

CDC Report to the HHS CFS Advisory Committee

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Activities to Improve Health Services for CFS

- ❑ Educational initiatives
- ❑ Studies of CFS and CFS surveillance activities
- ❑ Communication and outreach

Advance recognition and treatment of CFS

EDUCATIONAL INITIATIVES

11th IACFS/ME Biennial Conference

- ❑ CDC provided financial support for AV equipment and was part of planning committee
- ❑ Five CDC personnel attended
- ❑ Two oral presentations
 - A genome-wide analysis of differential methylation associated with chronic fatigue syndrome – Rajeevan MS
 - Impaired natural killer cells in CFS: Methodological considerations in a multi-site clinical study – Querec TD
- ❑ Three posters and one session chair

Additional Scientific Meetings

- ❑ **Presentation at 2014 Stanford ME/CFS Symposium – Advances in Clinical Care and Translational Research**
 - Epidemiology of ME/CFS, what have we learned?
- ❑ **35th Annual Meeting and Conference of the Society for Behavioral Medicine**
 - Poster presentation “Social determinants of barriers to healthcare utilization in CFS” – Oakley L, Philyaw M, Lin JM
 - Citation Award and Meritorious Student Award
 - Displayed educational materials on CFS at table sponsored by CDC’s Division of Cancer Prevention and Control

Pediatric CFS Added to CDC's CFS Webpage

- ❑ Content developed in consultation with patient advocacy groups, clinical experts and school educators
- ❑ Includes fact sheets for health care professionals, parents and teachers
- ❑ Spanish translation is complete and will be posted soon

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A-Z Index A B C D E F G H I J K L M N O P Q R S T U V W X Y Z #

Chronic Fatigue Syndrome (CFS)

Chronic Fatigue Syndrome

General Information

Pediatric

- Definition and Diagnosis
- Management and Treatment
- Factsheets
- Information for Healthcare Professionals
- News & Highlights
- CDC Publications
- CFS Toolkit
- Education
- Meetings & Workshops
- CFS Programs
- Related Links

Chronic Fatigue Syndrome

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Chronic Fatigue Syndrome (CFS) in Children and Adolescents


Chronic fatigue syndrome (CFS) is a disabling illness of unknown cause and origin. CFS is often thought of as a problem in adults, but it also affects children and adolescents. Between 0.2% and 2.3% of children or adolescents suffer from CFS. CFS is more prevalent in adolescents than in younger children. In children, particularly in adolescents, CFS is more likely to develop after an acute flu-like or mononucleosis-like illness, but gradual onset of illness may occur. Currently, the diagnosis is made on the basis of ruling out other conditions that could explain most of CFS symptoms.


Definition and Diagnosis of Chronic Fatigue Syndrome (CFS) in Children and Adolescents

Several case definitions can be used to diagnose CFS in adults. Examples include the 1994 International CFS Case Definition, the 2003 Clinical Canadian ME/CFS case definition, and the 2011 International Consensus Criteria for Myalgic Encephalomyelitis (ME). These three case definitions include a criterion that the individual must have had severe chronic fatigue for 6 or more months. While the 1994 International CFS Case Definition has been primarily used to diagnose CFS in adults, it is also used to diagnose children and adolescents. In 2006, the International Association of Chronic Fatigue Syndrome Pediatric Case Definition Working group developed a case definition specifically for children and adolescents with ME/CFS. This definition requires a 3-month duration of fatigue. However, many doctors treating children and adolescents may not feel comfortable making a final CFS diagnosis after only 3 months.

International CFS Awareness Day

Highlighted in CDC Features page

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CDC A-Z INDEX ▾

CDC Features

CDC Features

Data & Statistics

Diseases & Conditions

Chronic Fatigue Syndrome Awareness Day—May 12

Emergency Preparedness & Response

Environmental Health

Healthy Living

Injury, Violence & Safety

Life Stages & Populations




Travelers' Health

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Features Media

[CDC](#) > [CDC Features](#) > [Diseases & Conditions](#)


Chronic Fatigue Syndrome Awareness Day—May 12

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May 12 is Chronic Fatigue Syndrome (CFS) Awareness Day. This date was chosen to honor the birthday of Florence Nightingale, who was a social reformer, statistician, and founder of modern nursing. Nightingale was virtually bedridden with a painful and fatiguing illness resembling CFS or fibromyalgia, yet went on to inspiring accomplishments, including establishing the Nightingale Training School.

CFS is a debilitating and complex disorder characterized by profound fatigue that is not improved by bed rest and that may be worsened by physical or mental activity. Symptoms affect several body systems and may include muscle or joint pain, impaired memory or mental concentration, and insomnia, which can result in reduced participation in daily activities. In some cases, CFS can persist for years.

The cause of CFS has not yet been identified, and no tests can diagnose CFS. There is no cure, and no prescription drugs have been developed specifically



Data to understand CFS

STUDIES AND SURVEILLANCE ACTIVITIES

Collaboration with CDC's Behavioral Risk Factor Surveillance System (BRFSS)

- ❑ **Nation's premier system of health-related telephone surveys that collect state data about US residents**
 - Health-related risk behaviors, chronic health conditions, and use of preventive services
- ❑ **Proposal to include CFS questions presented at 2013 BRFSS Conference**
 - Allowed state public health leaders to learn about the public health importance of CFS
 - Fourteen states chose to include CFS questions
- ❑ **Cost-effective way to monitor self-reported CFS and to study CFS in relation to other BRFSS topics**
 - Nutrition, health care access, quality of life, physical activity, health status

Collaboration with CFS Expert Clinicians: Multi-site Clinical Study of CFS

- ❑ **Collect standardized data on major illness domains of CFS from patients cared for by 7 expert clinicians**
 - Describe heterogeneity of CFS patients between practices and follow longitudinally
 - Enrollment based on expert opinion rather than any one case definition
- ❑ **Methodology presented to the IOM Diagnostic Criteria for ME/CFS Committee, January 2014**
- ❑ **Stage 1 complete**
 - 471 CFS patients enrolled, exceeding target of 450
- ❑ **Contracts for Stage 2 awarded September 2012 and Stage 3 awarded September 2013**

Stage 2 Progress

- ❑ Follow-up Stage 1 CFS patients, enroll healthy controls and ill comparison groups
- ❑ Collect saliva for wakening cortisol profile and blood for DNA and RNA archive
 - Protocol IRB approved May 2013, renewed through 2015
 - 85% enrollment, 75% completion CFS follow-up
 - 40% enrollment, 35% completion healthy/ill comparison groups
- ❑ Adolescent/pediatric CFS (not all sites participating)
 - Protocol IRB approved September 2013
 - 35% enrollment, 25% completion
- ❑ Combined cognition and exercise
 - Protocol IRB approve March 2014

Stage 3 Progress

- ❑ **Follow-up on adult, pediatric CFS cases, healthy and ill comparison groups**
 - Amendments to protocols under IRB review
- ❑ **Additional components to be conducted at some clinics**
 - Enroll home-bound (severely ill) CFS
 - Enroll incident cases of CFS (within 2 years of illness onset)
 - NK cell function and serum sample for archive

Partnerships to address CFS

COMMUNICATION AND OUTREACH

CFS Patient Centered Outreach and Communication Activity (PCOCA Call)

❑ One hour conference call format

- Update on CDC's CFS program activities (15 min.)
- Talk from invited expert (30 min.)
- Answer questions submitted to expert and CDC through PCOCA mailbox (15 min.)

❑ Fourth call – February 25, 2014

- Gudrun Lange, PhD – Invited expert – “CFS and Cognitive Function”

❑ Fifth call planned for September 9, 2014

- Lucinda Bateman, MD – Invited expert – “Can ME/CFS and FM Sleep Research Help You Sleep?”

Thank You

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The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

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High-Consequence Pathogens and Pathology

