

## **Clinical Trials Are Key to New Therapies Allow SSI Beneficiaries to Participate in Clinical Trials**

Cystic fibrosis (CF) is a life-threatening genetic disease that affects more than 30,000 people nationwide. Thanks to innovative and aggressive research, more potential therapies continue to emerge to treat the disease. More than 30 potential therapies are in the CF drug development pipeline today, more than in the entire history of CF research.

Yet researchers face a real challenge to recruit more people than ever before to help test new drugs. Because CF affects a relatively small group of people, a significant percent of the patient population is needed to participate in clinical trials. However, people with CF – and many other diseases – are experiencing a very real disincentive to participating in the clinical trials that could produce new therapies to treat their condition.

*“Hearing about different drugs that are being tested for people with CF gives me tremendous hope and optimism for the future. I hope everyone affected by CF feels inspired to ask how they can help.”*

*--Kurt, a 23-year-old with cystic fibrosis.*

### **Eliminating Barriers to Clinical Trial Participation**

**The Problem:** Current rules regarding eligibility for Supplemental Security Income (SSI) prevent many people with diseases like cystic fibrosis who receive SSI from participating in clinical trials.

- The inability of SSI beneficiaries to accept research compensation for participation in a clinical trial has been shown to be a significant deterrence to research participation.
- Nearly 50% of the CF population receives SSI benefits, significantly reducing the number of patients able to help test promising new therapies.

**The Solution:** Co-sponsor legislation to waive the current rule that counts research compensation for participation in a clinical drug study as income for determining SSI eligibility. Such a waiver would:

- Help potential new therapies for CF and other diseases to move swiftly from the research stage into the hands of patients who need them.
- Reduce the administrative costs of dis-enrolling a beneficiary one month and re-enrolling the beneficiary the next month.

*“Sean” is an adult with cystic fibrosis. Due to his illness, he is unable to work, however he wanted to help and so he enrolled in a research study and was paid \$747 in January, 2009 and \$685 in February, 2009.*

*Sean contracted pneumonia however was told that because of his earnings from participating in the study in January, he was no longer eligible for his health benefits. He now owes \$80,000 for the two weeks of treatment he received when he had pneumonia.*

Support clinical research and cystic fibrosis patients by co-sponsoring legislation to help more people participate in clinical trials. For more information, please contact Mary Dwight: [mdwight@cff.org](mailto:mdwight@cff.org) or 301-841-2639.

**National Office**

6931 Arlington Road Bethesda, Maryland 20814

(301) 951-4422 (800) FIGHT CF Fax: (301) 951-6378 Internet: [www.cff.org](http://www.cff.org) E-mail: [info@cff.org](mailto:info@cff.org)