Providing Healthcare

For

Adults with

Chronic & End Stage Renal Disease

In

Pennsylvania

A Guide for the Renal Professional

Maryland Patient Advocacy Group

2003

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Glossary/Resources

AdultBasic Program: a program for adults, between 19-64, who have been denied coverage from the private insurance industry.
http://www.ins.state.pa.us/ins/cwp/view.asp?a=1278&q=527068

American Kidney Fund: This organization has a fund that pays for Medicare, Medigap, private insurance or KDP premiums for patients who meet certain income requirements.
http://www.akfinc.org/Programs/ProgramsContentHIPP.htm

Center for Medicare and Medicaid Services (CMS): This section of the Department of Health and Human Services oversees Medicare and Medicaid.
http://cms.hhs.gov/

Chronic Renal Disease Program Handbook: explains Pennsylvania's CRD Program.
http://www.dsf.health.state.pa.us/health/lib/health/renal_handbook.ps.pdf

Chronic Renal Disease Program Drug Formulary: this link identifies drugs that are covered under the Program.
http://ecapps.health.state.pa.us/renalformulary/

End Stage Renal Disease (ESRD): "…that stage of kidney impairment that appears irreversible and permanent and requires a regular course of dialysis treatments or kidney transplantation to survive."

End Stage Renal Disease Program: A Medicare Program that oversees the delivery of dialysis and kidney transplant care.
http://cms.hhs.gov/providers/esrd/default.asp

Federal Poverty Level (FPL): This represents the basic income levels, or percentages thereof, tied to family size as set by the Federal government and used to award various monetary or health benefits.
http://aspe.os.dhhs.gov/poverty/03poverty.htm

Managed Care Organization (MCO): An insurance company responsible for overseeing the delivery of healthcare.

Medicaid (MA): A joint Federal and State program providing healthcare to low income aged, blind, disabled, pregnant women and children.
http://www.dhmh.state.md.us/mma/mmahome.html

Medicare (MC): A Federal program which provides healthcare to the elderly and disabled.
http://www.medicare.gov/

Medicare Rights Center (MRC): **The MRC educates and advocates for Medicare beneficiaries.**
http://www.medicarerights.org/

MidAtlantic Renal Coalition (MRC): **Under contract to CMS, MRC oversees the delivery of ESRD care to Network 5 which includes Maryland.**
http://www.esrdnetworks.org/networks/net5/net5.htm

PA Power Port: **provides access to all areas of Pennsylvania government.**
http://www.state.pa.us/

PA Access to Social Service Applications: **You may apply on line for CHIPs. Medicaid, adultBasic, or food stamps by going to:**
http://www.state.pa.us/papower/taxonomy/taxonomy.asp?DLN=31734&papowerPNavCtr=|31760|#31760

Pennsylvania Free Clinics: **provides free or reduced primary care in various counties**
http://www.freeclinicpa.org./

Qualified Medicare Beneficiary (QMB): A Medicare beneficiary, within certain income limits, whose Medicare premium, co-payments and deductibles are covered by Medicaid.
http://www.peoples-law.org/Public%20Benefits/Government%20Benefits/qmb.htm

Social Security Administration (SSA): An agency of the Federal government that oversees the retirement and disability system.
http://www.ssa.gov/

Social Security Blue Book: A set of medical guidelines that must be met to award disability and Medicare benefits. The link below takes you to the renal guidelines.
http://www.ssa.gov/disability/professionals/bluebook/106.00-Genito-Urinary-Childhood.htm

Social Security Offices: These are local offices of the Social Security Administration at which to apply for Medicare benefits.
http://s00dace.ssa.gov/pro/fol/fol-home.html.

Supplemental Security Income (SSI): A Federal income supplement program funded by general tax revenues (*not* Social Security taxes) designed to help the aged, blind and disabled that have little or no income.
http://www.ssa.gov/notices/supplemental-security-income/

MARYLAND PATIENT ADVOCACY GROUP

OBJECTIVE: To advocate for access to healthcare for all those with chronic or end stage renal disease.

MISSION STATEMENT: Maryland Patient Advocacy Group's mission is to assist all those who are afflicted with chronic or end stage renal disease, "CKD" or "ESRD", obtain necessary medical care. As a non-profit agency we are dedicated to alleviating the burden of disease and to making the day-to-day lives of these patients easier.

GOAL: This document will be the basis on which to develop a short pamphlet for parents that will clearly and simply explain how children with ESRD can benefit from Medicare coverage, what it covers and how to apply it.

The purpose of this document is to:

1) Explain mechanisms that ensure access to care for children with both CKD and ESRD

2) Identify issues delaying access to Medicare, Medicaid and Chronic Renal Disease Program.

3) Explain the Medicare ESRD Program pointing out the differences between basic Medicare and this program and how they serve this population

4) Identify various common scenarios and how they might be addressed

5) Identify barriers to care

6) Identify and address problems that patients encounter

7) Place access to Medicare in context (i.e. one portion of a continuum of programs assuring reimbursement and thus access to care)

8) Identify different advocacy resources

We look to you, the renal professional, to identify for us what information you need to ensure that your patients receive the medical care they need.

Thank you for your time and dedication.

Very truly yours,

Pearl L. Lewis, President
Maryland Patient Advocacy Group

Section I: Introduction

This document has been prepared for renal professionals to help you assist your patients with both chronic and end stage renal disease access coverage for their care. It addresses the various forms of healthcare coverage – private, Medicaid, Medicare, the Chronic Renal Disease Program, and the various prescription drug programs for those without private coverage. It identifies pitfalls that can arise and explains what can happen if one does not apply for appropriate coverage in a timely manner. It will also identify resources available to assist patients in dealing with the various forms of coverage.

1. What is a Patient's and Physician's Responsibility, once a Diagnosis of Chronic or End Stage Renal Disease is Made?

One of the most important things a patient can do for themselves when diagnosed with a chronic health condition is to educate themselves about the disease, its medical and financial implications and set in motion a plan to meet those needs. Depending of the severity of the disease, this should include not only access to healthcare but also income maintenance. Any healthcare professional working with a patient/family in this situation owes it to them to inform them of what they should do to protect themselves and their family.

2. Federal and State Healthcare Programs – Medicare and Medicaid

Healthcare does not exist without a method of reimbursement. For those with chronic kidney disease access to services can be difficult. If one does not have private insurance coverage, depending on their income level, they must turn to the various Federal and State programs for assistance. Both Medicaid and Medicare eligibility depends on the patient meeting the Social Security Disability Guidelines; only if the disease process has progressed to the point of meeting these criteria is the patient eligible for benefits.

In Pennsylvania, for those with end stage renal disease there is care available; however, some families may not be aware of their options. Between Medicare, Medicaid, and the Chronic Renal Disease Program all medically necessary care is covered.

4. Advocacy Resources When There are Insurance Problems

Maryland Patient Advocacy Group advocates for individuals to ensure access to all forms of healthcare reimbursement including Social Security Disability. For more information, call 410-872-2846.

For a website on Education and Information on chronic and end stage renal disease, visit: www.kidneyadvocacy.50megs.com.

The Medicare Rights Center (MRC) advocates for those on Medicare nationwide no matter the age. http://www.medicarerights.org/

Section II: Providing care for those with Chronic Kidney Disease

1. If your patient has been diagnosed with chronic kidney disease has been denied insurance coverage because of a pre-existing condition or he/she has been rated causing premiums to be unaffordable how does he get coverage?

First, in order to see if someone with CKD is eligible for Medicaid or Medicare you must see if they are "disabled" according to the Federal disability guidelines available at http://www.ssa.gov/disability/professionals/bluebook/106.00-Genito-Urinary-Childhood.htm while Medicare has no income guidelines, Medicaid does.

If you believe your patient is disabled according to the Blue Book have him/her go to Social Security and apply for SSDI/SSI.

2. If you feel they do not meet the disability guidelines perhaps they are eligible for adultBasic.

Introduction/Summary

Pennsylvania is committed to quality health care for all of its residents. In June 2001, Governor Tom Ridge signed into law the Health Investment Insurance Act (Act 77 of 2001). Act 77 is a dramatic initiative that invests the proceeds of the state's tobacco settlement in the health of Pennsylvania consumers. The state is expected to receive approximately $11 billion over the course of 25 years.

The largest single component of the settlement will provide health insurance to a number of uninsured Pennsylvanians between the ages of 19 and 64. The program will provide health insurance for adults meeting certain income requirements and who do not have health care coverage.

This new program -adultBasic- is administered by the Pennsylvania Insurance Department and offers basic benefits, including, preventive care, physician services, diagnosis and treatment of illness or injury, in-patient hospitalization, out-patient hospital services and emergency accident and medical care.

Eligibility Requirements

Participation in the adultBasic Program is based on certain eligibility requirements, which include:

- **Having no other health care coverage (including Medicaid or Medicare)**
- **Lack of prior coverage under any other insurance plan for 90 days prior to enrollment; except for a person (and their spouse) who has been laid off his/her job**
- **Are ages 19 through 64**
- **Having family income below 200 percent of the Federal Income Guideline (see table below)**
- **Having lived in Pennsylvania for at least 90 days prior to enrollment; and**
- **U.S. citizenship or a permanent legal alien status**

The following chart explains the number of people in the family versus the maximum income in order to be eligible for the program:

Benefit Package

The adult insurance program is designed to provide basic insurance benefits, including:

- **Hospitalization (unlimited days)**
- **Physician Services (primary care and specialists)**
- **Emergency Services**
- **Diagnostic Tests (e.g. X-rays, mammograms and laboratory tests)**
- **Maternity care**
- **Rehabilitation and skilled care (in lieu of extended hospitalization)**

Modest co-pays for certain benefits are required. They are:

Doctor Visit- $5.00
Emergency Room-$25.00 (waived if admission occurs)
Specialists - $10.00

How can I enroll?

Applications for enrollment in the adultBasic Program are available from adultBasic contractors or by calling toll-free number 1-800-G0-BASIC. On-line application is also available. See "Application for adultBasic" or reference www.compass.state.pa.us. Coverage will begin July 2002.

Frequently Asked Questions

1. **Who qualifies for the adultBasic Program?**

2. What are the eligible income limits in order to participate in the program?
3. What if a person has Pre-existing conditions?
4. What medical benefits are available?
5. Any costs/co-pays involved?
6. How can I enroll?
7. What is the funding source and how much is available?
8. Is this the same as CHIP?

Who qualifies for the adultBasic Program?

Participation in the adultBasic Program is based on certain eligibility requirements, which include:

- **Having no other health care coverage (including Medicaid or Medicare);**
- **Having no coverage under any other insurance plan for at least 90 days prior to enrollment; except for a person (and their spouse) who has been laid off his/her job;**
- **Being between the age of 19 through 64;**
- **Having family income below 200 percent of the Federal Income Guidelines (see table below); and**
- **Having lived in Pennsylvania for at least 90 days prior to enrollment; and**
- **U.S. Citizenship or a permanent legal alien status.**

What are the eligible income limits in order to participate in the program?

The following chart explains the number of people in the family versus the maximum income in order to be eligible for the program:

Eligibility Requirements	
Number in Family	**Maximum Income**
1	**$17,960**
2	**$24,240**
3	**$30,520**
4	**$36,800**
5	**$43,080**
6	**$49,360**
7	**$55,640**
8	**$61,920**

Income Guidelines according to February 7, 2003 Federal Register

What if a person has a pre-existing condition?

The program will not exclude coverage based on a pre-existing health condition.

What medical benefits are available?

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- **Emergency Services**
- **Diagnostic Tests (e.g. x-rays, mammograms and laboratory tests)**
- **Maternity care**
- **Rehabilitation and skilled care (in lieu of extended hospitalization)**

Any costs/co-pays involved?

A monthly premium of $30.00 must be made prior to enrollment and each month thereafter for coverage to continue.

Modest co-pays for certain benefits are required. They are:

- **Doctor Visit- $5.00**
- **Emergency Room-$25.00 (waived if admission occurs)**
- **Specialists - $10.00**

How can I enroll?

Applications for enrollment in the adultBasic Program are available from adultBasic contractors or by calling the toll-free number 1-800-G0-BASIC. On-line application is also available. See "application for adultBasic" or reference www.compass.state.pa.us. Coverage will begin July 2002.

What is the funding source and how much is available?

Funding for this program comes from a portion of the Commonwealth's share of the Tobacco Settlement money. Under this agreement with the country's major tobacco companies, the Commonwealth is slated to receive an estimated $11.5 billion over the next 25 years, or approximately $400 million a year.

Suggest that they bring the following documents when they apply for benefits:

- **multiple copies of birth certificates for all family members,**
- **marriage certificates,**
- **income documentation,**
- **residence verification,**
- **copies of bank statements, list of liquid assets,**
- **insurance policies of all types,**
- **rent/mortgage verification,**
- **and utility bills.**

Suggest that they:

- **mail documents by certified mail,**
- **keep an ongoing record of who they speak to, date and time, what was said**
- **and keep copies of all documents**

3. What if their income is above the 200% of Federal Poverty required for adultBasic?

Pennsylvania has a free clinic in virtually every county funded by the Foundation of the Pennsylvania Medical Society.

For further information or questions about the Free Clinic Association of Pennsylvania, please contact

Helen Heidelbaugh
President and CEO
Community Volunteers in Medicine
300 B Lawrence Drive
West Chester, PA 19380-4263

Phone: 610-836-5990, ext. 102
Fax: 610-836-5998
E-mail: hheidelbau@aol.com http://www.freeclinicpa.org./

Section III: History and Role of the Federal ESRD System

The federal End Stage Renal Disease (ESRD) Program was established in 1972 pursuant to the provisions of Section 2991, Public Law 92-603. This legislation extended Medicare coverage to virtually all individuals with ESRD who require dialysis or transplantation to sustain life.

This legislation and subsequent regulations also established health and safety standards applicable to providers of ESRD services and required the establishment of ESRD Network Coordinating Councils. Networks serve as liaisons between the federal government and the providers of ESRD services.

In 1978, the ESRD Network program was designed to provide an oversight system uniting dialysis providers with the common goals of:

1. Providing immediate access to treatment;

2. Treating patients with quality care through medical standards developed by the scientific community;

3. Helping patients to maintain a quality of life; and

4. Enabling each individual to live as a functioning member of society.

The 18 Networks are currently in immediate contact with 4,153 dialysis facilities and 242 transplant centers, serving in excess of 300,000 patients. The ESRD Network budget is funded through dialysis payments to facilities. The budget for the national Network program is under $12 million annually, less than .007 percent of the total Medicare budget for 1994.

Each Network is required by federal contract to be active in the areas of:

1. Data Collection;

2. Quality Improvement;

3. Patient Satisfaction; and to serve as a

4. clearinghouse for federal agencies, renal related organizations, patients and their families.

Section IV: Providing Healthcare for Adults with ESRD

1. How is the Medicare ESRD System Different from Standard Medicare?

To be eligible for Medicare the patient, patient's spouse, or patient's parent (if the patient is a dependent) must have worked and paid into the Social Security System for 40 quarters [*Social Security Act*, § 214(a)]. However, q*uarters are prorated for young adults if the determination is based on the patient's work record. The younger the patient, the fewer quarters needed to qualify.*

Work Quarters Needed To Qualify for Medicare Due to ESRD

If the date of onset is before age 24, they, their spouse or parent must have worked 1.5 years in the 3 years ending with the quarter of the date of onset.

If the date of onset is age 24 to 31, they or their spouse must have worked 1.5 years out of the last 3 years and 3 months.

If they are 31 and over, they need to have worked 10 years total with 5 of the years worked in the 10 years prior to the date of onset.

a. When Medicare ESRD Coverage Begins;

People who receive Social Security disability qualify for Medicare in the 25th month after the date of disability; however for those with ESRD Medicare begins;

1. **The months in which you have a kidney transplant**
2. **Three months after beginning a course of out patient hemodialysis**
3. **The month you begin a course of home peritoneal or hemodialysis**

To fill in this three months gap many states have a kidney disease program or patients rely on Medicaid or private insurance.

Due to potential penalties, non-elderly, non-disabled ESRD patients with EGHP coverage, and that includes children who are covered by their parent's policy, should be encouraged to file for Medicare Part B at the same time when filing for Medicare Part A. If application for Medicare Part B coverage is not made, enrollment in it can only take place during an open enrollment period (typically January through March of each year) with coverage becoming effective in July. This could mean a gap in coverage and higher premiums. Patients should carefully review their EGHP policy on coordinating with Medicare.

b. Who is eligible?

Anyone, with chronic renal failure, who has paid into the SS system, whose spouse has paid into the system or anyone, of any age, who is a dependant of anyone who has paid into the system is eligible for ESRD Medicare coverage, however there is no pamphlet for parents' whose children are ESRD. To be eligible for Medicare adults must meet the Social Security Disability Guidelines for Renal Disease as outlined in the Blue Book can be found at http://www.ssa.gov/disability/professionals/bluebook/6.00-Genito-Urinary-Adult.htm
To determine eligibility go to http://www.ssa.gov/pubs/10026.html.

c. What has to be done, when one is diagnosed, to assure coverage under the Medicare ESRD system?

By regulation, within 45 days of diagnosis of chronic renal failure a physician must fill out a CMS 2728, a patient's "birth certificate" into the Medicare End Stage Renal Disease Program. One copy must me sent to Social Security, one to the Renal Network and one retained in the medical file in the dialysis unit or transplant center. However if this is not done immediately there will be a lag time in obtaining benefits and medical coverage. Make sure the parent takes the form to their local Social Security Office and obtains a receipt.

2. How does the ESRD patient obtain healthcare during the 3 months prior to Medicare coverage?

Either the patient has private insurance, is eligible for Medicaid, adultBasic or the Chronic Renal Disease Program.

3. Sample Cases – What should this person be eligible for?

Scenario a: The patient's income meets the Medicaid financial criteria and they have no healthcare coverage -

The patient should be eligible for SSI and Medicaid and possibly Medicare if he/she has worked enough covered quarters. The Social Security Field Office has a "presumptive disability" process which allows them to award SSI benefits and thus Medicaid while the patient waits for Disability Determination Services (DDS) to formally determine the medical condition and award Medicare. The State Review Team has the same responsibility on the State level as DDS does for SSDI/Medicare and also applies the "presumptive disability" concept.

Scenario b: The client has income/assets over the MA level but no healthcare coverage.

Under this scenario the client would not be eligible for SSI. Check Medicare eligibility; investigate adultBasic and the Chronic Renal Disease Program.

Scenario c: The client has income and health insurance.

The client should ascertain if his/her insurance adequately covers all ESRD costs. If a transplant is anticipated Medicare should be considered since Medicare, in the future will only cover transplant drugs if Medicare pays for the transplant. Also, if there are high co-payments and deductible under the private plan by being covered by Medicare the providers would have to accept Medicare's capitated rates thus lowering the co-payments and deductibles which Medicare would cover. The client should consider applying to CRDP to cover the coinsurance/copayments.

4. Problems:

a. Oftentimes a family declines Medicare or other coverage due to its premiums.

There are penalties for not accepting Medicare initially. If an ESRD patient does not accept Medicare during the first 7 months of eligibility they will pay a higher premium in the future if they decide to seek Medicare coverage. If the family has limited income

perhaps they are eligible for the Qualified Medicare Beneficiary, SLMB, etc. programs. Additionally, if the client is a dialysis patient the American Kidney Fund has a program that will pay health insurance premiums – private, Medicare and CRDP. For information contact http://www.akfinc.org/Programs/ProgramsContentHIPP.htm or call *800.638.8299.*

Name		**Qualified Medicare Beneficiary (QMB - pronounced "quimby")**
Non-Financial Eligibility Conditions		**Eligible for Medicare (but NOT financially eligible for Medical Assistance)**
Income Eligibility Conditions		***(Apply $20 income disregard - see note below)*** **Income not more than:** **$739 for an Individual** **$995 for a Couple** ***Note: $20 may be subtracted from the individual's or couple's gross income; if the $20 subtraction reduces the income to the number listed above, then the individual or couple probably qualifies for the benefit.***
Asset Eligibility Conditions		**Assets not over:** **$4,000 for an individual** **$6,000 for a couple**
Benefit		**Pays your Medicare deductibles, co-payments and premiums**

b. Pitfalls in Obtaining Medicare/Medicaid/CRDP

Access to these forms of reimbursement cannot be viewed alone; they are a part of a continuum depending on both federal and state workers each to do their job correctly. However, due to the current fiscal crisis and hiring freeze the waiting time from first contact at DSS to the awarding of benefits can take up to 9 months. Additionally in order for a patient to access Medicaid during the months prior to Medicare coverage, the system that should automatically enter a client once SSI has been awarded into the Medicaid system, must be functioning properly. For Medicare premiums to be paid under Qualified Medicare Beneficiary or Medicaid, state workers must be doing their job efficiently. With benefits in one program relying on another program to pay premiums or awarding benefits from one program depending on documentation of acceptance or denial from another it is taking months to assure reimbursement is in place.

c. Problems Identified During the Medicare Application Process

The renal networks, under contract to the Center for Medicare and Medicaid Services, are charged with assuring "immediate access to treatment" however;

- **patients are waiting extended periods of time for Medicare/Medicaid coverage,**
- **Clients who could benefit from Medicare coverage are not aware of their eligibility or the benefits of Medicare coverage if they themselves have not worked but they are the spouse/dependent of someone who has.**

d. Long periods of time without MC/MA coverage.

- **While the CMS 2728 is an ESRD patient's "birth certificate" into Medicare the 2728 fails to get to Social Security and the Renal Network in a timely manner in some cases or be accepted as medical evidence in others.**
- **While the Field Office (FO) is allowed to adjudicate an ESRD patient who files for SSI/SSDI having no income and assets as one with a "presumptive disability" based on the CMS 2728 and award SSI and Medicaid, it is not always being done. Additionally, focus is placed on one's eligibility through one's own record sometimes failing to recognize eligibility through a deceased spouse or parent.**

5. Resources in Pennsylvania for ESRD patients

PA Chronic Renal Disease Program
Department of Health
Division of Special Health Care Needs
P.O. Box 90, Rm. 632
Health & Welfare Bldg.
Harrisburg, PA 17108
(717) 787-9772
Ms. Jane Renaut, Administrator

Eligibility Requirements: US citizen, PA resident and end stage renal patient.
The patient must first apply for all other programs they are eligible for.
For income eligibility guidelines call Carolyn Cass at 717-783-5436.

The Program covers all ESRD related prescription drugs. For information call 1-800-835-4080.

Fee schedule for procedures reimbursable under the Chronic Renal Program
http://www.health.state.pa.us/pdf/core/schedule/chronicrenaldisease.pdf

Section V: Providing Healthcare for the Adult Child with CKD who Ages-Out of CHPS

1. Disabled Adult Child – parent is receiving SSDI/SS

If you are faced with an "adult" who has been judged disabled since childhood – meaning before the age of 18 (Disabled Adult Child – DAC) Social Security will evaluate the disability of an adult child (age 18 or older) who is applying for Social Security for the first time, or who is being converted from a Social Security dependent child's benefit, by using adult disability criteria. To qualify for disability, an adult must have a physical or mental impairment, or combination of impairments, that is expected to keep him or her from doing any "substantial" work for at least a year or is expected to result in death. (Generally, a job that pays $740 or more per month is considered substantial.)

If the family has been receiving SSI, the child reaches majority and the parent(s) either become disabled or retire the adult child might be eligible for benefits under the parent's record and that might be greater than the current $552 SSI monthly maximum. For information go to http://www.ssa.gov/pubs/10026.html .

2. What happens if the parent is not receiving SS benefits?

If their medical condition meets the SS Blue Book Guidelines, since the parent's assets are no longer counted, he or she can get SSI and thus Medicaid. If a disabled child getting SSI turns 18 and continues to live with his or her parents, but does not pay for food or shelter, a lower SSI payment rate may apply. It is to that families benefit to "pay" room and board to the parent to receive the full SSI benefit.

3. Are there insurance policies for young adults with kidney disease who are denied coverage from the insurance industry?

In Pennsylvania there is the adult Basic Program is based on certain eligibility requirements. See the previous explanation of this Program.