

Cystic Fibrosis Policy Bulletin

A Newsletter of the Cystic Fibrosis Foundation



FALL 2011

Dear Colleagues,

We are pleased to introduce the first issue of our new newsletter, *Cystic Fibrosis Policy Bulletin!*

Our goal is to provide you, our partners, with up-to-date information on policy issues affecting CF patients and families.

We look forward to partnering with you as we continue to work toward a brighter, healthier future for those with CF.

Sincerely,

Mary Dwight
VP, Government Affairs

Jason Ranville
Public Policy Manager

IN THIS ISSUE

- > Medicare and Medicaid Changes
- > Health Reform Updates
- > Federal and State Budgets
- > Patient Assistance Resource Library

MEDICAID AND MEDICARE CHANGES

State Medicaid programs continue to search for cost-saving methods. In the past year, **over 20 states have made changes to preferred drug lists (PDLs)** to limit spending on expensive medications.

By linking CFF care center physicians with state review committees, we have retained open access for enzymes and other CF treatments, such as inhaled antibiotics in nearly all 20 states. We look to continue this trend. **Please contact Jason Ranville at jranville@cff.org should you learn that a state review may impact the ability of patients to access their care.**

Many states have begun to **move Medicaid patients from traditional fee-for-service structures to managed care**. If this move is not properly coordinated, it could negatively affect CF Medicaid beneficiaries' ability to continue care with their current team of providers in CF Foundation-accredited care centers.

To ensure that **Ohio** CF patients' needs were covered, the Foundation was able to delay this transition until 2013 with support from in-state advocates.

After a successful agreement with the Medicaid program in **South Carolina** allowing the local CF Foundation-accredited care center to serve as an advisor to the state when making Medicaid coverage decisions, the Foundation will be exploring similar proposals in targeted states in the coming months. We look forward to updating you more as we identify specific states and begin talking to decision-makers.

HEALTH REFORM UPDATES

Following the passage of the Affordable Care Act, the CF Foundation continues to articulate its position on the needs of CF patients as the law is implemented. The Foundation has submitted comments on:

- [Preexisting Conditions, Coverage Limits, Rescissions, and Patient Protections](#)
- [Health Exchanges](#)
- [Coverage for Dependents up to Age 26](#)
- ["Grandfathered" Health Plans](#)
- [Accountable Care Organizations](#)

FEDERAL AND STATE BUDGETS

Federally, the CF Foundation is working toward preserving support for key programs and agencies including Medicare, Medicaid, the [National Institutes of Health](#), and the [Food and Drug Administration](#). We plan to continue this effort [throughout the fall](#).

Twenty states have programs designated to help adult CF patients access their care. All states provide aid to children with CF, usually through the Children's Special Healthcare Needs program.

As **states** continue to cope with the effects of the economic downturn, this year's budget cycles presented numerous threats to CF care programs.

Adult CF Care Programs

With the help of our industry partners and volunteers, the Foundation successfully retained a number of programs and preserved funding in many of them:

Adult CF care programs have been preserved in 20 states, despite threats to cuts. States include **California, Michigan, Nebraska, New Mexico, New York, and Wisconsin**.

Pennsylvania has seen a 30% reduction in funds for the adult CF care program. Efforts are underway to restore funds through additional legislative opportunities in the fall.

Florida patients will see a loss of outpatient benefits for the state-funded adult CF care program, but the addition of nursing benefits.

New Jersey will also lose outpatient benefits for the state-funded adult CF care program.

Ohio will see a reduction in both inpatient and outpatient benefits for the state-funded adult CF care program.

Nine other states with adult care programs have retained funding with minimal changes to program operations. Those states are **Connecticut, Indiana, Mississippi, Missouri, New Hampshire, North Carolina, Tennessee, Texas and Vermont**.

An additional Adult Care program is administered at Tulane University in **Louisiana**.

PATIENT ASSISTANCE RESOURCE LIBRARY

This fall, the Foundation is set to launch the Patient Assistance Resource Library, the newest tool in the CF Foundation's assistance network.

The Library will help patients, providers, and insurers find the best CF-related resources to help patients access the care they need to stay healthy.

The Library will include:

- guides and templates for completing prior authorizations, appeals, exemptions, and network exceptions
- clinical information and evidence-based publications
- information on CF medications and treatments
- sample forms and letters to insurers

If you have materials that may be useful in helping patients and providers access care and tackle coverage issues please send via email to publicpolicy@cff.org.

Materials may include clinical information, sample forms or letters, publications on CF, or guides on insurance processes.

NEED MORE INFORMATION?

More information about the CF Foundation's Public Policy Department can be found online at our [home page](#). For information on Public Policy initiatives visit the [Public Policy Agenda](#) and CFF's [Briefings and Testimonies](#) pages.

We'd love to hear from you!

While we're happy to share any information we have with you, we'd also love to hear from you when there are issues that you believe deserve our attention.

Please direct all updates, comments and questions to:

Jason Ranville	Jackie Erdo
(301) 841-2617	OR (301) 841-2628
iranville@cff.org	jerdo@cff.org