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 A Guide to Health Insurance
and Social Security Benefits
for People With CF

What you may need to know

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Introduction

Children and adults with cystic fibrosis (CF) need some form of insurance coverage to help pay for medical care and medications needed to treat the disease.

Gilead has developed this guide in collaboration with Beth Sufian, the author, to assist people with CF, their families, and healthcare providers in identifying potential health insurance coverage options. Some options include group health insurance policies offered by an employer, and government programs such as Social Security benefits, Medicaid, Medicare, and state-government programs. In addition, the Affordable Care Act (known as "Healthcare Reform") may help people with CF access coverage.

The information presented in this guide, including the case studies, is to help educate you on potential options that you can consider to help pay for your medications and treatments. The information is general in nature, and not meant as legal advice or a guarantee of coverage from any of the programs discussed.

After reading this guide, you may have questions about your ability to access insurance coverage or Social Security benefits. At the end of this guide (Section 12), you will find a list of additional resources for information, including a free and confidential service called the CF Legal Information Hotline. The attorneys at the CF Legal Information Hotline can provide free and confidential information on these topics to people with CF, their family members, and healthcare providers. The Hotline can be reached by calling 1-800-622-0385 or sending an e-mail to cflegal@cff.org. This Hotline is sponsored by the CF Foundation and is not associated with, or sponsored by, Gilead Sciences, Inc.



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SECTION 1

Social Security Benefits Overview

The Social Security Administration (“Social Security”) administers 3 programs that may provide health insurance coverage to a person with CF.

Social Security Disability Insurance (SSDI) is a federal program that provides a monthly benefit and Medicare coverage. A person must meet work and medical requirements in order to receive SSDI benefits. A person who has never worked will not be eligible for SSDI benefits.

Supplemental Security Income (SSI) is a federal program that provides a monthly benefit and Medicaid coverage. A person must meet certain low-income, low-asset, and medical requirements in order to receive SSI benefits.

Social Security benefits based on a retired, disabled, or deceased parent

If a parent of a child with CF is eligible for Social Security, then a child under the age of 18 could receive benefits from Social Security based on the retired, disabled, or deceased parent’s Social Security earnings record.

Once the child turns 18, he/she will not continue to receive Social Security benefits unless he/she meets the Social Security medical criteria, in which case he/she will continue to receive benefits based on his/her retired, disabled, or deceased parent’s benefit record. After receiving the SSDI benefit check for 24 months, he/she will become eligible for Medicare.

A child with CF will only be eligible if he/she meets the Social Security medical criteria prior to turning 22 years old. If the benefit amount is larger than the SSI benefit in a state, the person with CF may not be eligible for SSI or Medicaid benefits in his/her state.

Social Security Medical Criteria

A diagnosis of CF alone does not make a person eligible for Social Security benefits. A person applying for SSDI or SSI benefits must meet certain medical criteria. Both SSI and SSDI have the same medical criteria. Social Security calls the medical criteria “The Social Security Listing.”

A summary of the Social Security CF respiratory medical criteria:

- The person has a low FEV₁ (approximately 50% or below) throughout the year prior to applying for benefits; or
- The person has either been hospitalized at least 3 times or had at least 6 physician interventions in the year prior to applying for benefits for treatment of episodes of bronchitis, pneumonia, or hemoptysis (coughing up blood); or
- The person has a persistent pulmonary infection requiring intravenous or nebulized antimicrobial use at least once every 6 months. The adult over 18 must also show that he/she spends a significant amount of time performing treatments, typically between 2-4 hours a day, which prevents him/her from working. A child under 18 must show that significant treatment time prevents him/her from engaging in certain activities of daily living; or
- The child has a significant growth impairment (for children only).

There are also Social Security medical criteria for lung transplant, digestive issues, diabetes, liver disease, depression, and other medical conditions. Go to www.ssa.gov for more information on the Social Security medical criteria.

A Case Example:

*Lauren, an adult, is applying for Social Security benefits and can show she has a persistent pulmonary infection, *Pseudomonas aeruginosa*, evidenced by sputum cultures performed at least once every 6 months. Lauren also has medical records that show the dates she has been on an inhaled antibiotic in the past year. One way that Lauren can show Social Security that her treatment time throughout the day is significant is by explaining the time it takes to perform each breathing treatment, airway clearance therapy, and other daily medical treatments.*

Applying for Benefits

Social Security will base its decision about medical eligibility on the medical records it receives and review of the application. CF is a complex disease and the person reviewing the application will usually have little knowledge of CF. A complete application should be submitted because if the application is denied, Social Security may not issue a decision on the appeal for up to **2 years**.

The CF Social Security Project, a service funded by the CF Patient Assistance Foundation, may be able to provide free representation to a person with CF who plans to apply for Social Security benefits. The CF Social Security Project is not associated with or endorsed by Gilead Sciences, Inc. The application process is complicated and one wrong answer on the application could result in a denial of benefits and up to a 2-year wait for an appeal decision. The CF Social Security Project can be reached at 1-800-622-0385.



Andrew, 19, lives with CF.

SECTION 2

Social Security Disability Insurance (SSDI)

SSDI is a program that provides a monthly benefit check and Medicare coverage. The monthly SSDI benefit will be based on the applicant's work history. Benefit checks do not start until 5 full months after the person becomes unable to work full-time. Medicare coverage begins after 29 months of SSDI benefit eligibility.

SSDI eligibility

- A person must meet one of the Social Security medical criteria and must have worked for a specific amount of time prior to applying for Social Security benefits.
- In 2012, a person applying for SSDI benefits cannot make more than \$1,010 a month (gross) from part-time work. This amount changes each year as dictated by the Social Security Administration.
- A person who is self-employed has a different monthly earnings test. *See Section 12 for additional resources on this issue; for example, the CF Legal Information Hotline at 1-800-622-0385.*
- A person cannot be receiving unemployment benefits and apply for SSDI benefits at the same time. This is because unemployment benefits are for individuals who are able to work full-time and SSDI benefits are for those who cannot work full-time due to health.
- SSDI benefit checks do not start until 5 full months after a person becomes unable to work full-time. Therefore, consider saving money to pay for 5 months of living expenses.
- A person has 60 days to file an appeal if the application is denied. Benefits accrue while the appeal is pending. It may take up to 2 years to receive an appeal decision. Contact the CF Legal Information Hotline for more information on appealing a decision at 1-800-622-0385.

A Case Example:

Max stops work, due to a decline in his health, on August 13 and applies for SSDI benefits on August 14. He is approved for benefits on October 18 with a date of disability of August 13. Max is eligible for his first SSDI benefit check on February 1. August does not count as part of the 5-month waiting period because Max stopped work in the middle of the month. Max will not receive a SSDI benefit check for September 1–January 31 because those months are part of his 5-month waiting period.

Insurance: SSDI Benefits and Medicare Eligibility

- Medicare coverage begins 29 full months from the date of disability (the 5-month waiting period plus 24 months) of receiving SSDI benefit checks, assuming you are eligible for SSDI benefits.
- To prevent a lapse in insurance coverage once you have resigned from employment due to a disability, you can enroll in COBRA. Typically a person has 18 months of COBRA if he/she loses or leaves his/her job. However, if a person is eligible for SSDI benefits the person may be eligible for 11 more months of COBRA coverage, which can help provide coverage until Medicare begins. *See Section 8 for more information.*
- Before a person decides he/she cannot afford COBRA, he/she should calculate the cost of paying for medication and treatments on his/her own. It is almost always cheaper to find a way to pay for COBRA. If COBRA is not available a limited number of options exist. Some states may have a state program that provides coverage. Another option in most states is the Federal Pre-existing Condition Insurance Plan, which allows a person to purchase insurance under the plan after 6 months without ANY coverage. *See Section 8 for more information.*

Medicare Coverage

Medicare has different parts that provide coverage for different medical needs. If you are SSDI-eligible for benefits, then Medicare covers a variety of treatments and medications for people with CF who have been eligible for SSDI benefits for 29 full months. People who are over 65 are also eligible for Medicare. There are programs that can help with Medicare premiums and co-pays for those who have low income and assets. *See Section 12 for resources to help you understand Medicare coverage.*



Mark, 55, lives with CF.

Part A

Coverage for hospitalization costs. No premium is required, but there is a \$750 deductible for each hospitalization.

Part B

Coverage for physician services, lab work, pulmonary function tests, sputum cultures, durable medical equipment (such as a nebulizer), and other services. A person must pay a monthly premium and a 20% co-pay for services.

Part C

A person exchanges Medicare for Medicare HMO/PPO. This type of plan may have advantages in terms of lower co-pays for medications and services. However, these plans restrict where policyholders can go for treatment. Most CF care centers do not accept Medicare HMO/PPO plans.

Part D

Prescription drug coverage is offered by a number of private insurance companies. Premiums and co-pays vary among plans. The Medicare Low Income Subsidy program helps with Part D costs. Applications can be obtained from a local Social Security office.

Social Security Programs That Allow Work Activity for Those on SSDI

In limited situations, a SSDI recipient may be able to work and still receive SSDI benefits and Medicare. Failure to follow the rules under a Social Security work program may result in termination of Social Security benefits and Medicare coverage.

1. Minimum work rules

- In 2012, a person can work part-time but cannot earn more than \$1,010 a month (gross) from this part-time work as dictated by the Social Security Administration. This amount is subject to change on an annual basis as dictated by the Social Security Administration.

2. Trial work period

- Once a person has waited 5 full months for SSDI benefit checks to begin, he/she is eligible for a 9-month trial work period. A person can make more than \$1,010 a month from work activity during those 9 months and still receive a SSDI benefit check.
- A SSDI recipient must continue to meet the Social Security medical requirements and report work activity each month to Social Security during the 9-month trial work period.
- The 9-month trial work period does not need to be performed in consecutive months.
- Social Security counts any month during which a person earns more than \$720 as one month of the trial work period. This amount is subject to change on an annual basis as dictated by the Social Security Administration.

A Case Example:

Joseph has been receiving SSDI benefits for 4 years and has not worked during this time period due to the time-consuming nature of his CF treatments. His health has improved and he would like to try working and make more than \$1,010 a month. Joseph is allowed to make more than \$1,010 a month from work activity for a total of 9 months. However, it is likely Social Security will review Joseph's case when work income is reported over \$1,010 a month. If Social Security decides he can work full-time, Joseph may lose his monthly SSDI benefit check and Medicare coverage.

3. Ticket to Work

The Social Security program "Ticket To Work" is available to those receiving SSDI who want to return to work full-time and may want to continue receiving Medicare. A person can return to a previous job or search for a new job, or Social Security can provide a "ticket" for vocational rehabilitation services, which can include job training and employment search assistance.

To qualify for this program, a person must formally enroll with Social Security in the Ticket To Work program before returning to work. Once enrolled in the program and after work begins, the SSDI benefit check stops. Medicare coverage can continue for up to 8.5 years as long as a person continues to meet the Social Security medical criteria. A person may have to pay a premium to keep Medicare coverage. This program is especially helpful if the new job does not offer health insurance coverage to employees.

SECTION 3

Supplemental Security Income (SSI)

SSI is a program that provides a monthly benefit check and Medicaid coverage even if you are able to work or work part-time. A person must meet certain low-income, low-asset, and medical criteria in order to receive SSI benefits. Medicaid starts the first month someone is eligible for SSI benefits.

Who is eligible for benefits?

There are 3 groups of individuals who may be eligible for SSI benefits.

- A child under the age of 18 who meets the medical and income criteria and whose parents meet the income guidelines; or
- An adult, a person age 18 or older, who meets the medical and income criteria but has not worked enough to receive SSDI benefits and is not working full-time; or
- An adult who meets medical and income criteria and who receives an SSDI benefit that is less than the SSI benefit amount in their state and is not working full-time.

Benefit review at age 18

A child who receives SSI will have a benefit review when he/she reaches age 18.

- To continue to receive SSI benefits, a person must show he/she continues to meet Social Security medical criteria, income, and asset requirements.
- A person must show he/she is not able to work full-time at any job in the national economy.
- A person must file an appeal within 10 days of the date on the notice of termination of benefits letter in order to continue SSI benefits and Medicaid while the appeal is processed.
- If a person fails to file an appeal within 10 days from when the notice of termination letter is dated, he/she must file an appeal within 60 days from the date on the notice of termination or he/she will not have an opportunity to appeal, and the termination of benefits can never be appealed later. If filing an appeal after 10 days from the notice of termination, he/she will not continue to receive SSI benefit checks and Medicaid during the time frame of the appeal.



Emily, 30, lives with CF.

SSI Adult Issues

An adult applying for SSI benefits must meet the medical, income, and asset criteria. During the application process, the adult cannot be engaged in work activity that results in earnings of more than \$1,010 a month. This amount is subject to change on an annual basis as dictated by the Social Security Administration.

- As part of the application process, the applicant's parents' income and assets will not be counted.
- If the adult lives with a parent or anyone else providing financial support, he/she needs a written agreement indicating he/she will pay his/her share of household expenses. Otherwise, the SSI benefit check is automatically reduced by one-third to account for support provided by another.
- The written agreement should be submitted to Social Security with the SSI application.

A Case Example:

James lives with his mother and is applying for SSI benefits. James has a written agreement to pay his mother his share of household expenses once his SSI application is approved. James submits the agreement with his SSI application. When James is approved for SSI, he receives the full benefit check and does not have any money deducted from his benefit check because he will be paying for his share of the household expenses.

Social Security Programs That Allow Work Activity for Those on SSI

There are limited situations where a SSI recipient may be able to work and still receive SSI benefits and Medicaid. Failure to follow Social Security work rules can result in termination of SSI benefits and termination of Medicaid coverage.

General minimum work rules

Social Security will deduct \$1 from an SSI check for every \$2 a person earns from part-time work activity. The first \$65 of earnings are not counted. A person must have a SSI benefit check of at least \$1 to maintain Medicaid.

Social Security Act Section 1619(b) – continued Medicaid eligibility

Section 1619(b) of the Social Security Act allows those receiving SSI to work and make a certain amount over the general minimum work rules and still retain their Medicaid coverage. Once the person exceeds the general minimum work rules, he/she will no longer receive their monthly SSI benefit check but they will be able to keep Medicaid coverage. A person must continue to meet the Social Security medical criteria and show he/she needs Medicaid coverage in order to work.

Plan to Achieve Self-Support (“PASS”) Program

The PASS Program allows a person receiving SSI to save money for the purpose of achieving a work goal, such as going to college, learning a trade, or starting a business. A written plan must explain how a person plans to achieve the work goal and must be approved by Social Security. If a PASS plan is approved, then Social Security does not deduct any money from the monthly SSI benefit check so long as the money is used to achieve the work goal. PASS applications are available at a local Social Security office or at www.ssa.gov.

A Case Example:

Cathy has been working part-time and Social Security has been deducting \$1 from her SSI benefit check for every \$2 she earns. She also takes one college course each semester. Cathy meets with Social Security and submits a PASS plan. Social Security approves the PASS plan, allowing her to save money to pay for college courses. Now Cathy will not have money earned from work deducted from her SSI benefit check and can use the money to pay for her college courses.



Dana, 28, lives with CF.

SECTION 4

Eligible for Both SSDI and SSI

Some young adults with CF may have worked a short amount of time before becoming unable to work. These young adults may be eligible for both SSDI and SSI. If so, these individuals are called "Dual Eligibles." A Dual Eligible does not receive the full amount of the SSI benefit; instead, the SSI benefit is reduced by the SSDI benefit amount. If the individual continues to work part-time in accordance with Social Security work rules, then the SSDI benefit will increase each year and the SSI benefit will decrease. A person must have at least \$1 in SSI in order to maintain Medicaid. If a person continues to work, his/her SSDI amount will eventually exceed the SSI benefit amount in his/her state and he/she will lose both SSI benefits and Medicaid coverage.

Most states only provide Medicaid to adults who are also receiving SSI benefits. As long as a person continues to be eligible for SSDI for 29 months, he/she will keep the Medicare, even if he/she loses Medicaid coverage.

A Case Example:

Crystal intends to work part-time but wants to determine the impact of working on her SSI and SSDI benefit checks and the impact on her Medicaid and Medicare coverage. In Crystal's state, the full SSI benefit check amount is \$698. Crystal receives \$500 in a SSDI benefit check. Her SSI benefit is reduced by the amount of SSDI she receives, and so her SSI benefit check is \$198. While receiving Social Security benefits, Crystal works part-time for 3 years and pays Social Security taxes, which will increase her Social Security check to \$798 a month.

Crystal will lose her SSI benefit check because her SSDI benefit check is more than the full SSI benefit amount in her state. Crystal also will now lose her Medicaid coverage because her state only provides Medicaid to adults who receive SSI benefits. Crystal will continue to be eligible for Medicare because she is still eligible for SSDI and has been receiving a SSDI benefit check for more than 29 months.



Shannon, 41, lives with CF.

SECTION 5

Social Security Overpayments

- A Social Security overpayment occurs when a person receives SSI or SSDI benefits to which he/she is not entitled.
 - Social Security will send a notice of overpayment for the amount owed.
- It is important to understand the Social Security income and asset requirements to avoid an overpayment.
 - Social Security has increased its efforts to investigate and pursue overpayments.
- Social Security can recoup an overpayment by withholding a portion of wages, withholding a federal income tax refund, or reducing or stopping the Social Security benefit a person is currently receiving.
 - If a person loses their SSI benefit, they will lose Medicaid coverage. Accordingly, if a person loses their SSDI benefit, they will lose Medicare coverage.
- You can appeal an overpayment decision. Contact the CF Legal Information Hotline for more information at 1-800-622-0385.

A Case Example:

Lisa is a single mother and has one child with CF who receives SSI and one child who does not have CF. She receives no child support. Lisa receives a salary of \$3,000 per month from her job. In 2012, under the SSI income allowable for a household of 3, Lisa's family is allowed to earn \$3,267 per month. Lisa works overtime in December and earns a total of \$3,750 for the month. Lisa does not report her increase in earnings to Social Security. Lisa still receives the SSI check. Lisa will have an SSI overpayment of \$483 for the month of December because she continued to receive SSI benefits when she earned over the SSI income monthly allowable amount. Social Security can stop both SSI and Medicaid coverage due to the overpayment.

SECTION 6

Medicaid Issues

In 39 states, SSI benefit approval automatically qualifies a child or adult for Medicaid coverage. In 11 states, once the SSI application has been approved, a separate application for Medicaid must be filed. The 11 states that require a separate application are: Connecticut, Hawaii, Illinois, Indiana, Minnesota, Missouri, New Hampshire, North Dakota, Ohio, Oklahoma, and Virginia.

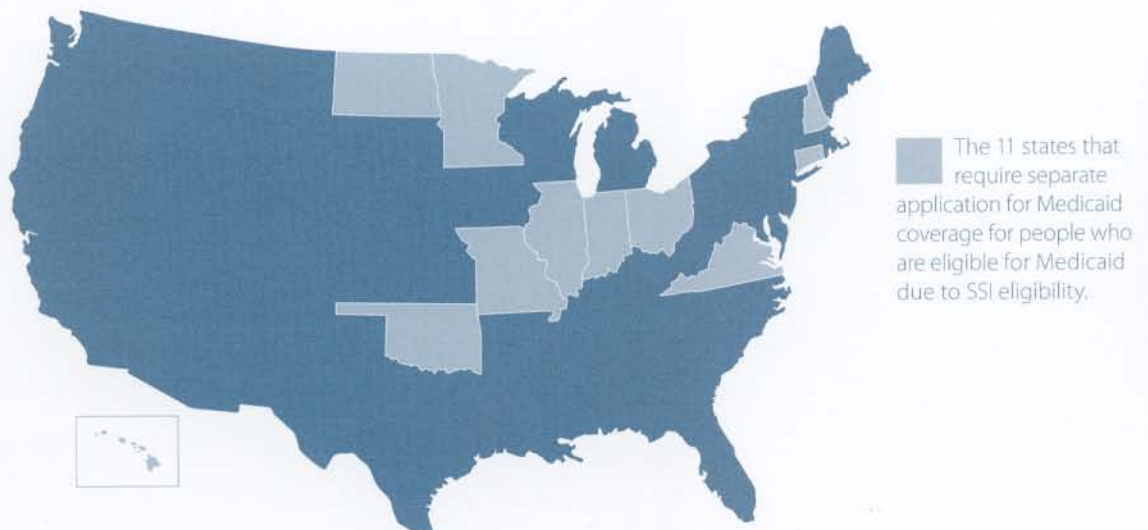
Notice of SSI approval in these 11 states will instruct the SSI recipient where to file the Medicaid application. Approval of the Medicaid application in those states should take approximately 30 days.

Exceptions to Medicaid HMO Requirements

- Many states require all Medicaid recipients to enroll in a Medicaid HMO which is run by a private company.
- A child under the age of 19 who has SSI and Medicaid does NOT have to enroll in a Medicaid HMO.
- A person who has both Medicare and Medicaid does NOT have to enroll in a Medicaid HMO.
- Fee-for-service Medicaid usually provides fewer restrictions than a Medicaid HMO, so if a person is eligible for a Medicaid HMO waiver, he/she might want to request a waiver from the state Medicaid agency.
- A Medicaid HMO may not provide coverage for care at your CF care center. Issues with Medicaid HMO coverage should be discussed with the CF care center as exceptions can be requested. The CF care center should file a request for an exception so that the person with CF can receive care at that center.

Medicaid Without SSI

In most states, children under the age of 18 (or in some states 19) who live in a household that meets certain low-income guidelines may be eligible for Medicaid even if the child is not eligible for SSI benefits. However, in most states, an adult MUST receive a SSI benefit in order to be eligible for Medicaid.



SECTION 7

Group Health Insurance Coverage

Half of the CF population has health insurance through a policy offered by their employer or other group.

The Health Insurance Portability and Accountability Act (HIPAA)

HIPAA is a federal law which provides protection to those who have group health insurance coverage and those who need to purchase health insurance. Under HIPAA:

- If an employer offers insurance to employees, all employees must be included.
- If an employer offers insurance to dependents, all dependents must be included.
- A pre-existing condition exclusion clause can only last up to 12 months.
- Pre-existing condition clauses can be waived if there is "creditable coverage," meaning credit for each month of enrollment on a prior employer's insurance plan, Medicare, Medicaid, or a high-risk pool. State programs that only cover CF-related costs do not count as creditable coverage.
- After a break of more than 63 days without health insurance, a person loses the ability to obtain creditable coverage for time spent on a prior policy. This means a person who is over the age of 19 will not have coverage for costs associated with the treatment of CF for the first 12 months he/she is on the insurance policy.
- Starting in January 2014, the Affordable Care Act (Healthcare Reform) will eliminate pre-existing condition clauses for people over the age of 19. Healthcare Reform already provides that a person under the age of 19 no longer needs to meet a pre-existing condition clause on an insurance policy. *See Section 10 for more details.*

Choosing the best insurance policy

Sometimes a person may have a choice of more than one policy if a spouse also has coverage, both parents of a child have coverage, or an employer offers more than one policy to employees. Sometimes one policy may have lower premiums than another policy offered, but the policy with the higher premium may be cheaper in the long run if it provides better coverage. Some things that you might want to ask potential insurers:

- Are all CF-related treatments and services needed covered?
- Is the CF care center a covered provider?
- Is there a limit on the total amount of coverage for prescription drugs?
- Are policyholders required to pay a co-pay or co-insurance for prescription drugs?
- Are there annual limits on specific services or treatments?
- What out-of-pocket expenses, such as deductibles or co-pays, will a policyholder need to pay?

Appealing a denial of coverage for treatment

Healthcare Reform has created new regulations already in effect to protect people who have had medical treatment or services denied by their health insurance plan. The new rules require all health insurance plans to:

- Allow insured persons to appeal when a health plan denies a claim for a covered service;
- Provide them with detailed information about the reason for the denial of the claim;
- Notify policyholders of their right to appeal and how the appeals process works;
- Ensure a full and fair review of the denial;
- Provide consumers with an expedited appeals process in urgent cases; and
- If the plan denies coverage after an internal appeal, allow the policyholder to appeal to an external reviewer. If the external reviewer finds the medical service is covered under the policy, the insurance company must pay for the medical service.

SECTION 8

COBRA Extension of Benefits

For employers with 20 or more employees, the Consolidated Omnibus Budget Reconciliation Act of 1985 (COBRA) provides a continuation of health insurance coverage if a qualifying event takes place. The coverage under the policy remains the same for a set period of time. (See table below for details.) Under COBRA, the employee pays the full premium. A late premium payment will result in permanent loss of coverage.

COBRA Qualifying Event	Extension Period
• Termination, resignation, or layoff	18 months
• Death of policyholder	36 months
• Divorce or separation from policyholder	36 months
• Adult becomes eligible for SSDI benefits	29 months
• Child reaches a limiting age under the policy	36 months

COBRA for Those Waiting for Medicare

Adults receiving SSDI benefits will have to wait 29 full months before becoming eligible for Medicare. To obtain coverage during this waiting period, one can elect for COBRA coverage. A person can elect 18 months of COBRA upon leaving work for health reasons. To obtain an additional 11 months of COBRA, 3 conditions must be met:

1. COBRA must start within 60 days of becoming unable to work due to health.
2. The Social Security benefit award letter must be obtained within the 18-month COBRA extension time period. The date on the letter, not the date the letter is received, must be within this time period.
3. The Social Security award letter must be given to the employer who sponsors the insurance plan and the insurance company within 60 days of the date on the Social Security benefit award letter in order to receive an additional 11 months of COBRA.



Jerry, 55, lives with CF.

SECTION 9

Other Insurance Programs

State Children's Health Insurance Program (SCHIP)

- SCHIP programs provide Medicaid coverage to children who have no other health insurance and where household income meets certain low income requirements. The SCHIP income limits are higher than the Medicaid guidelines.
- Coverage is for children under the age of 18 (or in some states under the age of 19).
- Young adults with CF should plan ahead and secure other health insurance coverage before SCHIP coverage ends when the young adult turns 18 (or in some states turns 19).

Children with Special Healthcare Needs (CSHCN)

- CSHCN state programs offer health insurance to children under the age of 18 who have CF or other conditions. A few states allow people with CF to enroll over the age of 18.
- CSHCN has its own income limits that are higher than the Medicaid income limits.

State-sponsored high-risk pools

- State-sponsored high-risk pools provide health insurance for state residents who are unable to obtain any other coverage due to health or pre-existing condition.
- Monthly premiums for the high-risk pool are determined by age and where the applicant lives.
- Some state risk pools have a waiting period before coverage begins.
- A limited number of states have state-sponsored risk pools.



Jacob, 13, and Kasey, 11, are siblings who live with CF.

SECTION 10

Affordable Care Act

The Affordable Care Act (also known as "Healthcare Reform") was enacted in 2010, and provides people with CF with a new means of obtaining or keeping insurance coverage. For instance, Healthcare Reform has made it possible for children under the age of 19 to purchase their own individual insurance policy regardless of a pre-existing condition. Individuals over the age of 19 will still find it difficult to purchase an individual insurance policy because federal law does not require an insurance company to sell an individual policy to anyone over the age of 19 who requests coverage. In January 2014, under Healthcare Reform, anyone wanting to purchase an insurance policy will be able to do so regardless of his/her health or pre-existing condition.

The Supreme Court is currently deciding whether certain sections of the Affordable Care Act will continue to be in effect, which may have an impact on the entire Act itself. This could affect the availability of the following coverage options:

Federal Pre-existing Condition Insurance Plan (PCIP)

- The PCIP was created under Healthcare Reform to provide coverage to people who have a pre-existing condition and have had NO health insurance for at least 6 months.
- The typical premium is \$150 per month.
- There are no income eligibility requirements.
- Coverage includes, but is not limited to, primary care, specialty care, hospital costs, home health care, mental health services, and prescription drug coverage.
- A person can apply online at www.healthcare.gov.

Access to individual policies for children under 19

- A child under the age of 19 must be allowed to purchase an individual health insurance policy regardless of the existence of a pre-existing condition. The parent of the child could contact an independent insurance agent or a health insurance company to arrange to purchase a health insurance policy.
- The premiums for such a policy will vary depending on the coverage provided.

No lifetime limit on coverage

- A health insurance policy cannot impose a limit on the amount of coverage the policy will provide during the entire time a person is enrolled in that plan. In the past, health plans would set a dollar limit on benefits a policyholder would receive. Healthcare Reform has outlawed this practice.
- Currently, annual caps on coverage for specific services are allowed. This means a health plan can restrict coverage for prescription drugs to \$5,000 each year. It is important to understand annual limits for specific services under an insurance policy.

Dependent coverage until age 26

An adult child can remain on their parents' insurance policy until age 26. The adult child under the age of 26 is eligible for coverage, even if they are:

- Married; or
- Not living with their parents; or
- Attending school; or
- No longer a student; or
- Not financially dependent on their parents; or
- Not listed as a dependent on their parents' tax returns.

SECTION 11

Important Issues for Transitioning Young Adults

Affordable Care Act

The Affordable Care Act allows a child to stay on his/her parents' insurance policy until the child turns 26. Once the child turns 26, there are other laws that may allow the child to continue coverage under his/her parents' policy.

State insurance law: continued coverage if a person over the age of 26 is incapable of self-support

- A person over the age of 26 must be incapable of self-support due to a physical or mental condition in order to be eligible for an extension of coverage.
- The coverage is extended until he/she is able to support himself or herself.
- An employer who contributes to premium payments continues to do so.
- A form must be signed by the treating physician indicating that the person over the age of 26 is incapable of self-support. The insurance company can require that the form be submitted once a year.
- The following states do not have a state law that extends coverage to people over the age of 26 incapable of self-support: Alabama, Alaska, Kansas, Maine, Oklahoma, and Oregon.

Extension of coverage under COBRA

- A person who turns 26 reaches a limiting age on their parents' policy. The young adult can extend coverage for another 36 months under COBRA but must pay the full premium to continue coverage. This section of COBRA can be helpful when a young adult reaches the age of 26 and is no longer an eligible dependent on their parents' policy but does not meet the criteria to be considered incapable of self-support under the policy.

A Case Example:

Joan is 25 and works full-time as a real estate agent. Her employer does not offer health insurance coverage to employees. Joan has coverage under her parents' health insurance policy. Coverage under her parents' policy will end when Joan turns 26. Joan can extend her parents' insurance coverage for 36 months under COBRA if she meets all of the COBRA requirements. Joan must pay the full premium.

Obtaining and maintaining health insurance coverage and Social Security benefits is crucial for people with CF to maintain their health. It is important for people with CF, their family members, and healthcare providers to understand the laws that provide insurance coverage and Social Security benefits to those with CF. See Section 12 for additional resources and information, including the CF Legal Information Hotline at 1-800-622-0385.

SECTION 12

Additional Resources

This list of third-party resources is provided as a convenience to you. Gilead Sciences expressly disclaims any and all liability and responsibility for these resources.

- The CF Legal Information Hotline provides free and confidential information about health insurance, Social Security benefits, employment rights, and education rights. The Hotline is sponsored by the CF Foundation. All calls are free and confidential. The Hotline can be reached at 1-800-622-0385 or at cflegal@cff.org.
- The CF Social Security Project, a case management service funded by the CF Patient Assistance Foundation, may be able to provide free representation for people with CF applying for SSI or SSDI benefits. The CF Social Security Project is funded by the CF Patient Assistance Foundation and can be reached at 1-800-622-0385.
- The CF Patient Assistance Foundation (CFPAF) provides assistance with co-pays for certain medications to people with CF who meet certain income guidelines. The CFPAF can be reached at 1-888-315-4154.
- Your CF care center has the *Advocacy Manual: A Clinician's Guide to the Legal Rights of People with Cystic Fibrosis*. You can review the *Advocacy Manual* when you visit your CF care center. The *Advocacy Manual* contains information on health insurance benefits, Social Security benefits, rights in education, and employment rights.
- The CF Foundation has information about certain state programs that may provide insurance coverage to people with CF. Go to www.cff.org for more information.
- CF care center staff may know of specific programs in their state or city that may help with medial costs.
- For information on the Affordable Care Act, go to www.healthcare.gov.
- The Social Security Administration (SSA) Web site has information on Social Security programs and eligibility rules at www.ssa.gov. Individuals can also contact the SSA at 1-800-772-1213.

- A list of the Social Security medical criteria for a variety of conditions can be found at www.ssa.gov/disability/professionals/bluebook.
- For a list of Medicaid eligibility income guidelines by state, go to www.statehealthfacts.org/comparereport.jsp?rep=82&cat=4&gsa=2.
- For more information on Medicare, go to www.medicare.gov.
- For information about each state's SCHIP program, please visit www.insurekidsnow.gov.
- For information on HIPAA and obtaining creditable coverage toward a pre-existing condition clause, go to www.dol.gov/ebsa/faqs/faq_consumer_hipaa.html or www.healthinsurance.org/risk_pools/.
- The Department of Labor has information on COBRA at www.dol.gov/ebsa/COBRA.html.
- To find a Federal Vocational Rehabilitation agency in a specific state, visit <https://secure.ssa.gov/apps10/oesp/providers.nsf/bystate>.
- To obtain your state's Department of Insurance contact information, go to www.naic.org/state_web_map.htm.



About the author

Beth Sufian is an attorney in Houston, Texas, and has practiced law for 22 years. She is Director of the CF Legal Information Hotline, which has received over 26,000 calls. She is also Director of the CF Social Security Project. Beth assists the CF Foundation in their efforts to ensure insurance access to children and adults with CF. Beth is a 46-year-old adult living with CF who has a passion for advocating on behalf of people with CF who need coverage for medical treatment. Beth has presented seminars at 76 CF care centers around the country, informing people with CF, their families, and healthcare providers of the legal rights of people with CF.

This content was developed and reviewed in collaboration with people living with CF and their families.





CYSTIC FIBROSIS LEGAL INFORMATION HOTLINE®

The Cystic Fibrosis Legal Information Hotline® is a service sponsored by the CF Foundation. The CF Legal Information Hotline provides confidential information free of charge to individuals with cystic fibrosis, their family members and their CF Care Center team members.

The CF Legal Information Hotline provides reliable information about Social Security eligibility and benefits, Medicaid, Medicare, private health insurance, education and employment. All the information is focused on the unique experiences of individuals with cystic fibrosis.

The CF Legal Information Hotline is staffed by attorneys with many years of experience advocating for the rights of people with cystic fibrosis. The Hotline is an informational resource and does not provide legal representation to individuals.

Telephone: 1-800-622-0385
E-mail: CFLegal@cff.org



CYSTIC FIBROSIS SOCIAL SECURITY PROJECT

The Cystic Fibrosis Social Security Project (CFSSP) is a case management service funded by the CF Patient Assistance Foundation, a subsidiary of the CF Foundation.

The CFSSP provides representation to individuals with cystic fibrosis free of charge when filing an initial application for Social Security benefits. The CFSSP also represents individuals already receiving benefits who are undergoing a review of eligibility by the Social Security Administration.

The CFSSP provides representation by an attorney beginning with the initial Social Security application through the final determination of a claim. The CFSSP is not able to begin representation in a claim that has already been filed.

Eligibility criteria for participation apply.

Telephone: 1-800-622-0385
E-mail: CFSSP@sufianpassamano.com