least four times a day and sleep with solution in their abdomen at night. With CAPD, it is not necessary to perform an exchange during the night.

- **Continuous cycling peritoneal dialysis (CCPD)**. CCPD uses a machine called a cycler to fill and empty your child's abdomen many times at night during sleep. In the morning, the child begins one exchange with a dwell time that lasts the entire day. An additional exchange without the cycler may be added in the middle of the afternoon to increase the amount of waste removed and to reduce the amount of fluid left behind.
- Both types of peritoneal dialysis can be performed in the home without help from a nurse or doctor. If your child is very young, you will need to help with the exchanges or set up the cycler. Older children can do it themselves. You and your child will receive detailed instructions and extensive training so you feel confident when you perform the exchanges.

- The most common problem with peritoneal dialysis is peritonitis, a serious abdominal infection that can occur if the opening where the catheter enters the body becomes infected or if contamination occurs as the catheter is connected or disconnected from the bags. Peritonitis requires antibiotic treatment prescribed by your child's nephrologist.
  - To avoid peritonitis, you must be careful to follow the correct procedures exactly and learn to recognize the early signs of fever, unusual color or cloudiness of the used fluid, and redness or pain around the catheter. Report these signs to your child's caregiver immediately so treatment for infection can begin promptly.

HEMODIALYSIS

- In hemodialysis, your child's blood is sent through a filter to remove harmful wastes, extra salt, and extra water. Hemodialysis helps control blood pressure and keeps the proper balance of potassium, sodium, calcium, and bicarbonate.
- Hemodialysis uses a special filter called a dialyzer. During treatment, blood travels from the child's body through tubes into the dialyzer, which filters out wastes and extra water. Then the cleaned blood flows through another set of tubes back into the child's body. The dialyzer is connected to a machine that monitors blood flow and disposes of the wastes.
- Hemodialysis usually takes place in a clinic three times a week, but it may be required more often in smaller children. Each treatment lasts from 3 to 4 hours. Some clinics offer home hemodialysis, which allows more flexibility in scheduling but requires the caregiver to take weeks of training. During treatment, the child can do homework, read, write, sleep, talk, or watch TV.
- If you choose hemodialysis for your child, the doctor will need to create an access to the bloodstream (*vascular access*) several months before the first treatment. The child may be able to complete the procedure for the vascular access in one day or your child may need to stay overnight in the hospital.
- When a child starts hemodialysis, problems can be caused by rapid changes in the body's water and chemical balance during treatment. Muscle cramps and a sudden drop in blood pressure are two common side effects. Low blood pressure, called hypotension, can make a child feel weak, dizzy, or nauseated.
- Most children need a few months to adjust to hemodialysis. Side effects can often be treated quickly and easily, so you should always report them to your doctor and dialysis staff. You can avoid many side effects by making sure your child gets a proper diet, limits liquid intake, and takes all medicines as directed.

ROLE OF THE HEALTH CARE TEAM

Because the treatments for kidney failure involve complicated procedures with a number of steps, many skilled professionals must work together to ensure that your child gets the best possible care. As a parent or guardian, you are the most important member of your child's team. You may need to speak for your child or ask questions when instructions are not clear. Knowing the roles of the different team members can help you ask the right questions and contribute to your child's care.

Pediatrician

- A pediatrician is a doctor who treats children. Your child's pediatrician is likely to be the first to recognize a

kidney problem either during a routine physical exam or while treating an ailment. Depending on how well the kidneys are working, the doctor may decide to monitor your child or advise you to see a specialist. (Your health insurance plan may require a written referral from the pediatrician in order for you to make an appointment with a specialist.) As your child's regular doctor, the pediatrician should talk with any specialists who become involved. A referral for consultation should optimally occur soon after chronic kidney disease is diagnosed, even if dialysis and transplantation are still a long way off.

Nephrologist

- A nephrologist is a doctor who treats kidney diseases and kidney failure. If possible, your child should see a pediatric nephrologist because they are specifically trained to take care of kidney problems in children. In many areas of the country, pediatric nephrologists are in short supply, so you and your child may need to travel. If traveling is not possible, some nephrologists who treat adults can also treat children in consultation with a pediatric nephrologist.
- The nephrologist may prescribe treatments to slow disease progression and will determine when referral to a transplant center or to a dialysis clinic is appropriate.

Dialysis Nurse

- If your child needs dialysis, a nurse with special training will make sure all procedures are followed carefully. If you and your child choose peritoneal dialysis, the dialysis nurse will train you so you feel comfortable doing the exchanges at home. For hemodialysis in a clinic, the dialysis nurse will make sure that all needles are placed correctly and watch for any problems. The dialysis nurse can talk to you about the advantages and disadvantages of the different types of dialysis and explain the laboratory reports that indicate how well the treatments are working.

Transplant Coordinator

- A coordinator at the transplantation center will be your main contact. He or she will schedule any required examinations and procedures and make sure your child's medical information is complete and properly placed on the UNOS national waiting list. The transplant coordinator will make sure that every member of the child's health care team has all the necessary information and paperwork.

Social Worker

- Every dialysis clinic and transplant center has a social worker who can help you locate financial assistance and social services like transportation or family counseling and help with applications for Medicare. The social worker can tell you about support groups in your community and ways to reduce the stress that caring for a child with a chronic illness can cause.

Psychologist, Psychiatrist, or Counselor

- Kidney disease can disrupt a child's life and create emotional turmoil. A psychologist or counselor can help your child find ways to express emotions constructively. Adults and siblings may also find that counseling helps them with the conflicts and stresses they face. For example, medical bills can strain family finances. A parent or guardian may need to give up work to care for the child full-time. Siblings may feel resentment over the huge amount of attention given to their sibling and guilt over thinking bad thoughts about the sick child. Couples sometimes report increased tension in their marriage when a child is sick. A counselor can help families deal with conflicts that may arise, and social workers or financial counselors can help families meet the financial obligations that chronic illness creates.

Dietitian

- When the kidneys stop working, wastes and excess fluid build up in the body and create chemical and hormonal imbalances. In children, however, these problems are especially troublesome because they can interfere with physical growth and mental development. Avoiding certain foods can help minimize the buildup of wastes and prevent chemical imbalance, but it can also lead to nutritional deficiencies. The

buildup of wastes often makes children lose their appetite, causing further nutritional problems. These complications are the reason your clinic's dietitian is so important.

- Proper nutrition is extremely important for children with chronic kidney disease. Every dialysis clinic has a dietitian to help patients understand how the food they eat affects their health. The dietitian can help you develop meal plans that will fit your child's restricted diet and will talk with you about laboratory reports that may show nutritional deficiencies caused by your child's kidney disease. They may recommend special dietary supplements or formulas so that your child receives the best nutrition possible.
- You can also ask your dietitian for recipes and titles of cookbooks for patients with kidney disease. Following the restrictions of a kidney disease diet might be hard at first, but with a little creativity, you can make tasty and satisfying meals. Reading Eat Right to Feel Right on Hemodialysis, a booklet from the NIDDK, can help you get started.

VACCINATIONS AND IMMUNOSUPPRESSION

- The wastes and toxins that build up in the bloodstream of a child with kidney disease can weaken the immune system and make the child vulnerable to infections and the kinds of diseases that vaccines are designed to prevent. Children with kidney failure should receive the standard vaccinations recommended for all children, plus additional vaccinations for pneumonia and influenza.
- Children who take immunosuppressive medication to treat an autoimmune disease or to prevent rejection of a transplanted kidney, however, should not receive vaccines containing live viruses, that is, the oral polio vaccine, the measles, mumps, and rubella (MMR) vaccine, or the varicella (chicken pox) vaccine. Children who are likely to need a transplant may benefit from early immunization with these vaccines before immunosuppressive drugs are needed.
- The body's immune system protects against foreign substances like bacteria and viruses that can cause disease. But the immune system also attacks transplanted organs, and the medicines that recipients must take to prevent rejection leave them vulnerable to infections. Children need relatively higher doses of immunosuppressive drugs than adults because their immune systems are more active. But these high doses can slow down growth and development. Over a long period of time, immunosuppression may lead to malignant growths. Immunosuppressive drugs can also have side effects such as weight gain, unusual hair growth, and acne. Children, especially teenagers, cite these side effects as the reason they do not take their pills, a problem that contributes to the high rate of organ rejection in children.

MEDICAL COMPLICATIONS OF KIDNEY FAILURE

The kidneys not only clean waste and extra fluid from the blood, they also help make red blood cells and balance nutrients needed for strong bones and growth. In addition, the kidneys may play a role in the metabolism of growth hormone (*somatotropin*). Chronic kidney disease can make children feel more tired, limit physical growth, and interfere with their ability to concentrate in school.

ANEMIA

Diseased kidneys do not make enough of a hormone called erythropoietin, or EPO, which stimulates the bone marrow to produce the red blood cells needed to carry oxygen to vital organs. Anemia is a shortage of red blood cells, and it is common in children with kidney disease. A child with anemia may tire easily and look pale. Anemia may also contribute to heart problems. A genetically engineered form of EPO injected under the skin one or more times a week can treat this form of anemia.

BONE PROBLEMS AND GROWTH FAILURE

- The kidneys help keep bones healthy by balancing phosphorus and calcium levels in the blood. When the kidneys stop working normally, phosphorus levels in the blood can become high and interfere with bone formation and normal growth.
- Your child's caregiver may recommend dietary changes and food supplements to treat growth failure. Dietary changes may include limiting foods that contain large amounts of phosphorus, such as milk, cheese, cola, dried beans, peas, and nuts. Since avoiding all of these foods is impossible, caregivers will need to

work with a dietitian to find a healthy way to limit the phosphorus in the child's diet while maintaining a desirable intake of the calories, protein, and other nutrients necessary to maintain growth and general health. In addition to dietary restrictions, most children will need to take specific medications called phosphate binders to lower their blood phosphorus levels.

FINANCIAL HELP FOR TREATMENT OF KIDNEY FAILURE

No matter what treatment method your family chooses, medical expenses will be high. Fortunately, the Federal Government and many other organizations offer programs to help with the cost of treatments.

Role of the Social Worker

Your child's dialysis or transplant center has a social worker who can help you apply for Medicare and locate other sources of financial assistance.

HOPE THROUGH RESEARCH

Through its Division of Kidney, Urologic, and Hematologic Diseases, the NIDDK supports several programs and studies devoted to improving treatment for patients with progressive kidney disease and kidney failure. The NIDDK maintains the Pediatric Nephrology Program, which supports research into the causes, treatment, and prevention of kidney diseases in children, including congenital malformations of the urinary tract, polycystic disease, primary glomerular disease, and postinfection glomerulonephritis.

ORGANIZATIONS

Several groups offer information and services to patients with kidney disease. You may wish to contact one of the following:

American Association of Kidney Patients 3505 East Frontage Road Suite 315 Tampa, FL 33607 Phone: 18007492257 or 8136368100 Email: info@aakp.org Internet: www.aakp.org American Society of Pediatric Nephrology Northwestern University Feinberg School of Medicine Pediatrics W140 303 East Chicago Avenue Chicago, IL 606113008 Phone: 3125034000 Email: aspn@northwestern.edu Internet: www.aspneph.com National Kidney Foundation 30 East 33rd Street New York, NY 10016 Phone: 18006229010 or 2128892210 Email: info@kidney.org Internet: www.kidney.org	American Kidney Fund 6110 Executive Boulevard Suite 1010 Rockville, MD 20852 Phone: 18006388299 or 3018813052 Email: helpline@akfinc.org Internet: www.akfinc.org Life Options Rehabilitation Program c/o Medical Education Institute Inc. 414 D'Onofrio Drive Suite 200 Madison, WI 53719 Phone: 18004687777 or 6082322333 Email: lifeoptions@MEIresearch.org Internet: www.lifeoptions.org and www.kidneyschool.org United Network for Organ Sharing P.O. Box 2484 Richmond, VA 23218 Phone: 18888946361 Internet: www.unos.org

Document Released: 01/29/2007 Document Re-Released: 03/14/2011
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