



Medicare Advocacy Toolkit

Medicare for Individuals with End-Stage Renal Disease

An Advocate’s Toolkit for Helping Individuals with Medicare Due to ESRD

Winter 2021

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About the Medicare Rights Center

Based in New York, the Medicare Rights Center is a national, nonprofit consumer service organization that works to ensure access to affordable health care for older adults and people with disabilities through counseling and advocacy, educational programs, and public policy initiatives. Since 1989, Medicare Rights has helped people with Medicare understand their rights and benefits, navigate the Medicare system, and secure the quality health care they deserve. Medicare Rights is committed to:

1. Serving as a **kind and expert** health insurance counselor, educator, and advocate for those who need it most.
2. Providing **independent, timely, and clear** information on Medicare, Medicaid for dual-eligibles, and related topics to communities nationwide.
3. Fostering **diverse** partnerships and points of view.
4. Finding **lasting** solutions to systemic problems that prevent older adults and people with disabilities from accessing needed health coverage and care.

About the Advocacy Toolkits

With over 30 years of counseling and advocacy experience, the Medicare Rights Center possesses specialized knowledge about the barriers people with Medicare face in accessing affordable health care, as well as strategies for overcoming these barriers. This series of Medicare Advocacy Toolkits has been developed for any New York advocate who is helping older adults and people with disabilities navigate health insurance benefits. The goal of this project is to empower New York advocates and those they serve to navigate Medicare coverage so that they can access needed care. While intended for a New York audience, the Medicare Advocacy Toolkits may offer lessons to other states and be useful resources as advocates and policymakers think about ways to improve the federal Medicare program, which today serves 60 million Americans.

Advocates with additional questions can contact Medicare Rights' professional email inbox at professional@medicarerights.org. Consumers with questions can call Medicare Rights' national consumer helpline at 1-800-333-4114.

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The Medicare Rights Center provides these Medicare Advocacy Toolkits as a public service. They are not intended as personalized legal advice, nor is Medicare Rights acting as a private attorney in providing guide content. For the latest information about toolkit topics and customized assistance, contact Medicare Rights, 1-800-MEDICARE, or a local [State Health Insurance Assistance Program](#) (SHIP).

Introduction: ESRD Medicare

Every year, hundreds of callers reach out to the Medicare Rights Center's national helpline with issues related to accessing ESRD-related care. Medicare coverage for ESRD is vital, since the only two modalities of treatment for the disease, transplantation and dialysis, are prohibitively expensive for all but the wealthiest uninsured individuals.¹ Unfortunately, many individuals can find it difficult to navigate the enrollment process into ESRD Medicare and, even when they do, can face issues with coordination of benefits and access to the medication they need.

This Medicare Advocacy Toolkit serves as a step-by-step resource to help advocates and people eligible for Medicare due to ESRD. The toolkit first describes the problem and target audience, then provides an overview of ESRD Medicare issues and strategies to resolve them, as well as offering case examples to demonstrate how to evaluate and use these strategies in complex scenarios. Throughout the guide, content is organized in a way that parallels how our counselors evaluate and troubleshoot actual Medicare issues. In addition, the guide contains citations to the relevant rules that form the basis for helping people solve their Medicare problems.

The Problem

Around three quarters of a million Americans have ESRD, with that number rising by about 20,000 people a year.² This means that access to a kidney transplant and medication or regular (usually three times a week) dialysis is vital to the survival of hundreds of thousands of individuals across the country. Congress created the first and only Medicare entitlement based on a diagnosis in 1972.³ This legislation came after years of advocacy to increase the role of the federal government in paying for expensive, but life-saving, treatments for ESRD: dialysis and kidney transplantation.⁴ Yet, Medicare Rights hears from dozens of callers annually who face barriers to accessing dialysis, immunosuppressant medication, and other needed medical

¹ A kidney transplant is estimated to cost nearly \$450,000. See Milliman Research Report, [2020 U.S. organ and tissue transplants: Cost estimates, discussion, and emerging issues](#) (Jan. 2020), p. 5. Dialysis can cost even more. See Kaiser Health News, [First Kidney Failure, Then A \\$540,842 Bill For Dialysis](#) (July 25, 2019).

² United States Renal Data System, [US Renal Data System 2019 Annual Data Report: Epidemiology of Kidney Disease in the United States](#), p. 22.

³ [42 U.S.C. §426-1](#).

⁴ Rettig, Richard A., [Origins of the Medicare Kidney Disease Entitlement: The Social Security Amendments of 1972](#), *Biomedical Politics* (1991), pp. 180-81.

services. These problems vary from enrollment issues, coordination of benefits confusion, coverage denials, and affordability. Lack of access often has a cascading, negative effect on the lives of Medicare beneficiaries with ESRD. Every year, Medicare Rights hears from people who are going without the care they need, facing overwhelming anxiety due to out-of-control medical bills, or rationing what is left of their medication. Accessing appropriate medical care is a key component to ensuring the survival, health, and quality of life for individuals with ESRD.

Target Audience

This Medicare Advocacy Toolkit is designed to help advocates address the needs of New Yorkers who are eligible for Medicare due to ESRD. Medicare's benefits and coverage rules do not change based on how you are entitled to Medicare (i.e., age, disability, or ESRD diagnosis); however, ESRD Medicare has significantly different enrollment and coordination of benefits rules. This guide covers those differences. Special considerations are noted throughout this guide for when an individual is dually entitled to Medicare due to ESRD and age/disability.

Eligibility

In order to be eligible for ESRD Medicare, individuals must be diagnosed with End-Stage Renal Disease, have access to sufficient work history, be a citizen or have a certain qualifying immigration status, be receiving treatment for their ESRD, and have submitted an application for ESRD Medicare. This guide will explain each of these eligibility requirements in turn before explaining how and when eligibility can end.

Diagnosis

ESRD Medicare is based on a specific diagnosis: "irreversible damage to a person's kidneys so severely affecting the ability to remove or adjust blood wastes that, to maintain life, he/she must have either a regular course of dialysis... or a kidney transplant... ." ⁵ This means that a medical provider will need to document the diagnosis, which is done through the application process. ⁶ It also means that individuals without an ESRD diagnosis, including those on dialysis but suffering from other kidney ailments, are ineligible for ESRD Medicare. ⁷

Work History

In order to qualify for ESRD Medicare, an individual must have sufficient work history with Social Security (or the Railroad Retirement Board) ⁸ or have access to sufficient

⁵ Social Security Administration ("SSA"), Program Operations Manual System ("POMS") [HI 00801.191\(B\)\(1\)](#). Before a nephrologist, a doctor who specializes in kidney care, can give an ESRD diagnosis, they must perform a glomerular filtration rate (GFR) test. A GFR test measures how an individual's kidney is functioning. The results of the test must show that there is permanent kidney damage.

⁶ SSA, POMS [HI 00801.196\(A\)](#).

⁷ SSA, POMS [HI 00801.186\(A\)\(1\)](#).

⁸ While this guide will continue to reference only Social Security work history, please note the same rules apply to individuals with Railroad Retirement Board work history.

work history through a family member.⁹ Social Security measures work history in units called quarters of coverage (QCs). Each QC represents a quarter of a calendar year in which an individual met Social Security's earnings requirement (\$1,470 in 2021).¹⁰ Individuals can meet the work history requirement for ESRD Medicare eligibility in four different ways.

Work History Requirement

To qualify for ESRD Medicare, individuals must either be:¹¹

1. **Fully Insured** (usually, this means 40 QCs or ten years of work history);
2. **Currently Insured** (usually, this means someone was working regularly before they started dialysis or needed a transplant);
3. **Entitled to Social Security Benefits** (retirement, disability, or survivor's);
or
4. **The spouse or dependent child¹² of someone who meets any of the above requirements.**

Each of these routes to meeting the work history requirement can be confusing, so this guide explains each in detail.

Timing

Individuals do not have to, necessarily, meet ESRD Medicare's work history requirements by the first day they meet the treatment or application requirements; instead, if they meet the work history requirement later, then ESRD Medicare can still begin at that later date.¹³

1. Fully Insured

For all Social Security benefits, individuals are fully insured when they have 40 QCs (often called ten years of work history).¹⁴ This amounts to one QC for every year between the ages of 21 and 62 (i.e., between the earliest age individuals can become entitled to Social Security disability benefits and the earliest age individuals can take out their Social Security retirement benefits).¹⁵ Again, no matter the individual's age, if they have 40 QCs, then they are fully insured.

⁹ SSA, POMS [HI 00801.191\(C\)\(2\)](#) and [HI 00801.201\(A\)](#). Throughout the POMS, Social Security refers to ESRD Part A as "R-HI" and ESRD Part B as "R-SMI." It is worth noting again that there is no difference in coverage between ESRD Medicare and Medicare due to age or disability, the differences are only in enrollment rules and coordination of benefits. [HI 00801.186\(B\)\(2\)](#).

¹⁰ SSA.gov, [Quarter of Coverage](#).

¹¹ SSA, POMS [HI 00801.191\(C\)\(2\)](#).

¹² Medicare.gov, [Children & End-Stage Renal Disease \(ESRD\)](#).

¹³ SSA, POMS [HI 00801.206](#) and [HI 00801.191\(B\)\(2\)](#).

¹⁴ SSA, POMS [HI 00801.201\(B\)\(3\)](#); [20 C.F.R. §404.110\(a\)-\(b\)](#).

¹⁵ SSA, POMS [HI 00801.201\(B\)\(3\)](#).

For individuals with ESRD who are under age 62, the fully insured amount is pro-rated based on their age. In other words, they can be fully insured with less than 40 QCs. Individuals under age 62 need one QC for each year between age 21 and the year they start dialysis or need a transplant.¹⁶ So, for instance, if an individual begins dialysis when they are 32, they would need ten QCs to be fully insured (one QC each for ages 22, 23, 24, 25, 26, 27, 28, 29, 30, and 31). However, there are three exceptions:

1. **Minimum Requirement:** All individuals need a minimum of six QCs to be fully insured.¹⁷
 - a. So, if an individual begins dialysis at age 25, then they need six QCs to be fully insured, not the three that would be expected based upon the pro-rated formula.
2. **Disability Freeze:** Individuals do not need QCs for any years (including partial years) in which Social Security considered them to have a disability.¹⁸ This is called the “disability freeze.”¹⁹ Individuals can still accrue QCs during the freeze.²⁰
3. **HI Freeze:** Individuals do not need QCs for any quarters (including partial quarters) in which they previously had ESRD Medicare.²¹ This is called the “HI freeze” and it most commonly applies to individuals who had ESRD Medicare, received a transplant, the transplant failed after three (or more) years, and now they need to restart dialysis or get another transplant.²² The freeze applies even to quarters where an individual has started dialysis but not yet enrolled in ESRD Medicare and lasts until they no longer have ESRD Medicare.²³ Individuals can still accrue QCs during the freeze.²⁴

2. Currently Insured

To be currently insured means to have been working recently. Specifically, an individual applying for ESRD Medicare is currently insured when they have at least 6 QCs in the last 13 calendar quarters.²⁵ Calendar quarters when the individual was considered to have a disability by Social Security are not counted as one of the 13 quarters unless the individual had the earnings to qualify that quarter for a QC.²⁶

¹⁶ SSA, POMS [HI 00801.201\(B\)\(3\)](#); [20 C.F.R. §404.110\(b\)](#).

¹⁷ SSA, POMS [HI 00801.201\(B\)\(3\)](#).

¹⁸ SSA, POMS [HI 00801.201\(B\)\(3\)](#); [HI 00801.261\(B\)](#); [20 C.F.R. §404.110\(c\)](#).

¹⁹ SSA, POMS [HI 00801.201\(B\)\(3\)](#); [DI 25501.240](#).

²⁰ SSA, POMS [HI 00801.201\(B\)\(3\)](#).

²¹ SSA, POMS [HI 00801.261\(B\)](#).

²² SSA, POMS [HI 00801.261\(A\)](#).

²³ SSA, POMS [HI 00801.261\(C\)](#).

²⁴ SSA, POMS [HI 00801.261\(B\)](#).

²⁵ SSA, POMS [HI 00801.201\(B\)\(4\)](#). Also, see [20 C.F.R. §404.120](#).

²⁶ SSA, POMS [HI 00801.201\(B\)\(4\)](#). It is not completely clear when the 13 months that are counted end: “a period of 13 calendar quarters ending with the quarter of ESRD onset, the quarter of death (if the individual on whose account entitlement is being established is deceased), or some later quarter.”

3. Entitled to Social Security's Retirement, Disability, or Survivor's Benefits

Entitled to benefits does not, necessarily, mean receiving benefits: an individual can be entitled to Social Security benefits and qualify for ESRD Medicare, but also not actually be receiving the benefits due to a suspension or deduction.²⁷ For example, someone entitled to Social Security Disability Insurance payments may not be receiving them if they are earning above a certain amount at their job; however, they can still qualify for ESRD Medicare based on their entitlement to these benefits.

4. The spouse or dependent child of someone who meets any of the above requirements.

An individual can qualify for ESRD Medicare if they are the spouse or dependent child of someone who is fully insured, currently insured, or entitled to Social Security's retirement, disability, or survivor's benefits.²⁸

- **Spouse:** An individual can use their spouse's work history if they are currently married.²⁹ In addition, if the individual's spouse is deceased or divorced from them, they may also be able to use their spouse's work history if they meet the same relationship requirements as found in the provisions for Social Security benefit entitlements.³⁰
- **Dependent Child:**³¹ An individual can use their parent's work history if they are unmarried and either: 1) under age 22; 2) have a disability that began before age 22; or 3) are under age 26 and have received at least one-half support from the parent whose work history they are trying to use since before age 22.³²

Case Study: Work History

Max, who is not entitled to any Social Security benefits, had ESRD Medicare for almost a decade before getting a kidney transplant. When his transplant failed more than three years later, he restarted dialysis and reapplied for ESRD Medicare. Social Security denied his enrollment saying he had 24 QCs which was not enough work history to qualify Max for ESRD Medicare. At the time of his most-recent ESRD Medicare application in February 2020, Max was 49 years old, had turned 21 in January 1991, was enrolled in ESRD Medicare from June 2002 (after starting dialysis in March 2002) until October 2011 (three years after a successful transplant), and restarted dialysis in January 2020.

²⁷ SSA, POMS [HI 00801.191\(C\)\(2\)](#); [HI 00801.201\(A\)](#).

²⁸ [42 C.F.R. 406.13\(c\)\(2\)\(iii\)](#).

²⁹ [42 C.F.R. 406.13\(b\)](#).

³⁰ [42 C.F.R. 406.13\(b\)](#); [20 C.F.R. 404.331](#). The duration of relationship requirements apply only to divorced spouses.

³¹ Medicare.gov, [Children & End-Stage Renal Disease \(ESRD\)](#).

³² [42 C.F.R. 406.13\(b\)](#).

- Max was not entitled to Social Security benefits, but he did believe he had actually earned 40 QCs, since he had worked for at least ten years. 40 QCs would qualify Max as fully insured in all cases, so he could have contacted the IRS and requested his work records in order to get his Social Security work history updated. If Max was correct that Social Security had missed part of his work history, he could enroll in Medicare once the system was updated.
- Max, however, found it more expedient to explain to Social Security that he was fully insured despite not having 40 QCs.
 - To be fully insured for ESRD Medicare, Max only needs 1 QC for each of the 27 years after he turned 21 and up to the year he restarted dialysis. So: 27 QCs. Since Social Security only has a record of 24 QCs, they would not find him fully insured just based on his age.
 - However, Max is eligible for the “HI Freeze” because he was previously entitled to ESRD Medicare for all or part of 40 calendar quarters (or 10 years). As a result, Max only needs 1 QC for the 17 years he was not on ESRD Medicare. So: 17 QCs. As a result, Max can appeal³³ Social Security’s decision by explaining that his 24 QCs are more than enough to make him fully insured because of his age and the HI freeze.
- If Max was not fully insured, he might be currently insured if he was recently working, or he may have a spouse (or a parent if he was a “dependent child”) who is entitled to Social Security benefits, fully insured, or currently insured.

Immigration Status

Individuals with ESRD do not need to be a citizen or legal permanent resident to qualify for Medicare; however, Medicare will not actually pay out any benefits on the individual’s behalf unless they are legally residing in the U.S. as defined by POMS [RS 00204.010](#).³⁴ In addition, Individuals who are considered “alien workers” also need to meet certain paperwork requirements.³⁵ In other words, the immigration status eligibility requirements for ESRD Medicare are slightly more generous than the immigration status requirements for ESRD Medicare to actually pay out benefits. There is a mismatch. As a result, some people who are enrolled in ESRD Medicare may find that their medical claims are denied because they have “alien status.” This can create serious payment issues.

³³ For information on the appeals process, see form [SSA-561](#), Request for Reconsideration; [20 C.F.R. § 404.902](#) *et seq.*

³⁴ SSA, POMS [HI 00801.191\(D\)\(2\)](#).

³⁵ SSA, POMS [RS 00301.102](#).

Case Study: Immigration Status

Emilia is enrolled in ESRD Medicare and in New York's Medicaid program. Both Medicare and Medicaid are denying her medical claims (Medicare because of "alien status" and Medicaid because Medicare is primary and the program believes Medicare should be paying).

- Ideally, Emilia would be able to update her immigration status by providing proof to Social Security that she is legally residing in the U.S. as defined by POMS [RS 00204.010](#).
 - Determining and updating Emilia's immigration status is outside of Medicare Rights' expertise, so we partner with advocacy organizations who specialize in immigration work to make sure our clients get competent assistance. If she has one, Emilia can also speak to her immigration attorney.
 - In this case, Emilia got assistance from a legal services provider to update her green card with U.S. Citizenship and Immigration Services. She then brought her original paperwork to Social Security and they updated her record.
 - Once Social Security updates their system with the corrected immigration status there will be an effective date for when Emilia is considered to be legally residing in the U.S. and eligible for Medicare payments on her behalf.
 - Emilia can now tell her providers to rebill Medicare for dates of service on or after the effective date of her corrected immigration status.
- If Emilia's immigration status cannot be changed, then her ESRD Medicare will not pay out on her behalf. She has at least two options:
 - Emilia can speak to Medicaid about how Medicare (although it is primary to Medicaid) will not pay on her behalf due to her immigration status. This also is beyond Medicare Rights' expertise, so we would refer Emilia to an advocacy organization specializing in Medicaid work.
 - Emilia may be able to withdraw her application for ESRD Medicare (if Emilia no longer has Medicare, then Medicaid becomes her primary insurance). Withdrawing an application means paying back any benefits that were paid out on her behalf, so this usually would only work if Emilia had not used her Medicare benefit at all.³⁶

³⁶ SSA, POMS [HI 00801.197\(A\)\(1\)](#): "An ESRD application may be withdrawn at any time after it is filed, even if entitlement has begun. Any Part A benefits paid to, or on behalf of, the claimant must be repaid to the Medicare program before the withdrawal is approved."

Treatment

The type of ESRD treatment an individual receives can affect when they become eligible for ESRD Medicare.³⁷

| Treatment | First month of eligibility | Exceptions |
|--------------------------------|--|---|
| Dialysis | Fourth month of dialysis. ³⁸ | If the individual previously had ESRD Medicare, then the first month of eligibility is their first month of dialysis. ³⁹ |
| Self-dialysis | First month of self-dialysis training. ⁴⁰ | If the individual is not “expected” to complete the training program, cannot “reasonably be expected to self-dialyze,” or does not actually complete the training for reasons other than death due to a deterioration of health, then there is no eligibility at all for self-dialysis. ⁴¹ |
| Transplant⁴² | Month of the transplant. ⁴³ | If the individual needs to be hospitalized for inpatient procedures preliminary to the transplant, then the first month of eligibility is up to two months before the transplant. ⁴⁴ |

Application

Unlike Medicare due to age and disability, ESRD Medicare is based on a specific diagnosis. Accordingly, applicants need to supply Social Security with medical documentation of their diagnosis. Individuals should provide this information by completing form [CMS 43](#) and having the physician treating their renal disease (usually with the help of a renal social worker or nurse) complete form [CMS 2728](#).⁴⁵ Together, these two forms should be submitted to Social Security in person or by mail, though dialysis centers and hospitals will often submit electronically on behalf of their patients.

³⁷ SSA, POMS [HI 00801.191](#); [HI 00801.215](#); CMS, [Medicare Coverage of Kidney Dialysis & Kidney Transplant Services](#) (Publication 10128), pp. 10-11.

³⁸ SSA, POMS [HI 00801.216\(A\)\(1\)](#).

³⁹ SSA, POMS [HI 00801.216\(A\)\(2\)](#).

⁴⁰ SSA, POMS [HI 00801.226](#) and [HI 00801.216\(A\)\(2\)](#).

⁴¹ SSA, POMS [HI 00801.226](#).

⁴² If an individual dies before their transplant, they cannot be retroactively eligible for ESRD Medicare due to a transplant. However, if an individual dies during or after their transplant, then they can be retroactively eligible for ESRD Medicare due to a transplant.

SSA, POMS [HI 00801.221\(A\)\(3\)](#).

⁴³ SSA, POMS [HI 00801.221\(A\)\(1\)](#). Here, the transplant facility does not need to be Medicare-approved for eligibility purposes but does need to be Medicare-approved for payment purposes.

⁴⁴ SSA, POMS [HI 00801.221\(A\)\(2\)](#): “R-HI based on transplant can also begin: with the month in which the individual is an inpatient in a hospital that is an approved renal transplantation center or in a hospital that is an approved renal dialysis center in anticipation of, or in preparation for, transplant surgery, provided such surgery takes place within the next 2 months; or with the second month prior to the month of transplant if the above condition was met but the transplant occurred more than 2 months after the preparatory services occurred. The inpatient stay for preparatory services does not have to be continuous from the time the decision is made to proceed to transplant until the transplant occurs.” Here, the facility does need to be Medicare-approved for both eligibility and payment purposes.

⁴⁵ SSA, POMS [HI 00801.196\(A\)](#).

Applications are not valid if submitted too early, so the earliest an individual should submit an ESRD Medicare application is the month before the month they actually become eligible.⁴⁶

Applying as a Representative

ESRD takes a dramatic toll on the health of many of those with the diagnosis. Consequently, an individual may not be well enough to submit a Medicare application or may die before they complete the process. Social Security allows representatives to enroll their loved one in Medicare after they have died or while they are, otherwise, unable to do so themselves.⁴⁷ A spouse, child, parent, legal representative, or a supplier of dialysis services can submit applications on an individual's behalf.⁴⁸ In cases where the individual is alive, Social Security will accept an application from a representative if the individual "cannot transact business."⁴⁹ In addition, the representative should sign a statement explaining their relationship to the individual and why the individual cannot submit the application themselves.⁵⁰

Protected Filing Date

The date an individual applies for ESRD Medicare, called the "filing date," affects when their enrollment begins.⁵¹ If timing is important, but an individual cannot submit a completed application immediately, they can create a protected filing date, submit their complete application later, and still benefit from the earlier filing date.

Individuals can request a protected filing date in a variety of ways: all that is necessary is for Social Security to receive "any signed request for or inquiry about Medicare on behalf of a specified ESRD patient."⁵² Although what is received must be signed, it does not have to be from the individual themselves. For instance, a representative can submit an application on behalf of an individual even if that individual is not incapacitated in order to reserve a protected filing date.⁵³ When Social Security receives the statement that triggers a protected filing date, they should send a written notice to the individual saying a completed application is still required before the individual's Medicare enrollment can be processed.⁵⁴ As long as the individual submits a completed application within six months after the month they receive the written notice, then their application's filing date is the protected filing date rather than the actual date they applied.⁵⁵

⁴⁶ [42 CFR § 406.13\(d\)\(2\)](#).

⁴⁷ SSA, POMS [HI 00801.196\(B\)](#).

⁴⁸ SSA, POMS [HI 00801.196\(B\)](#) and (D)(1).

⁴⁹ SSA, POMS [HI 00801.196\(B\)](#).

⁵⁰ Ibid.

⁵¹ SSA, POMS [HI 00801.186\(B\)\(1\)](#).

⁵² SSA, POMS [HI 00801.196\(A\)](#). In certain cases, a signed statement provided to a hospital indicating an intent to apply for ESRD Medicare or Social Security Disability Insurance can also trigger a protected filing date. See [HI 00801.022\(D\)](#) and [HI 00801.196\(D\)\(2\)](#).

⁵³ SSA, POMS [HI 00801.196\(B\)](#).

⁵⁴ Ibid.

⁵⁵ SSA, POMS [HI 00801.196\(A\)](#).

When Eligibility Ends

ESRD Medicare eligibility does not last forever; instead, eligibility (and enrollment if the individual is enrolled) ends:⁵⁶

- The day an individual dies;
- Three years after the month of a successful kidney transplant; or
- A year after the month dialysis ends (unless dialysis ended because of a successful transplant).

ESRD Medicare enrollment does not end if someone loses their connection to adequate work history.⁵⁷ For example, if an individual has no work history of their own but uses their spouse's work history to enroll in ESRD Medicare, they are not disenrolled from ESRD Medicare if they divorce their spouse.⁵⁸ This is true even if the individual would no longer be eligible for ESRD Medicare if they had not already been enrolled.

Although Medicare Rights has seen Social Security determine this end date using information from Medicare's system, individuals are required to report to Social Security when they receive a transplant and when they stop dialysis.⁵⁹

Coordination of Benefits

ESRD Medicare uses different coordination of benefits rules than Medicare due to age or disability, so the coordination works differently with other types of health coverage.⁶⁰ Initially, the health care costs (ESRD-related and not ESRD-related) of those eligible for ESRD Medicare are borne primarily by, if they are enrolled in one, their current group health plan (or GHP, e.g., job-based insurance, retiree insurance, and COBRA⁶¹).⁶² If the individual stays in their GHP, only after 30 months should Medicare become the primary insurer.⁶³ In other words, Medicare is secondary to an individual's job-based insurance, retiree insurance, and COBRA for the first 30 months the individual is eligible for ESRD Medicare.⁶⁴ After this 30-month coordination period ends (or, if sooner, after the individual leaves their other insurance or the insurance ends), Medicare becomes the primary insurer.⁶⁵ This is true regardless of the size of the employer and whether the other insurance is through current employment.⁶⁶ Again, the 30-month coordination

⁵⁶ SSA, POMS, [HI 00820.030\(A\)\(1\)](#); [42 CFR § 406.13\(f\)](#); Medicare Interactive, [Ending Medicare for people with ESRD](#).

⁵⁷ SSA, POMS, [HI 00820.030\(A\)\(3\)](#).

⁵⁸ Ibid.

⁵⁹ SSA, POMS, [HI 00820.030\(A\)\(4\)](#); Evidence should be sent to "SSA, OCO/ODO, 1500 Woodlawn Drive, Baltimore, Maryland 21241-1500."

⁶⁰ CMS, [Medicare Coverage of Kidney Dialysis & Kidney Transplant Services](#) (Publication 10128), pp. 12-14.

⁶¹ CMS, Medicare Secondary Payer Manual, [Ch. 2](#), §20.2.

⁶² For a definition of group health plan, see CMS, Medicare Secondary Payer Manual, [Ch. 2](#), §20.

⁶³ SSA, POMS [HI 00801.247\(A\)-\(B\)](#); CMS, Medicare Secondary Payer Manual, [Ch. 1](#), §10.2.

⁶⁴ Ibid. To be "eligible," but not "entitled" to ESRD Medicare means the individual meets the requirements for ESRD Medicare but has not applied. See [Ch. 2](#), §20.

⁶⁵ SSA, POMS [HI 00801.247\(A\)-\(B\)](#); CMS, Medicare Secondary Payer Manual, [Ch. 1](#), §10.2; [Ch. 2](#), §20.

⁶⁶ Ibid.

period begins when an individual is **eligible** for ESRD Medicare, not necessarily when they are enrolled.⁶⁷

If the individual later loses eligibility for ESRD Medicare (i.e., 12 months after the month they stop dialysis or three years after a successful kidney transplant) but becomes eligible for ESRD Medicare again, then the 30-month coordination period will restart.⁶⁸

Interaction with Medicare Due to Age and Disability

The 30-month coordination period can apply differently if an individual is dually entitled to ESRD Medicare and Medicare due to age/disability:⁶⁹

- If an individual is first entitled to Medicare based on ESRD and subsequently becomes eligible for Medicare based on age or disability, then the 30-month coordination period still applies and Medicare pays secondary to a GHP during this time.
- If an individual is first entitled to Medicare based on age or disability but is covered under a GHP based on current employment status, then Medicare should pay secondary during the 30-month coordination period once the individual becomes eligible for Medicare based on ESRD (even if they do not apply for ESRD Medicare). At the end of this 30-month coordination period, Medicare will pay primary going forward. Note that in these cases, Medicare pays primary even if it would have been secondary insurance based on the coordination of benefits rules for Medicare due to age or disability. When someone already has Medicare due to age or disability and later becomes eligible for Medicare due to ESRD, then the ESRD Medicare coordination of benefits rules apply.
- If an individual is first entitled to Medicare based on age or disability and is covered under a GHP based on retirement status, and subsequently becomes entitled to Medicare due to ESRD, then Medicare remains the primary payer, and the 30-month coordination period does not apply.
- If an individual is dually entitled to Medicare due to ESRD and age/disability but they lose their eligibility for ESRD Medicare, then their coordination of benefits will be based solely on their remaining Medicare entitlement through age or disability.

⁶⁷ Ibid.; [Ch. 2](#), §20.1.

⁶⁸ CMS, Medicare Secondary Payer Manual, [Ch. 2](#), §20.1.2.

⁶⁹ SSA, POMS [HI 00801.247\(C\)\(2\)](#); CMS, Medicare Secondary Payer Manual, [Ch. 2](#), §20.1.3.

What does it mean for Medicare to pay secondary?

Just because an individual has Medicare as a secondary payer, does not mean they lose the benefits of Medicare. Instead, it means that claims should be filed first with the other insurance and, then, any remainder can be sent to Medicare. If the other insurance denies the claim, then Medicare will pay (or not pay) as if it was primary insurance.⁷⁰ If the other insurance pays on the claim, but less than what the provider is obligated to accept as full payment and less than what is payable by Medicare, then Medicare will often cover the remainder.⁷¹

ESRD Medicare and Marketplace Coverage

Individuals are not required to sign up for ESRD Medicare and some choose to stay, or enroll, in a Qualified Health Plan (QHP) through their state Marketplace (e.g., New York State of Health).⁷² These individuals may be eligible for tax credits and reduced cost-sharing through the Marketplace if they meet the income requirements and do not enroll in ESRD Medicare.⁷³ In some cases, charitable organization may also be willing to cover an individual's Marketplace premiums. There are not clear rules for how Marketplace coverage and ESRD Medicare coverage are supposed to coordinate, so individuals who wish to keep their Marketplace plans and delay enrolling in ESRD Medicare should consider the possible cost differences, access to care, and ability to cover transplant and immunosuppressant costs.

Enrollment

Individuals eligible for ESRD Medicare can enroll in Part A at any time. When they do so, Part A will be retroactive for up to 12 months (but cannot be effective earlier than the first month the person was eligible for ESRD Medicare).⁷⁴ Individuals can restrict the retroactivity of their Part A as long as the effective date is within the 12 months preceding their filing date and is a month they were eligible for ESRD Medicare.⁷⁵ Individuals can choose an effective date by signing a statement showing the reason for their choice.⁷⁶ Family members can also retroactively file for ESRD coverage after a person with ESRD dies.⁷⁷

⁷⁰ CMS, Medicare Secondary Payer Manual, [Ch. 1](#), §10.8.

⁷¹ Ibid. For details, and the interaction with cost-sharing, please see § 40.

⁷² NY State of Health, [The Official Health Plan Marketplace](#).

⁷³ Medicare.gov, [I have End-Stage Renal Disease \(ESRD\)](#).

⁷⁴ SSA, POMS [HI 00801.196\(A\)](#).

⁷⁵ Ibid.

⁷⁶ Ibid.

⁷⁷ SSA, POMS [HI 00801.196\(B\)](#) and (D).

ESRD Medicare Part B enrollment piggybacks on Part A enrollment, so Part B can also be retroactive for up to 12 months.⁷⁸ For individuals who apply for Part A:

1. If the individual's Part A effective date is either prospective or less than six months retroactive, then the Part A and B effective date will be the same.⁷⁹
2. If the individual's Part A would be retroactive for six or more months, the individual has two choices:⁸⁰
 - a. First, they could choose to have Part B begin prospectively the month their application is submitted or the month it is processed.⁸¹ In that case, there would be different Part A and B effective dates even though enrollment was simultaneous. An individual might make this choice if they did not need Part B to cover any medical bills during the retroactive period and, so, they will save on having to pay the Part B premium during these months.
 - b. Second, they could choose to have Part B begin retroactively with Part A.⁸² Part B premiums are owed for any months of retroactive coverage. An individual might make this choice if they needed Part B to cover medical bills during the retroactive period that were more expensive than the Part B premium.

In almost all cases, an individual should apply for Part A and B at the same time.

ESRD Medicare's enrollment rules provide a lot of flexibility to individuals, but that flexibility is lost if they enroll in Part A but not Part B. Unlike with Medicare due to age or disability, people with ESRD Medicare are not entitled to the Part B Special Enrollment Period (SEP).⁸³ In other words, if they decline Part B when they enroll in Part A, then they will, in most cases, have to enroll in Part B during the General Enrollment Period (GEP), creating a gap in coverage and risking late enrollment penalties.⁸⁴ Furthermore, most dialysis services are covered under Part B,⁸⁵ so if Medicare is the individual's primary insurance, it is likely that their most expensive services will only be covered if they are enrolled in Part B.⁸⁶

Delaying enrollment if other coverage is primary. Those individuals with good health coverage that is primary to Medicare, such as job-based insurance during the 30-month coordination period, may want to consider delaying their enrollment in Medicare. If, for example, the individual's health insurance pays for their care at, or near, 100%, and covers all of the services they need, it may not be beneficial for them to carry Part B. This is because Part B is paying secondary and requires a premium. Before making this decision, the individual should talk to their insurance company to understand how much

⁷⁸ SSA, POMS [HI 00801.186\(B\)\(1\)](#); [HI 00801.191\(C\)](#).

⁷⁹ SSA, POMS [HI 00801.251\(A\)\(1\)](#).

⁸⁰ SSA, POMS [HI 00801.191\(D\)\(3\)\(a\)](#); [HI 00801.251\(A\)\(1\)](#); [HI 00801.251\(B\)](#).

⁸¹ SSA, POMS [HI 00801.251\(B\)](#).

⁸² Ibid.

⁸³ SSA, [POMS HI 00805.265\(A\)](#).

⁸⁴ The GEP takes place from January 1 to March 31 of each year, but coverage does not begin until July 1. POMS, [HI 00805.025\(A\)](#); Medicare Rights Center, [How to enroll in Medicare if you missed your Initial Enrollment Period](#).

⁸⁵ CMS, [Medicare Coverage of Kidney Dialysis & Kidney Transplant Services](#) (Publication 10128), p.16.

⁸⁶ SSA, POMS [HI 00801.251\(A\)\(1\)](#).

of dialysis, transplant, and non-ESRD related costs will be covered. Individuals should also understand how their coverage changes depending on whether Medicare covers their transplant.

Generally, someone who delays enrolling in ESRD Medicare should delay enrolling in both Parts A and B. Once they are ready to enroll, they can enroll into both at the same time. Often, individuals request enrollment in Part A and B when their 30-month coordination period is ending, since they will no longer be able to use their other insurance as primary. Enrolling in Part A and B at this time ensures there is no gap in coverage or Part B late enrollment penalty. If the individual is getting a kidney transplant, however, they should consider timing their Medicare enrollment to ensure their immunosuppressants are covered by Part B.⁸⁷ Even with employer coverage, a person getting a kidney transplant may want to consider enrolling in Medicare prior to the transplant to ensure that Medicare will cover their immunosuppressants following the 30-month coordination period. (See Other Issues section for more information about Medicare coverage of immunosuppressants.)

Interaction with Medicare Due to Age and Disability

Some people are dually eligible for Medicare, which means they are eligible because they have an ESRD diagnosis and because they are eligible due to age or disability.⁸⁸ When a dually eligible individual who already has Medicare due to age or disability becomes eligible for ESRD Medicare they have an optional Initial Enrollment Period (IEP) to enroll in Medicare.⁸⁹ The IEP begins three months before and ends three months after the first month of eligibility due to ESRD.⁹⁰ Most individuals have no reason to use this IEP because they are already enrolled in Medicare and coverage is the same no matter how the individual is eligible for Medicare. Still, some can benefit from the IEP, such as individuals who:⁹¹

- Are not enrolled in Part B (they can use the IEP to enroll immediately and without a penalty);
- Have a Part B or Part D⁹² late enrollment penalty (they can use the IEP to waive these penalties);
- Want to, and would be able to, use ESRD Medicare retroactive enrollment to get an earlier effective date for their Medicare; or

⁸⁷ SSA, POMS [HI 00801.247\(f\)](#).

⁸⁸ SSA, POMS [HI 00801.258\(A\)](#).

⁸⁹ SSA, POMS [HI 00801.258\(B\)-\(C\)](#). While the IEP is always optional for people with Medicare due to age, for people with Medicare due to disability, Social Security is supposed to always enroll the individual in ESRD Medicare. "The only exception to this requirement is where Medicare will be secondary payer of benefits and the individual does not wish to become entitled to SMI until the end of the 30-month ESRD coordination period as described in [HI 00801.247\(C\)\(2\)](#)."

⁹⁰ SSA, POMS [HI 00801.258\(D\)](#).

⁹¹ SSA, POMS [HI 00801.258\(C\)](#).

⁹² CMS, Medicare Prescription Drug Manual, [Ch. 4](#), §10.1.

- Have Medicare due to age and only qualify for premium Part A (they can use the IEP to enroll in premium-free Part A, since people with ESRD Medicare never have a Part A premium).

Reimbursement Rates and Enrollment Advice

Medicare's payment rates for dialysis are close to the actual estimated cost of the service.⁹³ This historically low reimbursement rate has contributed to the consolidation of the for-profit dialysis business: the majority of individuals receive dialysis from one of two for-profit companies operating the largest share of dialysis centers in the U.S, a multi-billionaire dollar business.⁹⁴ It also means that dialysis centers often look to commercial coverage (e.g., Marketplace plans,⁹⁵ job-based insurance, etc.) to ensure their profit margins. As a result, commercial insurance appears to pay over four times as much as Medicare for each dialysis session.⁹⁶

This substantial difference in reimbursement amounts between Medicare and commercial insurance can lead, indirectly, to Medicare enrollment issues. Since dialysis centers usually make considerably more money billing commercial insurance than Medicare, they have a financial incentive to keep patients on Marketplace coverage, job-based insurance, and other non-Medicare coverage for as long as they can. The health care provider, which also often serves as an advisor to patients on coverage enrollment decisions, may apply pressure to patients to avoid or delay enrolling in Medicare, such as by helping them secure funding for non-Medicare coverage.⁹⁷ In particular, then, it is vital for advocates to ensure individuals have the information they need to make the best enrollment decision for themselves rather than the finances of the dialysis center.

What if an individual enrolls in Part A but declines Part B? Some individuals with ESRD enroll in Part A but not Part B. Often, this happens when the individual is covered by job-based insurance, retiree coverage, or COBRA. Unfortunately, if they want primary coverage, in most cases, they will need to enroll in Part B at the end of the 30-month coordination period but will not have a problem-free enrollment period to use. This is because there is no Special Enrollment Period connected to the end of the coordination period, and the Part B SEP does not apply to people who have ESRD Medicare (even if they also have Medicare eligibility through age or disability).⁹⁸ Furthermore, it is almost never a good idea to enroll in Part A and then use

⁹³ JAMA Internal Medicine, Childers CP, Dworsky JQ, Kominski G, Maggard-Gibbons M. [A Comparison of Payments to a For-profit Dialysis Firm From Government and Commercial Insurers](#) (2019).

⁹⁴ Ibid.

⁹⁵ Medicare Rights Center, [Qualified Health Plan \(QHP\) basics, Medicare and the Marketplaces](#).

⁹⁶ JAMA Internal Medicine, Childers CP, Dworsky JQ, Kominski G, Maggard-Gibbons M. [A Comparison of Payments to a For-profit Dialysis Firm From Government and Commercial Insurers](#) (2019).

⁹⁷ CMS, [CMS Fact Sheet: Promoting Transparency and Appropriate Coverage for Dialysis Patients](#).

⁹⁸ SSA, POMS [HI 00805.265\(A\)](#).

the General Enrollment Period (GEP) to enroll in Part B. This is true because of the gap in coverage (individuals apply for the GEP between January and March, but Medicare benefits do not become effective until July) and because the individual will likely be given a Part B late enrollment penalty, even if they carried job-based insurance through current employment.⁹⁹

If an individual enrolls in Part A, declines Part B, and later needs to enroll in Part B, they may have options other than the GEP. Advocates should consider whether the individual qualifies for one of the following three options.

The Medicare Savings Programs (MSPs): MSPs are federally funded, state-run benefits that, at a minimum, pay the monthly Medicare Part B premium for beneficiaries with limited income and assets.¹⁰⁰ Importantly, enrollment in an MSP also enables an individual to enroll in Part B outside of usual enrollment periods and have any Part B late enrollment penalty waived.¹⁰¹ Using MSPs as an enrollment mechanism—through what is known as the Part B Buy-in—has enabled Medicare Rights to help many beneficiaries who had no other immediate enrollment period available to them.¹⁰²

MSPs are available nationwide, but eligibility rules differ by state.¹⁰³ Most states have both income and asset requirements for MSP eligibility, but New York has no asset requirement.¹⁰⁴ Since income limits change annually based on federal poverty guidelines, it is important to use up-to-date numbers.¹⁰⁵ Even if an individual's income is above the threshold, they may still be eligible for an MSP if they can claim certain income disregards or they qualify for certain types of trusts.¹⁰⁶ There are three primary types of MSP recipients: Qualifying Individual (QI), Specified Low-Income Medicare Beneficiary (SLMB), and Qualified Medicare Beneficiary (QMB). For information about the benefits available to enrollees in each program, visit Medicare Rights' Medicare Interactive resource.¹⁰⁷ An important difference between the different MSP types are their effective dates, since the effective date of the MSP will also be the effective date of Part B (if the individual does not already have Part B).¹⁰⁸

Applications for MSPs are processed by local Departments of Social Services, such as the Human Resources Administration in NYC.¹⁰⁹ Applicants must complete form [DOH-4328](#) and submit proof of their income, date of birth, New York State residency, and identity.¹¹⁰ The local Department of Social Services should notify someone within 45

⁹⁹ SSA, POMS [HI 01001.010\(B\)\(2\)](#).

¹⁰⁰ Medicare Rights Center, [Medicare Savings Program basics](#).

¹⁰¹ [42 U.S.C. § 1395v\(a\),\(e\)](#); POMS, [HI 00815.001](#), [009](#), [018](#), [039](#), and [00801.140](#); Medicare Rights Center, [Using MSPs to enroll in Part B](#).

¹⁰² Medicare Rights Center, [Using MSPs to Enroll in Part B](#).

¹⁰³ Medicare.gov, [Medicare Savings Programs](#); National Council on Aging, [Medicare Savings Programs \(MSPs\): Eligibility and Coverage \(2019\)](#).

¹⁰⁴ Medicare Rights Center, [Medicare Savings Program financial eligibility guidelines](#).

¹⁰⁵ Medicare Rights Center, [MSP information sheet](#).

¹⁰⁶ See, generally, [18 CRR-NY § 360-4.3](#); New York State Department of Health, [Medicaid Reference Guide](#); New York State Department of Health, [GIS 19 MA/04](#).

¹⁰⁷ Medicare Rights Center, [MSP basics](#).

¹⁰⁸ POMS, [HI 00815.039](#).

¹⁰⁹ Medicare Rights, [Applying for a Medicare Savings Program](#).

¹¹⁰ New York State Department of Health, [Medicare Savings Program Application](#).

days of the submission of their application if they are eligible for the MSP.¹¹¹ Medicare Rights helps New York advocates (and particularly those in New York City) assist their clients with MSP applications. For assistance, contact Medicare Rights' professional email inbox at professional@medicarerights.org. Local HIICAP offices also help with MSP applications.¹¹²

| 2020 New York State MSP Income Eligibility Levels | | | |
|---|-------------|---------|---|
| MSP | Individuals | Couples | Effective Date of the MSP |
| QI | \$1,456 | \$1,960 | Three months before the month of application (or January if the month of application is January, February, or March). |
| SLMB | \$1,296 | \$1,744 | Three months before the month of application. |
| QMB | \$1,084 | \$1,457 | The month after the month of application. |

Equitable relief: Sometimes an individual delays enrolling in Medicare Part B because of an error, misrepresentation, or inaction by a federal employee, such as a Social Security or 1-800-MEDICARE representative.¹¹³ For example, Medicare Rights' callers have been incorrectly told by Social Security representatives that they can delay enrolling in Part B without penalty because they have retiree insurance. In other instances, Medicare Rights' helpline callers have applied for Part B during an enrollment period but never heard back from Social Security. In these cases, the individual may be able to enroll in Part B through a process known as equitable relief.¹¹⁴ For those with ESRD Medicare, Social Security representatives are supposed to explain the dangers of declining Part B, so, it is possible that a representative's failure to provide this warning could constitute grounds for equitable relief.¹¹⁵

To request equitable relief, an advocate or beneficiary should write a letter to the local Social Security office explaining that an error, misinformation, or inaction by a federal employee caused a delay in Part B enrollment. (Medicare Rights offers step-by-step directions and a [model letter](#) on its website.)¹¹⁶ The letter should be as specific and detailed as possible. For example, if a Social Security representative has provided misinformation, the letter should include the representative's name or description, the office they work in, what they said, the date and time they said it, and whether the

¹¹¹ [45 C.F.R. § 206.10\(a\)\(3\)\(i\)](#).

¹¹² New York State Office for the Aging, [HIICAP Local Offices](#).

¹¹³ Unfortunately, misinformation provided by state employees, employers, insurance companies, and benefits administrators does not seem to be covered by equitable relief. See [42 C.F.R. § 407.32](#): "...a Federal employee or any person authorized by the Federal Government to act in its behalf..."

¹¹⁴ Medicare Rights Center, [Equitable relief](#).

¹¹⁵ See, e.g., POMS, SSA [HI 00801.246](#): "All prospective R-HI enrollees should be informed about their SMI enrollment rights and the advantages of enrolling in the program."; [HI 00801.247\(F\)](#): "It is extremely important to properly inform ESRD patients (including dual eligibles) who have GHP coverage about their options with respect to filing an application for R-HI... ESRD patients with GHP coverage should be discouraged from filing for R-HI while rejecting R-SMI at initial eligibility."; [HI 00801.251\(A\)\(3\)](#): "If an R-HI beneficiary wants to decline SMI before being awarded HI, explain the effect of such a decision. Document when SMI is refused to show that the beneficiary understands the consequences of his/her action."

¹¹⁶ Medicare Rights Center, [Part B Enrollment Toolkit](#).

information was conveyed in person or by phone. Such detailed information will not be available in all cases, but as much information as possible should be included in the letter to help ensure its chances of success. In addition, the letter should clearly request the result the beneficiary seeks (e.g., to be enrolled in Part B retroactive to a specific date, to have a Part B LEP waived).

Social Security is not required to respond to equitable relief requests within any set timeframe, though Medicare Rights typically sees action taken within three months. In addition, Social Security does not have to send the beneficiary a formal decision letter in response to the equitable relief request and, as a result, such letters are rare.

Typically, the effective Part B date for successful equitable relief applications will be the same as if the error, misrepresentation, or inaction had not happened. This means that the effective date could be retroactive, and the beneficiary may need to inform Social Security as to how they will pay for back premiums. However, if retroactive coverage would involve six or more months of back premiums, beneficiaries can also elect to have Part B start prospectively.¹¹⁷

Withdrawing from Part A and simultaneously re-enrolling in Parts A and B: While rare, Medicare Rights has seen this third option work in practice and, in addition, there is firm grounding for it in Social Security's guidance.¹¹⁸ The idea behind the maneuver is that individuals who withdraw their original application for Part A can immediately re-enroll in Part A (retroactive for up to 12 months)¹¹⁹ and Part B at the same time (since Part B enrollment piggybacks on Part A enrollment in ESRD Medicare).¹²⁰ The main drawback is the individual would be responsible for paying back all of the payments Part A made on their behalf.¹²¹ However, someone who used this maneuver would not have to pay back Part A payments if their re-enrollment would cover the same time period.¹²² To withdraw and re-enroll, individuals should go in person to their local Social Security office and specifically request the process found in POMS [HI 00801.197](#).

Enrollment in an MA Plan. Historically, individuals with ESRD generally could not enroll in a Medicare Advantage Plan ("MA Plan").¹²³ Due to the 21st Century Cures Act, this prohibition is changing effective 2021, when the restrictions on MA Plan enrollment will be lifted.¹²⁴

Other Issues

Immunosuppressants

¹¹⁷ SSA, POMS, [HI 00805.195](#).

¹¹⁸ SSA, POMS [HI 00801.197](#). Withdrawing from Part A would also retroactively disenroll an individual from Part B, had they been enrolled. In such a case, the individual would not be refunded their Part B premiums. [HI 00801.197\(A\)\(3\)](#).

¹¹⁹ SSA, POMS [HI 00801.197\(A\)\(4\)](#).

¹²⁰ In addition, because the re-entitlement to Part A creates an IEP for Part B, any Part B late enrollment penalty would be waived. SSA, POMS [HI 00801.197\(A\)\(2\)-\(4\)](#).

¹²¹ SSA, POMS [HI 00801.197\(A\)\(1\)](#).

¹²² SSA, POMS [HI 00801.197\(A\)\(1\)](#).

¹²³ CMS, [Medicare Coverage of Kidney Dialysis & Kidney Transplant Services](#) (Publication 10128), pp. 8-9.

¹²⁴ Medicare Rights Center, [Medicare Advantage eligibility for people with ESRD](#).

Immunosuppressive drugs are medications used to prevent the body from rejecting a kidney transplant.¹²⁵ It is crucial that kidney transplant patients continually take these drugs to prevent their transplant from failing and having to restart dialysis.¹²⁶ Medicare will cover immunosuppressants under Part B if the transplant occurred in a Medicare-approved facility and the beneficiary had Part A at the time of the transplant (or they have retroactive Part A back to that date) and Part A paid for the transplant, or it didn't pay because it was secondary to employer coverage.¹²⁷

Medicare used to only cover immunosuppressants under Part B for a limited period of time, but now it covers them for as long as the beneficiary has Part B (it does not matter whether Part B is through ESRD, disability, or age). This is true even if there is a gap between different Medicare entitlements.¹²⁸ For instance, an individual might have ESRD Medicare when they have a transplant so their immunosuppressants are covered by Part B. Three years later, they are no longer eligible for ESRD Medicare, so Medicare no longer covers their immunosuppressants. Ten years later, they turn 65 and enroll into Medicare due to age, so Medicare again begins covering their immunosuppressants under Part B.

In cases where the immunosuppressants are not covered by Part B, they may still be covered by Part D (Medicare's prescription drug benefit).¹²⁹ Individuals should check with their Part D plan to determine their cost-sharing for the immunosuppressants, what brands are covered, and any coverage restrictions. Since cost-sharing for Part B and Part D are different and are uniquely affected by supplementary coverage and low-income benefit programs, which one covers immunosuppressants can have a significant effect on affordability.

Troubleshooting Tip

Since immunosuppressants can be covered under Part B or Part D depending on when someone is entitled to Medicare and when they had their transplant, Medicare Rights often hears about billing errors. There are two common issues:

1. Pharmacies may incorrectly bill immunosuppressants to the wrong part of Medicare. CMS has released information to educate pharmacies on how to correctly bill, so advocates should share these resources with the provider.¹³⁰

¹²⁵ CMS, [Medicare Coverage of Kidney Dialysis & Kidney Transplant Services](#) (Publication 10128), pp. 25-26.

¹²⁶ Ibid.

¹²⁷ CMS, Medicare Claims Processing Manual, [Ch. 17](#), §80.3; SSA, POMS [HI 00801.248](#)(B). The individual can have ESRD Medicare or Medicare due to age/disability. See [HI 00801.248](#)(C)(2).

¹²⁸ SSA, POMS [HI 00801.248](#)(E).

¹²⁹ Medicare Rights Center, [Medicare Drug Coverage: Part D vs. Part B](#).

¹³⁰ CMS, MLN Matters, [Clarification of the Billing of Immunosuppressive Drugs](#) (MM10235); [Pharmacy Billing of Immunosuppressive Drugs](#) (SE17032).

2. Part D plans may incorrectly pay for immunosuppressants that should be covered under Part B. In some cases, this incorrect billing and payment has gone on for years. Recently, CMS has encouraged Part D plans to use CMS' transplant claims information to deny immunosuppressants that should be covered under Part B.¹³¹ Advocates should understand that just because a Part D plan has covered an individual's immunosuppressant in the past does not mean the plan did so correctly. Advocates should ask individuals for their dates of Medicare entitlement and transplant to see which part of Medicare should be billed. Individuals can also reach out to 1-800-MEDICARE for this information. If their transplant date is missing or incorrect, individuals can ask their transplant surgeon to update CMS' system by contacting the Part A Medicare Administrative Contractor for their area.¹³²

Affording Cost-Sharing

Dialysis, transplants, and immunosuppressants are expensive. This is true even for people with health coverage like Original Medicare or an MA Plan, which generally only pay 80% of the cost of each dialysis visit. For this reason, it often makes sense for people with ESRD Medicare to maintain other types of health coverage. There are also resources available, in certain cases, for charities to help pay the premiums, especially for Medigap¹³³ and Marketplace¹³⁴ plans.

As a result, we hear that a majority of people on dialysis find a way to stay covered on private insurance. In addition, kidney charities (and at least 15 state ESRD programs) will also pay Medigap premiums, QHP premiums, and other expenses to help cover the cost.¹³⁵ Callers having trouble affording their care may want to talk to one of these organizations or their dialysis center to see how they can get help.

¹³¹ CMS, HPMS Memo, [Using CMS Data when making B vs D Coverage Determinations for Immunosuppressants used to Prevent Transplant Rejections](#) (Apr. 1, 2019).

¹³² In New York, this is [National Government Services](#).

¹³³ Medicare Rights Center, [Supplemental insurance for Original Medicare](#) (Medigap plans).

¹³⁴ Medicare Rights Center, [Qualified Health Plan \(QHP\) basics, Medicare and the Marketplaces](#).

¹³⁵ Dialysis Patient Citizens Education Center, [State-by-State Resources](#).

Case Example: Immunosuppressants and Cost-Sharing

Alice is 30 years old and enrolled in ESRD Medicare. She received a kidney transplant on January 15, 2020, when she was covered by Medicare and a Medigap.¹³⁶ Since then, Alice has had a very difficult time affording her immunosuppressants. Her doctor says she needs to take them or risk losing her transplanted kidney. In order to afford the medication, Alice has stopped paying her Part B and Medigap premiums. How can you try to help Alice?

- Is the pharmacy correctly billing Alice's immunosuppressants?** Based on the fact that Medicare paid for Alice's kidney transplants, her immunosuppressants should be covered under Part B. If her immunosuppressants were being correctly billed, then Alice would not likely have trouble affording them since Part B and her Medigap plan would cover that cost. Based on this, it is likely that Alice's pharmacy is incorrectly billing her Part D plan for the immunosuppressants rather than Part B. A first step then, would be to request that the pharmacy bill her immunosuppressants to Part B instead.
- Is Alice eligible for low-income benefit programs?** If Alice qualifies for an MSP, this would cover her Part B premium for her. If Alice qualifies for Extra Help (either independently or because she is deemed into it by enrolling in an MSP) this could help with any Part D costs she has.¹³⁷
- What is the cost of losing Part B and her Medigap for failing to pay the premiums?** It is important for Alice to understand the consequences of failing to pay her Part B premium and Medigap premium. If she is disenrolled from her Medigap, she loses all of the cost-sharing benefits from the plan. If she loses Part B, she loses her only primary health coverage outside of Part A. If Alice cannot pay both premiums, she would want to, at least, consider paying her Part B premium to maintain primary health coverage.

Complaints and Grievances

Congress created ESRD Network Organizations in order to ensure Medicare beneficiaries were getting good quality of care from dialysis and transplant centers.¹³⁸ In

¹³⁶ In New York State, individuals who are under age 65 and eligible for Medicare due to disability or ESRD can purchase a Medigap policy even if they are under age 65. If you are helping a beneficiary who lives outside New York, contact their State Health Insurance Assistance Program (SHIP) (www.shiptacenter.org) to learn if the individual's state has expanded Medigap enrollment rights for people under age 65.

¹³⁷ Medicare Rights Center, [Extra Help basics](#).

¹³⁸ CMS, [Medicare Coverage of Kidney Dialysis & Kidney Transplant Services](#) (Publication 10128), p.37. For general information on ESRD Network Organizations, see CMS, [Medicare ESRD Network Organizations Manual](#); The National Forum of ESRD Networks, [ESRD Networks – contact information](#).

New York, this is IPRO ESRD Network of New York, Network 2.¹³⁹ One service these organizations provide is to help with beneficiaries' complaints and grievances, including those relating to care, treatment, or other provider issues.¹⁴⁰ Individuals should call their ESRD Network Organization for help with a variety of issues, including: help getting correct enrollment paperwork to Social Security, assistance in finding an appropriate dialysis center, and ensuring their dialysis center is providing the required services and medications.

CMS also explains that individuals can file a quality of care complaint with State Survey Agencies.¹⁴¹ In New York, that means you can file a complaint with the NYS Department of Health.¹⁴² In Medicare Rights experience, this complaint route is not as immediately and directly helpful as reaching out to the ESRD Network Organization.

¹³⁹ IPRO, [Grievances & Concerns](#).

¹⁴⁰ CMS, Medicare ESRD Network Organizations, [Ch. 7](#).

¹⁴¹ CMS, [Medicare Coverage of Kidney Dialysis & Kidney Transplant Services](#) (Publication 10128), pp.37-38.

¹⁴² New York State Department of Health, [Consumer Health Care Information](#). CMS also periodically puts out a list of direct state contacts for issues concerning different types of facilities, see Department of Health and Human Services, [State Survey Agency Directors](#).