Dialysis School Packet
For students requiring chronic dialysis treatment

Seattle Children's offers interpreter services for Deaf, hard of hearing or non-English speaking patients, family members and legal representatives free of charge. Seattle Children's will make this information available in alternate formats upon request. Call the Family Resource Center at 206-987-2201. This handout has been reviewed by clinical staff at Seattle Children's. However, your child's needs are unique. Before you act or rely upon this information, please talk with your child's healthcare provider.

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Date: ____________________________________________

Child’s Name: ____________________________________________

Dear School Staff:

The student named above has end stage renal disease and requires chronic dialysis treatment. Our hope is that this student can participate as fully as possible in all school activities. However, it may help to develop new or review existing health, special education, or 504 plans for this student.

This packet contains information about:

End stage renal disease (ESRD)

Dialysis treatments

The impact of this disease and treatment on learning and the learning environment

This information will help you understand the direct impact on school participation for this child:

<table>
<thead>
<tr>
<th>Type of Dialysis</th>
<th>Schedule</th>
<th>Access</th>
</tr>
</thead>
<tbody>
<tr>
<td>In-center hemodialysis</td>
<td>Monday: __________</td>
<td>HD catheter</td>
</tr>
<tr>
<td>Home dialysis</td>
<td>Tuesday: _________</td>
<td>Fistula: ______________</td>
</tr>
<tr>
<td>Peritoneal dialysis</td>
<td>Wednesday: ________</td>
<td>Graft: ________________</td>
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<tr>
<td></td>
<td>Thursday: __________</td>
<td>PD catheter</td>
</tr>
<tr>
<td></td>
<td>Friday: __________</td>
<td></td>
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<td></td>
<td>Saturday: __________</td>
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</tr>
<tr>
<td></td>
<td>Other: ______________</td>
<td></td>
</tr>
</tbody>
</table>

This packet contains handouts about:

- Kidney disease
- Recommendations about accommodations
- School services at Children’s (see below)
- Care for students on dialysis
- *School & Family Problems of Children with Kidney Failure*
- Resources

Please review the information in this packet, and contact Children’s Dialysis Team with any questions or concerns. Thank you for your time and consideration in this difficult situation.

Sincerely,

Dialysis Social Worker
Seattle Children’s Hospital
206-987-_______

Dialysis Team Members

<table>
<thead>
<tr>
<th></th>
<th>Phone Numbers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary Nurse: ------</td>
<td>206-987-______</td>
</tr>
<tr>
<td>Social Worker: ------</td>
<td>206-987-______</td>
</tr>
<tr>
<td>Hospital Teacher:</td>
<td>206-987-______</td>
</tr>
<tr>
<td>Dietitian:</td>
<td>206-987-______</td>
</tr>
<tr>
<td>Nephrologist:</td>
<td>206-987-______</td>
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</table>
Care for Students with Hemodialysis Catheters

- This student has a catheter that goes to their heart. If it gets pulled out, apply pressure and call 911.
- If this student gets a fever, it might indicate an infection in the catheter, which is very serious. Call home and call the kidney doctor. Dial 206-987-2000 and ask the operator for the nephrologist (kidney doctor) on call.
- This student may become dizzy, nauseated, weak, and/or pale. They can rest for a while. If you are concerned, call the parent/guardian.
- This student needs to take medication (Renvela or Phoslo) before all meals and snacks - it should be stored in the nurse’s office.
- This student may have other medications that need to be taken at school. The parent will work with the school nurse to establish a plan for medication management.
- This student has serious food restrictions (NO chocolate, dairy of any kind, nuts, potatoes, tomatoes or foods or drinks high in sodium. This student must also limit fluid intake between dialysis runs (usually between 40 and 60 oz.).
- This student may have restrictions related to physical education; for example, no contact sports or no swimming. The student may need more rest, and the catheter needs to remain protected from being pulled or twisted.
Kidney Disease and Primary Treatment Options for Kidney Failure

Healthy Kidney Function

Most people have two kidneys located on either side of the backbone, just above the small of the back. Healthy kidneys have several major functions:

- Filtering out waste products from the blood through urine
- Maintaining balance of certain chemicals in the body (potassium, sodium, phosphorus, acids)
- Producing a hormone that helps the bone marrow make red blood cells
- Producing a hormone that helps bones grow
- Producing an enzyme that plays a role in helping the body control blood pressure

Causes of Kidney Failure

There are many possible causes for kidney failure. The causes most common in childhood include:

- Congenital birth defects (problems with the way the bladder, kidneys, or ureters develop in utero)
- Genetic diseases that affect the growth or function of the kidney
- Acquired illnesses that impact the function of the kidneys
- Direct injury to the kidney

A person cannot live without kidney function. End stage renal disease (ESRD) is the term used when a person’s kidneys no longer function well enough to support life. There is no cure for ESRD. It is a chronic and life-threatening condition.

When the kidneys don’t work properly, all major body functions are impacted. Children with kidney failure cannot make urine properly, cannot maintain a healthy balance of fluids and chemicals in the body, can become anemic, can become hypertensive, can develop bone disease, and can have difficulty growing and developing at the same rate as healthy peers.

Treatment for ESRD

Treatment for ESRD involves medications, specialized diets, and a form of renal replacement therapy (substitute kidney function). The three primary options include:

1. **Hemodialysis** – A machine removes blood from the body and cleans it through an artificial kidney or filter. Patients need blood “access” via a catheter, fistula, or graft.
Kidney Disease and Primary Treatment Options for Kidney Failure

2. **Peritoneal Dialysis** – A cleansing solution is pumped into the peritoneum (abdominal cavity), is allowed to pull toxins from across the peritoneal membrane, and then drains the toxins out of the body. Patients need an abdominal catheter.

3. **Transplant** – The patient is given a new kidney from a living or deceased donor.

**Hemodialysis**

- Treatment is typically done 3 hours per day, 3 days per week, but can vary as much as 2 to 4 hours per day, 3 to 6 days per week.
- This treatment is usually provided “in-center” and patients need to travel to Seattle Children’s Hospital for their treatments.
- In-center hemodialysis has a significant impact on school attendance.
- With extensive training, some patients are able to do this type of dialysis in the home.
- Patients are typically able to watch television, play games, or do some homework while on dialysis.
- Patients with needle access (fistula or graft) in their arm may be prevented from writing or using a computer during treatments.
- Some patients feel lightheaded after hemodialysis treatments, and some patients experience cramping or nausea during the treatment.
- Children receiving hemodialysis treatments often have good days and bad days as the level of toxins in their body fluctuates.

**Peritoneal Dialysis**

- Treatment is typically 10 hours overnight every night.
- Treatment is typically done at home while the patient sleeps. Patients and parents are the primary dialysis providers in the home.
- Treatment requires a dialysis machine and significant medical supplies in the home.
- Sometimes children have loss of appetite or feel lethargic in the mornings after treatment.
- Children receiving PD at home will need to see the doctor once a month at Seattle Children’s Hospital.
Kidney Transplant

- Kidneys can come from living donors or deceased donors.
- Living donors are typically relatives or close family friends willing to give one kidney to the child. Living donors can live full healthy lives with only one remaining kidney. Children do not have to be on a waiting list for a living donor kidney. Living donors must be over 18 years old and must complete a thorough evaluation before being eligible to donate a kidney.
- Deceased donor organs are allocated by the United Network of Organ Sharing. Children need to be on a waiting list to receive a deceased donor kidney. Children must complete a thorough evaluation before being eligible to be placed on the deceased donor waiting list.
- Children get preference over some adults on the deceased donor waiting list.
- Kids can be transplanted with adult-size kidneys.
- Transplanted kidneys can fail due to infection, rejection or unknown reasons.
- Patients must take immunosuppressive medications and other prescription drugs to prevent rejection or infection of the transplanted kidney. Patients will take these medications for the lifetime of the transplant.
- Transplantation is a treatment for end stage renal disease, but it is not a cure. Transplanted kidneys typically survive 10 to 15 years before losing function.
- When a transplant fails, the patient will need to receive dialysis treatments or another kidney transplant.
Accommodations for Dialysis Patients

Here are possible accommodations for your school setting. Parents, student and school staff may wish to use this list to help devise a plan that meets the unique learning needs of the student.

**Educational environment**
- Offer preferential seating near the teacher, near the front of class or in a quiet space
- Schedule core content courses around dialysis schedule (as much as possible)
- Assign peer anchor for orientation to class work and assignments
- Provide a predictable routine
- Provide a tutor
- Offer a study hall option to help student make up missing assignments
- Determine a clear plan to obtain missed assignments in case of absence

**Instructional strategies**
- Establish clear goals for mastery by the end of the school year in each subject area
- Use cooperative learning techniques where appropriate
- Give written directions to supplement oral directions
- Pre-teach new vocabulary for a lesson
- Break down assignments into shorter tasks
- Allow shortened responses
- Allow additional time for work in class or out of class
- Allow peer editing
- Reduce the number of items on homework and class assignments
- Allow open-book or notes for assignments
- Provide a second copy of textbooks for home use and/or dialysis unit
- Provide parallel text at student’s reading level
- Provide a designated note-taker or photocopy of other student or teacher notes
- Offer extended time on tests
- Offer individual administration of tests
- Allow student to complete individual projects in lieu of group work

**Communication**
- Use daily or weekly assignment sheet with clear directions and due dates for assignments
- Send daily or weekly reports home
Accommodations for Dialysis Patients

- Use a notebook with information exchanged between home, school, and dialysis teacher
- Provide weekly tracers from counseling office to classroom teachers to monitor student progress; feedback to student and family
- Hold regular appointments with school counselor

Grading modifications
- Use regular letter grades (A-F) - elementary, middle and high school regular grading system, when student is expected to learn the same concepts as the regular education students, even though they may use different materials or have alternative evaluation options
- Give modified letter grades (A-F) when there is a substantial modification of course content and the established curriculum goals that the student is expected to learn. Goals for which the student is held accountable must be identified.
- Use “P” for pass or “S” for satisfactory (credit/no credit) when the student has been showing effort in a class but has not completed enough assignments to earn a “C” or better
- Provide narrative or IEP update to accompany regular or special education grading system to document progress

Physical or health-related impairments
- General endurance guidelines
- Physical education guidelines
- Recess guidelines
- Transportation to/from school
- Stairs
- Medications at school
- Self-care guidelines (such as toileting, eating, drinking, etc.)
- Nurse pass as needed
- Student allowed extra time for travel between classes

Staff education
- Dietary/fluid restrictions
- Catheter/fistula care
- General End Stage Renal Disease / Dialysis information
- Blood pressure and symptoms such as weakness, cramping, nausea, vomiting, dizziness, fever, and puffiness

Other
- Attendance exception for all dialysis related absences, including but not limited to:
  - Dialysis treatments
  - Clinic appointments
  - Hospitalizations
Accommodations for Dialysis Patients

- Gum chewing permitted
- Permission to drink water during class (post-transplant)
- Open bathroom pass
- Student allowed to carry transplant pager or cell phone as needed
Education Services for Dialysis

If a child or teen needs to receive treatment at the hospital for a while, Children’s School Services help to keep students from falling behind with their regular school. The services are covered through a contract with Washington State and provided by certified teachers at no cost to families. Children and teens should have a school plan designed and managed by their community school. Children’s School Services are provided in addition to these services. Children and teens are encouraged to work with a hospital teacher during their treatment, but this is not required.

Who is eligible?
• A student who is enrolled in kindergarten through 12th grades
• A child birth to five years of age who has identified developmental disabilities, or who is considered at risk for developmental disabilities.

How do I get in touch with a hospital school teacher?
Parents, the student or anyone involved with the student’s care can call the Hospital School Referral Line at 206-987-6534. From inside the hospital, dial ext. 7-6534. A teacher will arrange to set up an appointment to meet with the patient and family.

What services are provided?
In general, services are designed to help students continue to move forward in the classes they are taking in their current school program. Hospital teachers do not design academic programs, but do support those provided by community schools. Hospital teachers use the student’s textbooks and assignments as much as possible throughout treatment. The hospital teachers offer:
• Individualized, one-on-one tutoring or small-group class instruction.
• Special education for a student who has an Individual Education Program (IEP).
• Planning with a student, parents and the community school teachers to best support the student’s progress on educational goals.

Where do students receive Children’s School Services?
Services are provided at bedside during dialysis or in the Hospital School Room on level 7 in the Mountain zone, room MB.7.412.
Resources

American Society of Pediatric Nephrology
Maintains extensive list of patient education resources
aspneph.com

Seattle Children’s Hospital
seattlechildrens.org

Kidney School
Educational and informational resources with online tutorials
kidneyschool.org

LifeCenter Northwest
Information about organ donation and transplantation
lcnw.org

National Kidney Foundation
Educational and informational resources
kidney.org

Northwest Renal Network
Patient advocacy and education
nwrn.org

Starbright World
Online support programs for youth with chronic illness
starbrightworld.org

Please note that other resources are listed on pages 4 and 5 of School & Family Problems of Children with Kidney Failure in this packet.