

Caring for Carcinoid Foundation

E-Update: Number 16, 2006

Special Alert!

[Advocate for Change](#)

[2006 Campaign - "Move Toward a Cure"](#)

- Unprecedented Opportunity to "Move Toward a Cure"
- Congressional Legislation
- CFCF Leadership
- CFCF Action Plan
 - Step #1: CFCF Partners with Key Government Leaders - Done!
 - Step #2: CFCF Sends a Letter to All U.S. Senators and Representatives - Done!
 - Step #3: CFCF Submits a Carcinoid Report to Congress - Done!
 - Step #4: Rally Carcinoid Community Support - Your Opportunity to Participate!
 - Spread the Word
 - E-mail Your U.S. Senators and Representatives
 - Update the Carcinoid Scoreboard
- Congratulations!

[Unprecedented Opportunity to "Move Toward a Cure"](#)

The carcinoid community has an unprecedented opportunity to change the course of carcinoid and related neuroendocrine tumor (NET) research.

Congress will soon vote on legislation that encourages the National Cancer Institute (NCI) to "move toward a cure" for carcinoid/NET. NCI is the world's largest funder of cancer research. It is the U.S. government's principal agency for cancer research and operated with a \$5 billion budget in 2005.

The Caring for Carcinoid Foundation is the leading national non-profit dedicated to discovering a cure for carcinoid. Therefore, we are 100% committed to passing and implementing this Congressional legislation.

You have an opportunity to participate in this unprecedented opportunity in three ways--by spreading the word, by e-mailing your U.S. Senators and Representatives, and by updating the Carcinoid Scoreboard.

See below to act now!

[Congressional Legislation](#)

The Congressional legislation that will help us "move toward a cure" for carcinoid/NET is House of Representatives Report 109-515.

This report was prepared by the Committee on Appropriations for the Departments of Labor, Health and Human Services, Education, and related agencies. It is attached to H.R. 5647 sponsored by Rep. Ralph Regula (Ohio, 16th District).

The Congressional legislation states:

"Carcinoid cancer and related neuroendocrine tumors are small, slow growing tumors found mostly in the gastrointestinal system, but can also be found in other parts of the body such as the pancreas and the lung. The Committee encourages the Director to expand and coordinate research and related activities with respect to carcinoid disease and carcinoid tumor biology across all relevant institutes, centers and offices, particularly at NCI, to help foster early and accurate diagnosis as well as develop new, safe, and effective treatments for the disease and **move toward a cure**. In addition, the Committee encourages NCI to hold a summit on carcinoid cancer and requests a report by June 1, 2007 on future research plans for carcinoid cancer."

[View Congressional Legislation \(House of Representatives Report 109-515\)](#)

CFCF Leadership

The Caring for Carcinoid Foundation is leading the carcinoid community's effort to pass and implement this Congressional legislation. We are uniquely positioned to play this leadership role for the following reasons.

[Read why CFCF is leading the carcinoid community](#)

CFCF Action Plan

The Caring for Carcinoid Foundation launched a 4-step action plan to pass and implement this Congressional legislation. We are proud to announce that we already completed:

- Step #1: CFCF Partners with Key Government Leaders - Done!
- Step #2: CFCF Sends a Letter to All U.S. Senators and Representatives - Done!
- Step #3: CFCF Submits a Carcinoid Report to Congress - Done!

However, Step #4 is the most critical:

- Step #4: Rally Carcinoid Community Support - Your Opportunity to Participate!

Step #4 requires the energy and commitment of the entire carcinoid/NET community. Specifically, you have an opportunity to participate in three ways--by spreading the word, by e-mailing your U.S. Senators and Representatives, and by updating the Carcinoid Scoreboard.

Step #4 is the key to success because it reflects the determination of the carcinoid/NET community. If you want to move carcinoid/NET toward a cure, then make your voice heard and Congress will listen!

See below to act now!

Step #1: CFCF Partners with Key Government Leaders - Done!

The Caring for Carcinoid Foundation met with all the key government leaders involved in this unprecedented opportunity to "move toward a cure" for carcinoid/NET. Specifically, we met with:

- U.S. Senate
- U.S. House of Representatives
- National Cancer Institute (NCI)
- National Institutes of Health (NIH)
- Food and Drug Administration (FDA)
- National Organization for Rare Disorders (NORD)

As a result of these meetings, the Caring for Carcinoid Foundation is partnering with key government leaders to pass and implement this Congressional legislation.

[Read how CFCF is partnering with key government leaders](#)

Step #2: CFCF Sends a Letter to All U.S. Senators and Representatives - Done!

The Caring for Carcinoid Foundation sent a letter to all 100 U.S. Senators and 435 U.S. Representatives. In our letter, we requested support for this Congressional legislation. We described the unprecedented opportunity to change the course of carcinoid/NET research and save thousands of lives.

[Read CFCF Letter to All U.S. Senators and Representatives](#)

Step #3: CFCF Submits a Carcinoid Report to Congress - Done!

The Caring for Carcinoid Foundation submitted a Carcinoid Report to Congress. This Carcinoid Report achieved three objectives:

- Summarized the current state of carcinoid/NET research
- Identified the most critical gaps in carcinoid/NET research
- Described how this Congressional legislation will "move toward a cure" for carcinoid/NET

Therefore, the Caring for Carcinoid Foundation's Carcinoid Report reinforced the importance of this Congressional legislation and further advocated for change.

Step #4: Rally Carcinoid Community Support - Your Opportunity to Participate!

Carcinoid community support is the key to success.

For a better future, all members of the carcinoid community should do the following:

Spread the Word

First, spread the word about this unprecedented opportunity. Tell everyone--including family, friends, doctors, nurses, and supporters--that we can "move toward a cure" for carcinoid/NET by supporting this Congressional legislation.

How should you spread the word? We suggest 5 ideas:

- Post a message to the [ACOR Carcinoid](#) bulletin board
- Notify your carcinoid support group
- Notify your hospital, treatment center, or doctor's office
- [E-mail us](#) your suggestions for spreading the word
- Send this page to everyone who supports the carcinoid/NET community

[E-mail Your U.S. Senators and Representatives](#)

Second, e-mail your U.S. Senators and Representatives to request support for this Congressional legislation.

The Caring for Carcinoid Foundation sent a letter to all 100 U.S. Senators and 435 U.S. Representatives. However, U.S. Senators and Representatives want to hear from their constituents--you!

We made this process simple, so it takes less than 15 minutes:

[Open This Letter Template](#)

[E-mail Your Two U.S. Senators by Visiting This Website](#)

Choose your state, click "Web Form" for each U.S. Senator, then copy and paste the letter template above and submit!

[E-mail Your One U.S. Representative by Visiting This Website](#)

Choose your state, enter your ZIP code, click "Contact My Representative", then copy and paste the letter template above and submit!

[Update the Carcinoid Scoreboard](#)

Third, update the Carcinoid Scoreboard. The Caring for Carcinoid Foundation created this Carcinoid Scoreboard to track the carcinoid community's progress in contacting U.S. Senators and Representatives.

It will take a team effort to "move toward a cure." The Carcinoid Scoreboard is critical to show how strongly our carcinoid community is working together as one team.

Congress will expect to see strong interest in this legislation. You must make your voice heard for

Caring for Carcinoid Foundation

Congress to listen! We will promote the results of this Carcinoid Scoreboard in our partnership with key government leaders.

Instructions

After you contact your U.S. Senators and Representatives, please [e-mail us](#) the name of your state, names of your two U.S. Senators, and name of your one U.S. Representative.

We will update the [Carcinoid Scoreboard](#) frequently to ensure we have real-time results on our progress. Check back often!

Congratulations!

Congratulations on participating in the Caring for Carcinoid Foundation's 2006 Campaign - "Move Toward a Cure".

We have an unprecedented opportunity to change the course of carcinoid/NET research. Each of you helps to turn this opportunity into reality!