Kroniskt Trötthetssyndrom
CFS/ME
World Public Health Issues 2008

Stockholm, Sweden
May 28, 2008

OVERVIEW

- Economic Impact
- Classification
  - ICD
  - World Health Organization
- US Governmental Agencies Approaches to CFS/ME

Center for Disease Control
National Institute for Health
Trans-NIH
definition
research (CFS Specific Funding)
Scientific/Research Components
Department for Human Health Services Advisory Committee

- International Organizations
  - IACFS
  - Alison Hunter Memorial Foundation
  - CFS Japan
  - ME Irish Trust
  - ME Research UK
  - And many others including Italy, Norway, Sweden
- US Private Association/Foundations/Institutes.
  - CFIDS: Suzanne Vernon, PhD -new Scientific Director
    Kimberly McCleary – CEO & President
  - Co-Cure
  - WP Institute
  - AIM
  - INFORMATICS

Many Regional & Local Organization / Chapters
Patient and or Hospital sponsored group
Support Groups with varying purposes

Kroniskt Trötthetssyndrom
CFS/ME
Illness of Many Names

Myalgic Encephalomyelitis (ME)

Low Natural Killer Cell Syndrome

Yuppie Flu

Chronic Fatigue Syndrome

Chronic Fatigue Immune Dysfunction Syndrome

Annual Economic Loss Due to CFS/ME

$ 9 billion USD

$ 1.6 billion
Swedish Kronor

- In the US, approximately 10% of the patients consume 70% of all healthcare dollars. Of this amount, a significant proportion is encountered by the diagnosis and management of chronic disease.

- CFS/ME is a significant contributor to the financial burden, as well as functional disability of the society at large.

Myth #1:
ME/CFS is a relatively rare disorder

Facts:

- Prevalence in U.S.

  400-600 per 100,000 people

- Number of people affected in U.S.

  800,000 people

- Number of people affected in Sweden

  32,000 – 40,000 people

Myth #2:

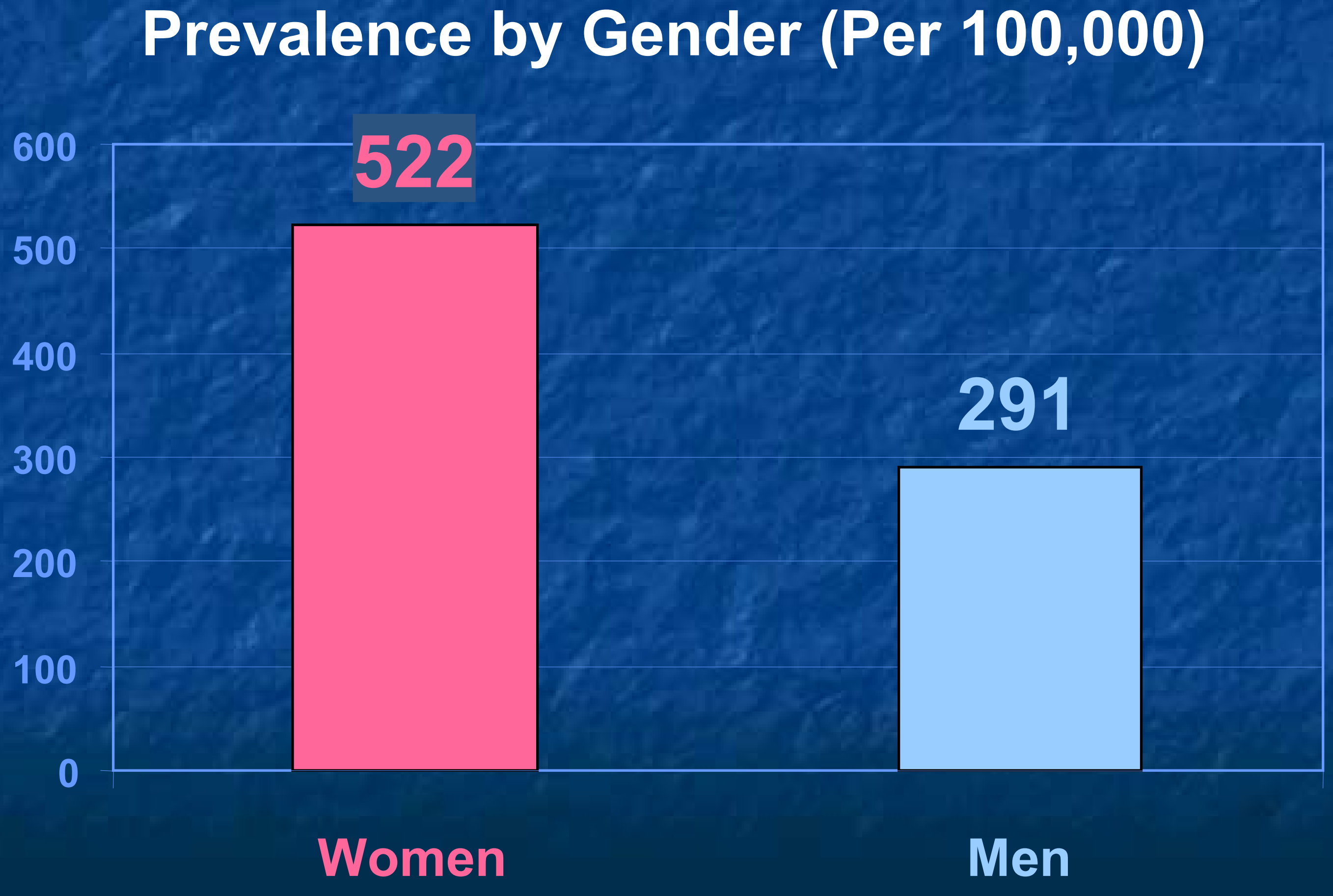
The highest prevalence is among young, affluent, white professionals

Fact:

Women, men and children from all socio-economic backgrounds are affected by CFS

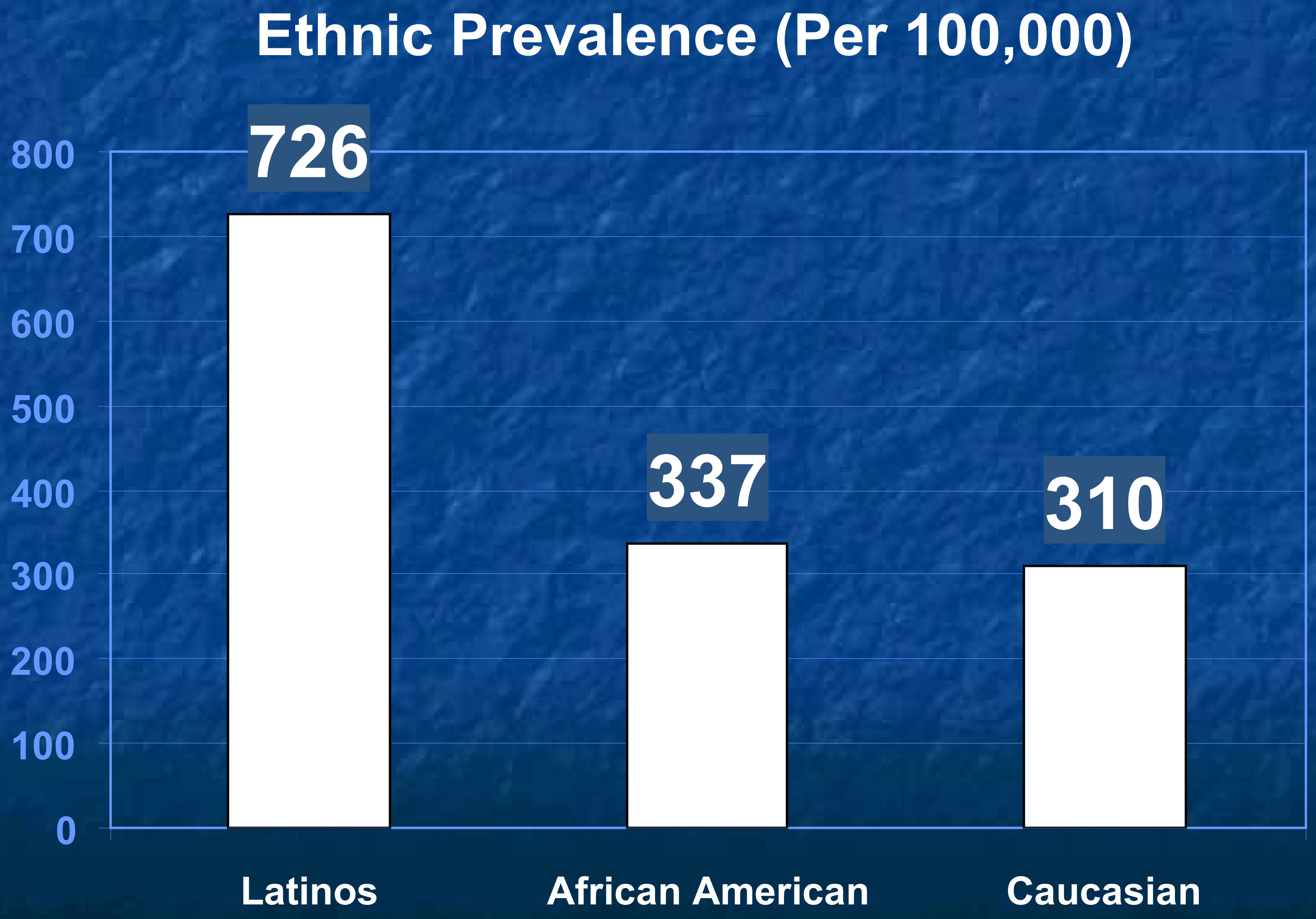
Fact: Gender

Women have a much higher rate of CFS than men



Fact: Race

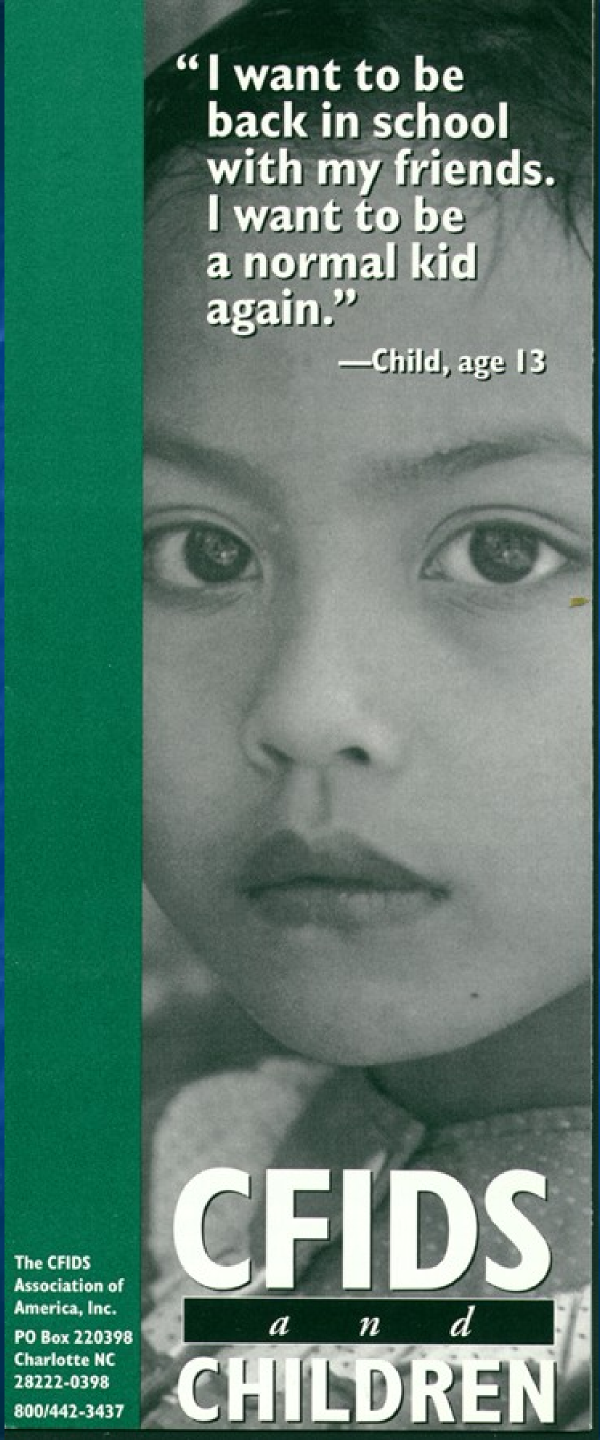
Latinos have highest prevalence of CFS



Overlooked Population

Fact:

Children with CFS are under-recognized and under-studied.



"I want to be back in school with my friends. I want to be a normal kid again."

—Child, age 13

The CFIDS Association of America, Inc.
PO Box 220398
Charlotte NC
28222-0398
800/442-3437

CFIDS
and
CHILDREN

Pediatric CFS

- Has significant impact on educational achievement
- May result in significant health identity confusion and prolonged disability

David Bell, M.D.
Lyndonville Pediatric Study

Economic Impact of ME/CFS, Individual and Societal Cost *

Background: CFS is debilitating fatigue accompanied by physical and cognitive symptoms.

- Economic impact of an illness is divided into direct and indirect costs.
- High prevalence rate and disabling nature suggested high-cost of ME/CFS to individual and society.

Results:

- Using ME/CFS prevalence of 0.042 indicate total annual direct cost of $8,675 per ME/CFS patient or a total cost to society of US $7 billion.
- Direct cost determined by medication usage, self-reported use of physicians, medical testing, and medical office visits.

*Leonard Jason, et. Al., Dynamic Medicine 2008, Volume 7;6

Economic Impact of ME/CFS, Individual and Societal Cost (cont)

Discussion:

These findings suggest high economic cost associated with ME/CFS for patient's families and society.

- These economic losses have substantial long-term impact on ME/CFS patients' standard of living and quality of life.
- High unemployment rates increase the cost burden and become even more problematic to individuals and families.
- In addition to direct medical cost imposed on individuals and society, substantial economic loss is related to lost productivity.
- Indirect cost to individual and society represent annual loss of approximately $20,000/patient; estimated indirect cost in the US $17 billion.
- Limitations of the study include archival data, data estimates, patient's self-reporting and varying severity of illness.

Together indirect and direct costs due to ME/CFS estimated to $17-24 billion.

*Leonard Jason, et. Al., Dynamic Medicine 2008 Volumes 7;6

Classifications:

-ICD

-WHO

ICD9-CM

- US currently uses the International Classification of Diseases, Ninth Revision
    - 780.71 Chronic Fatigue Syndrome

Difficulties:

- Heterogeneous group of disorders
- Not all neurological in nature
- Not all post viral
- Immune system abnormalities not universally found
- Overlap with other syndromes including fibromyalgia and primary psychiatric disorders.

World Health Organization
Geneva, Switzerland

- Responsible for maintaining ICD, International Code of Diseases.
- Post viral fatigue is classified under diseases of nervous system, G93.3.
- Neurasthenia and fatigue syndromes remain under mental and behavioral disorders, F48.0.
- US is not currently using ICD-10.
- ICD-9 establishes Chronic Fatigue Syndrome code 780.71.

Variety of other codes useful to describe symptom related to CFS/ME:
Malaise and fatigue R53.0,
Other malaise 53.81,
Chronic Fatigue unspecified, R53.82,
Unspecified viral encephalitis, A86

HIGHLIGHTS

AP/Greg Baker

61st World Health Assembly
19-24 May 2008

Daily reports
From the World Health Assembly

WHO, partners help China in restoring health system

20 May 2008 -- WHO is working with UN partners to identify priority health needs and obtain supplies for earthquake recovery efforts in China. WHO is providing national health authorities with technical guidance in the area of restoring the health care system damaged in the earthquake. The Chinese Ministry of Health has identified medical supplies and equipment urgently needed to enable prevention, surveillance and control of communicable diseases.

Latest situation in China

Myanmar focuses on containing disease outbreaks

20 May 2008 -- Myanmar health authorities are focusing on prevention steps such as ensuring clean water, food and shelter to reduce the risk of communicable disease outbreaks. WHO and partners have been asked to set up a surveillance system to collect information and verify rumours about diseases. About 100 000 patients have been treated in the cyclone-affected areas.

Latest situation in Myanmar

Communicable disease risk assessment and interventions [pdf 551kb]

61st World Health Assembly: key issues

60 WHO 60th anniversary

KEY WHO INFORMATION

Director-General
Director-General and senior management

Governance of WHO
WHO Constitution, Executive Board and World Health Assembly

Media centre
News, events, fact sheets, multimedia and contacts

International travel and health
Publication on travel risks, precautions and vaccination requirements

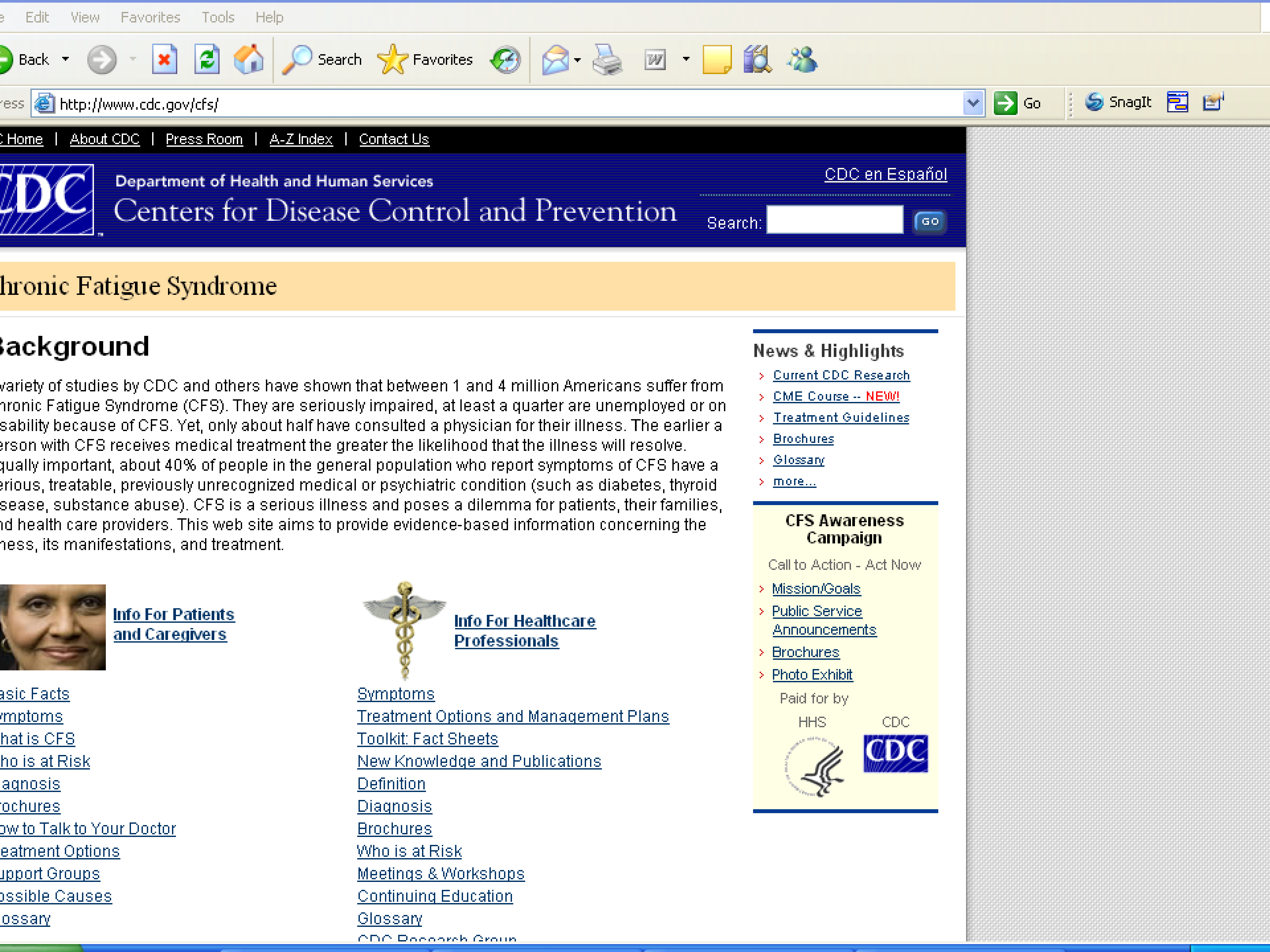
World Health Report
Annual report on global public health and key statistics

Reimbursement not a factor in deliberation of ICD placement.

However, third-party payors and governmental agencies frequently utilize coding to determine coverage and reimbursement policies.

US Governmental Agencies -Approaches to CFS/ME

-Center for Disease Control (CDC)
-National Institute for Health (NIH)
-Trans-NIH
-Department for Human Health Services (DHHS)



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Department of Health and Human Services
Centers for Disease Control and Prevention

Search: GO

hronic Fatigue Syndrome

ackground

variety of studies by CDC and others have shown that between 1 and 4 million Americans suffer from
hronic Fatigue Syndrome (CFS). They are seriously impaired, at least a quarter are unemployed or on
sability because of CFS. Yet, only about half have consulted a physician for their illness. The earlier a
erson with CFS receives medical treatment the greater the likelihood that the illness will resolve.
qually important, about 40% of people in the general population who report symptoms of CFS have a
erious, treatable, previously unrecognized medical or psychiatric condition (such as diabetes, thyroid
sease, substance abuse). CFS is a serious illness and poses a dilemma for patients, their families,
nd health care providers. This web site aims to provide evidence-based information concerning the
ness, its manifestations, and treatment.

Info For Patients and Caregivers

asic Facts
mptoms
hat is CFS
ho is at Risk
agnosis
rochures
ow to Talk to Your Doctor
eatment Options
upport Groups
ossible Causes
ossary

Info For Healthcare Professionals

Symptoms
Treatment Options and Management Plans
Toolkit: Fact Sheets
New Knowledge and Publications
Definition
Diagnosis
Brochures
Who is at Risk
Meetings & Workshops
Continuing Education
Glossary
CDC Research Group

News & Highlights

- Current CDC Research
- CME Course -- NEW!
- Treatment Guidelines
- Brochures
- Glossary
- more...

CFS Awareness Campaign

Call to Action - Act Now

- Mission/Goals
- Public Service Announcements
- Brochures
- Photo Exhibit

Paid for by

HHS CDC

CDC Philosophy

"CFS is a serious illness and poses a dilemma for patients, their families and health care providers"

CDC Basic Facts:

- CFS patients have substantially lower levels of activity. CFS may persist for years.
- The cause has not been identified nor specific diagnostic test available.
- Prevalence of CFS 0.4% or greater than 1 million people in the United States.
- Tens of millions of patients worldwide.

CDC Risk Factors

- People of every age, gender, ethnicity and socio-economic group susceptible to CFS.
- CFS affects women great than men.
- Most common age of CFS sufferer is 40s and 50s.
- CFS may be diagnosed in children.

CDC Case Definition

Introduction

- The 1988 chronic fatigue syndrome (CFS) working case definition (Holmes, et al) did not effectively distinguish CFS from other types of unexplained fatigue. For this reason, it was decided during a 1993 meeting of CFS investigators to develop a logical revision of that definition. The core of the revised CFS case definition is a set of uniformly applicable guidelines for the clinical and research evaluation of CFS and the other forms of fatigue.

- In the revised definition, a consensus viewpoint from many of the leading CFS researchers and clinicians (including input from patient group representatives), chronic fatigue syndrome is treated as a subset of chronic fatigue, a broader category defined as unexplained fatigue of greater than or equal to six month's duration. Chronic fatigue in turn, is treated as a subset of prolonged fatigue, which is defined as fatigue lasting one or more months. The expectation is that scientists will devise epidemiologic studies of populations with prolonged fatigue and chronic fatigue, and search within those populations for illness patterns consistent with CFS.

CDC

Guidelines for the Evaluation and Study of CFS

- A thorough medical history, physical examination, mental status examination, and laboratory tests (diagram) must be conducted to identify underlying or contributing conditions that require treatment. Diagnosis or classification cannot be made without such an evaluation. Clinically evaluated, unexplained chronic fatigue cases can be classified as chronic fatigue syndrome if the patient meets both the following criteria:

- Clinically evaluated, unexplained persistent or relapsing chronic fatigue that is of new or definite onset (i.e., not lifelong), is not the result of ongoing exertion, is not substantially alleviated by rest, and results in substantial Education in previous levels of occupational, educational, social, or personal activities.

- The concurrent occurrence of four or more of the following symptoms: substantial impairment in short-term memory or concentration; sore throat; tender lymph nodes; muscle pain; multi-joint pain without swelling or redness; headaches of a new type, pattern, or severity; unrefreshing sleep; and post-exertional malaise lasting more than 24 hours. These symptoms must have persisted or recurred during 6 or more consecutive months of illness and must not have predated the fatigue.

Conditions that Exclude a Diagnosis of CFS

- Any active medical condition that may explain the presence of chronic fatigue, such as untreated hypothyroidism, sleep apnea and narcolepsy, and iatrogenic conditions such as side effects of medication.
- Some diagnosable illnesses may relapse or may not have completely resolved during treatment. If the persistence of such a condition could explain the presence of chronic fatigue, and if it cannot be clearly established that the original condition has completely resolved with treatment, then such patients should not be classified as having CFS. Examples of illnesses that can present such a picture include some types of malignancies and chronic cases of hepatitis B or C virus infection.
- Any past or current diagnosis of a major depressive disorder with psychotic or melancholic features;
- bipolar affective disorders
- schizophrenia of any subtype
- delusional disorders of any subtype
- dementias of any subtype
- anorexia nervosa
- or bulimia nervosa
- Alcohol or other substance abuse, occurring within 2 years of the onset of chronic fatigue and any time afterwards.

- **Severe obesity as defined by a body mass index [body mass index = weight in kilograms ÷ (height in meters)2] equal to or greater than 45. [Note: body mass index values vary considerably among different age groups and populations. No "normal" or "average" range of values can be suggested in a fashion that is meaningful. The range of 45 or greater was selected because it clearly falls within the range of severe obesity.]**

Conditions that do not Exclude a Diagnosis of CFS

- Any condition defined primarily by symptoms that cannot be confirmed by diagnostic laboratory tests, including fibromyalgia, anxiety disorders, somatoform disorders, nonpsychotic or melancholic depression, neurasthenia, and multiple chemical sensitivity disorder.
- Any condition under specific treatment sufficient to alleviate all symptoms related to that condition and for which the adequacy of treatment has been documented. Such conditions include hypothyroidism for which the adequacy of replacement hormone has been verified by normal thyroid-stimulating hormone levels, or asthma in which the adequacy of treatment has been determined by pulmonary function and other testing.
- Any condition, such as Lyme disease or syphilis, that was treated with definitive therapy before development of chronic symptoms.
- Any isolated and unexplained physical examination finding, or laboratory or imaging test abnormality that is insufficient to strongly suggest the existence of an exclusionary condition. Such conditions include an elevated antinuclear antibody titer that is inadequate, without additional laboratory or clinical evidence, to strongly support a diagnosis of a discrete connective tissue disorder

Centers for Disease Control and Prevention; Atlanta, Georgia, 30301

Current position on Chronic Fatigue Syndrome:

Background:

- Acknowledge CFS as serious impairment with unemployment rate of at least 25%.
- Many patients undiagnosed.
- Earlier diagnosis and earlier treatment results in decreased morbidity.
- 40% of population diagnosed with CFS-like symptoms have other treatable disorders.

Diagnostic Criteria I: Chronic Fatigue Syndrome – CDC definition (1988) outline.

The first formal case definition included two major criteria along with the following minor criteria: 6 or more of the symptom criteria listed below and 2 or more of the physical criteria; or 8 or more symptom criteria.

Major criteria:

- New onset of persistent or relapsing, debilitating fatigue or easy fatigability in a person who has no previous history of similar symptoms, that does not resolve with bed rest, and that is severe enough to reduce or impair average daily activity below 50 percent of the patient's premorbid activity level for a period of at least 6 months
- Exclusion of other clinical conditions that may produce similar symptoms (e.g., malignancy, autoimmune disease, chronic psychiatric disease, and chronic inflammatory disease, among others)

Minor criteria:

- Symptom criteria
- Mild fever
- Sore throat
- Painful lymph nodes in the anterior or posterior cervical or axillary distribution
- Unexplained generalized muscle weakness
- Muscle discomfort or myalgia
- Prolonged (≥ 24 hours) generalized fatigue after exercise
- Generalized headaches
- Migratory arthralgia without joint swelling or redness
- Neuropsychologic complaints
- Sleep disturbance
- Physical criteria
- Low-grade fever
- Nonexudative pharyngitis

CFS – British Definition (1990)

- The "Oxford criteria" defined two broad syndromes: chronic fatigue syndrome and post-infectious fatigue syndrome (PIFS). CFS was defined by the following characteristics:
- Fatigue is the principal symptom.
- It is a syndrome of definite onset that is not lifelong.
- Fatigue is severe, disabling, and affects physical and mental functioning.
- Fatigue has been present for a minimum of 6 months, during which it was present for more than 50 percent of the time.
- Other symptoms may be present, particularly myalgia, mood, and sleep disturbance.
- Exclusion criteria included patients with established medical conditions known to produce chronic fatigue and those with certain psychiatric disorders (substance abuse, eating disorders, organic brain disease).

CFS – Australian definition (1990)

- The Australian criteria consisted of the following symptoms:
- Chronic persisting or relapsing fatigue of a generalized nature, exacerbated by minor exercise, causing significant disruption of usual daily activities, and present for more than 6 months
- Neuropsychiatric dysfunction including impairment of concentration evidenced by difficulty in completing mental tasks which were easily accomplished before the onset of the syndrome; new onset of short term memory impairment
- No alternative diagnosis reached by history, physical examination, or investigations over a 6-month period

CFS-The International Definition (1994)

- This revision of the 1988 CDC case definition remains the currently the accepted research definition, also known as the Fukuda definition, and was based on the presence of the following:
- Clinically evaluated, unexplained, persistent or relapsing chronic fatigue that is of new or definite onset (has not been lifelong); is not the result of ongoing exertion; is not substantially alleviated by rest; and results in substantial reduction in previous levels of occupational, educational, social, or personal activities
- The concurrent occurrence of four or more of the following symptoms, all of which must have persisted or recurred during 6 or more consecutive months of illness and must not have predated the fatigue:
  - Self-reported impairment in short-term memory or concentration severe enough to cause substantial reduction in previous levels of occupational, educational, social, or personal activities
  - Tender cervical or axillary lymph nodes
  - Muscle pain, multijoint pain without joint swelling or redness
  - Headaches of a new type, pattern, or severity
  - Unrefreshing sleep
  - Postexertional malaise lasting more than 24 hours

The International CFS Definition Revisited (2003)

- The 1988 case definition offered examples of conditions that would preclude a diagnosis of CFS, such as malignancy, autoimmune disease, chronic psychiatric disease, and chronic inflammatory disease. The International Chronic Fatigue Syndrome Study Group elaborated on these exclusionary criteria to include:
- Permanent medical exclusions:
  - Organ failure (e.g., emphysema, cirrhosis, cardiac failure, chronic renal failure)
  - Chronic infections (e.g., AIDS, hepatitis B or C)
  - Rheumatic and chronic inflammatory diseases (e.g., systemic lupus erythematosis, Sjorgren's syndrome, rheumatoid arthritis, inflammatory bowel disease, chronic pancreatitis)
  - Major neurologic diseases (e.g., multiple sclerosis, neuromuscular diseases, epilepsy or other diseases requiring ongoing medication that could cause fatigue, stroke, head injury with residual neurologic deficits)
  - Diseases requiring systemic treatment (e.g., organ or bone marrow transplantation; systemic chemotherapy; radiation of brain, thorax, abdomen, or pelvis)
  - Major endocrine diseases (e.g., hypopituitarism, adrenal insufficiency)
  - Primary sleep disorders (e.g., sleep apnea, narcolepsy)

- Temporary medical exclusions:
  - Conditions discovered at onset or initial evaluation (e.g., effects of medications, sleep deprivation, untreated hypothyroidism, untreated or unstable diabetes mellitus, active infection)
  - Conditions that resolved (e.g., pregnancy until 3 months post-partum, breastfeeding, major surgery until 6 months post-operation, minor surgery until 3 months post-operation, major infections such as sepsis or pneumonia until 3 months post-resolution)
  - Major conditions whose resolution may be unclear for at least 5 years (e.g., myocardial infarction, heart failure)
  - Morbid obesity (body mass index > 40)

- Permanent psychiatric exclusions:
  Lifetime diagnoses of bipolar affective disorders, schizophrenia of any subtype, delusional disorders of any subtype, dementias of any subtype, organic brain disorders, and alcohol or substance abuse within 2 years before onset of the fatiguing illness

Myalgic Encephalitis/CFS- Canadian Consensus Definition
(2003)

- Most widely used by clinicians due to clinical representation of diseases, ease of implementation and treatment guidelines

Canadian Consensus Document (Carruthers, 2003)

- Myalgic Encephalomyelitis / Chronic Fatigue Syndrome:
  - Clinical Working Case Definition
  - Diagnostic and Treatment Protocols

Journal of Chronic Fatigue Syndrome, Vol 11 (1), 2003

Canadian Clinical Working Case Definition of ME/CFS

A patient with ME/CFS will meet
The criteria for:

- Fatigue, post-exertional malaise, and/or fatigue, sleep dysfunction and pain

- Have two or more neurological/cognitive more symptoms from two of the categories of autonomic, neuroendocrine, and immune manifestations

- Adhere to item 7

Criteria

1. Fatigue
2. Post-exertional malaise and/or fatigue
3. Sleep dysfunction
4. Pain
5. Neurological/cognitive manifestations (two or more)
6. At least one symptom from two of the following categories:
    1. Autonomic manifestations
    2. Neuroendocrine manifestations
    3. Immune manifestations
7. Illness that persists for at least six months and has a distinct onset (although onset may have been gradual)

Neurological/Cognitive Manifestations

Two or more of the following:

- Confusion
- Impairment of concentration and short- term memory consolidation
- Difficulty with information
- Disorientation
- Perceptual and sensory disturbances
- Ataxia
- Muscle Weakness
- Fasciculation
- Overload phenomena: cognitive, sensory and emotional

1. Fatigue

- Significant degree of physical and mental fatigue
  - New onset
  - Unexplained
  - Persistent
  - Recurrent
- Fatigue substantially reduces activity level

2. Post-Exertional Malaise and/or Fatigue

- Inappropriate loss of physical and mental stamina
- Rapid muscular and cognitive fatigability
- Post exertional malaise and/or fatigue and/or pain
- Tendency for other association symptoms to worsen
- Pathologically slow recovery period – usually 24 hours or longer

3. Sleep Dysfunction

- Unrefreshed sleep, or
- Sleep quantity, or
- Rhythm disturbances, such as reversed or chaotic diurnal sleep rhythms

A small number of patients have no sleep dysfunction, but no other diagnosis fits except ME/CFS

4. Pain

- Significant degree of myalgia
- Pain in the muscles and/or joints, often widespread and migratory in nature
- Significant headaches of new type, pattern, or severity

A small number of patients have no pain, but no other diagnosis fits except ME/CFS

5. Other Symptoms

Autonomic Manifestations

- Orthostatic intolerance-neurally mediated hypotension (NMH)
- Delayed postural hypotension
- Light-headedness
- Extreme pallor
- Nausea and irritable bowel syndrome
- Urinary frequency and bladder dysfunction
- Palpitations with or without cardiac arrhythmias
- Exertional dyspnea

Neuroendocrine Manifestations

- Loss of thermostatic stability
- Marked weight change
- Loss of adaptability and worsening of symptoms with stress

Immune Manifestations

- Tender lymph nodes
- Recurrent sore throat
- Recurrent flu-like symptoms
- General malaise
- New sensitivities to food, medications, and/or chemicals

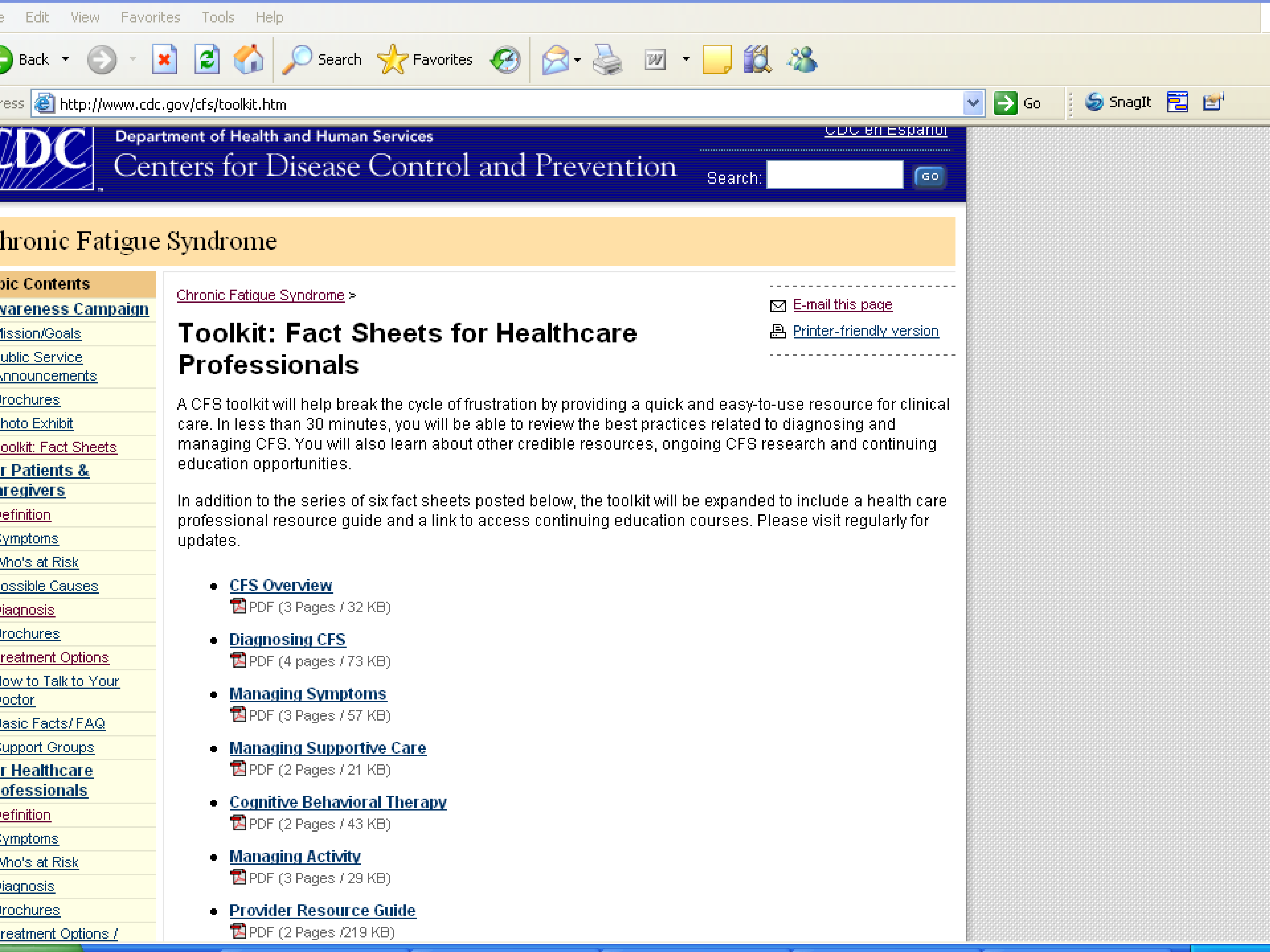
6. Illness Duration

- Illness persists for at least 6 months
- Usually a distinct onset, although it may be gradual
- (Preliminary diagnosis may be possible earlier than 6 months)
- (Illness duration of 3 months is appropriate for children)

Some patients may have been unhealthy for other reasons prior to onset of ME/CFS and lack detectable triggers, and/or have more gradual or insidious onset

CFS – CDC International Definition or Fukuda Definition (1994) outline

- Most widely accepted, currently for research, publication and research design requires compliance with this definition for legitimacy and publication



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Chronic Fatigue Syndrome >

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Toolkit: Fact Sheets for Healthcare Professionals

A CFS toolkit will help break the cycle of frustration by providing a quick and easy-to-use resource for clinical care. In less than 30 minutes, you will be able to review the best practices related to diagnosing and managing CFS. You will also learn about other credible resources, ongoing CFS research and continuing education opportunities.

In addition to the series of six fact sheets posted below, the toolkit will be expanded to include a health care professional resource guide and a link to access continuing education courses. Please visit regularly for updates.

- CFS Overview
  PDF (3 Pages / 32 KB)
- Diagnosing CFS
  PDF (4 pages / 73 KB)
- Managing Symptoms
  PDF (3 Pages / 57 KB)
- Managing Supportive Care
  PDF (2 Pages / 21 KB)
- Cognitive Behavioral Therapy
  PDF (2 Pages / 43 KB)
- Managing Activity
  PDF (3 Pages / 29 KB)
- Provider Resource Guide
  PDF (2 Pages /219 KB)

CDC
Awareness Campaign

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- Researchers
- Media
- Healthcare Providers
- Students and Educators
- Partners
- Policy Makers
- Businesses

NATIONAL INSTITUTES OF HEALTH

Nation’s Medical Research Agency

Research, Training & Scientific Resources

Quick Links

- Research in NIH Labs & Clinics
- Research Training
- Lab Research Support
- Clinical Research Support
- Computational Biology
- Other Federal Resources

Research in NIH Labs & Clinics

- » Intramural Research Scientific Programs
- » Search NIH Intramural Research Reports
- » NIH Scientific Interest Groups
- » Intramural Research Sourcebook
- » NIH Intramural Research News
- » Library and Literature
- » NIH Campus Info

^top

Research Training

- » Research and Training Opportunities at the NIH
- » Training for NIH Employees

^top

Lab Research Support

- » Bioethics Resources on the Web
- » Biological & Chemical Safety (Compliance)
- » Mercury Free Campaign
- » Model Organisms for Biomedical Research

Department of Human Health Services (DHHS)

DHHS Advisory Committee,
Department of Health and Human Services, Chronic Fatigue Syndrome Advisory Committee

- Established in 1996 to advise Department of Health and Human Services on policy with respect to Chronic Fatigue Syndrome.
- Brought together officials representing health agencies and seven appointed members of the public.
- Established Chronic Fatigue Syndrome Advisory Committee. Current membership: Biomedical researchers 7, disability and clinical care expertise patient advocates 4.
- Agencies represented:
    - National Institute of Health (NIH),
    - Centers for Disease Control and Prevention (CDC),
    - Food and Drug Administration (FDA),
    - Health Resources and Services Administration (HRSA),
    - Social Security Administration (SSA)

Chronic Fatigue Syndrome Advisory Committee (CFSAC)

- Hold meetings
- Activities:
  - has addressed expansion of CSF biomedical research
  - appropriate name change for the syndrome
  - pediatric CFS
  - disability
  - health provider education

Trans-NIH working group on Chronic Fatigue Syndrome

(Office of Research on Women's Health-ORWH) Diagnostic Criteria

Introduction: CFS is a clinically diagnosable condition with well-documented history.

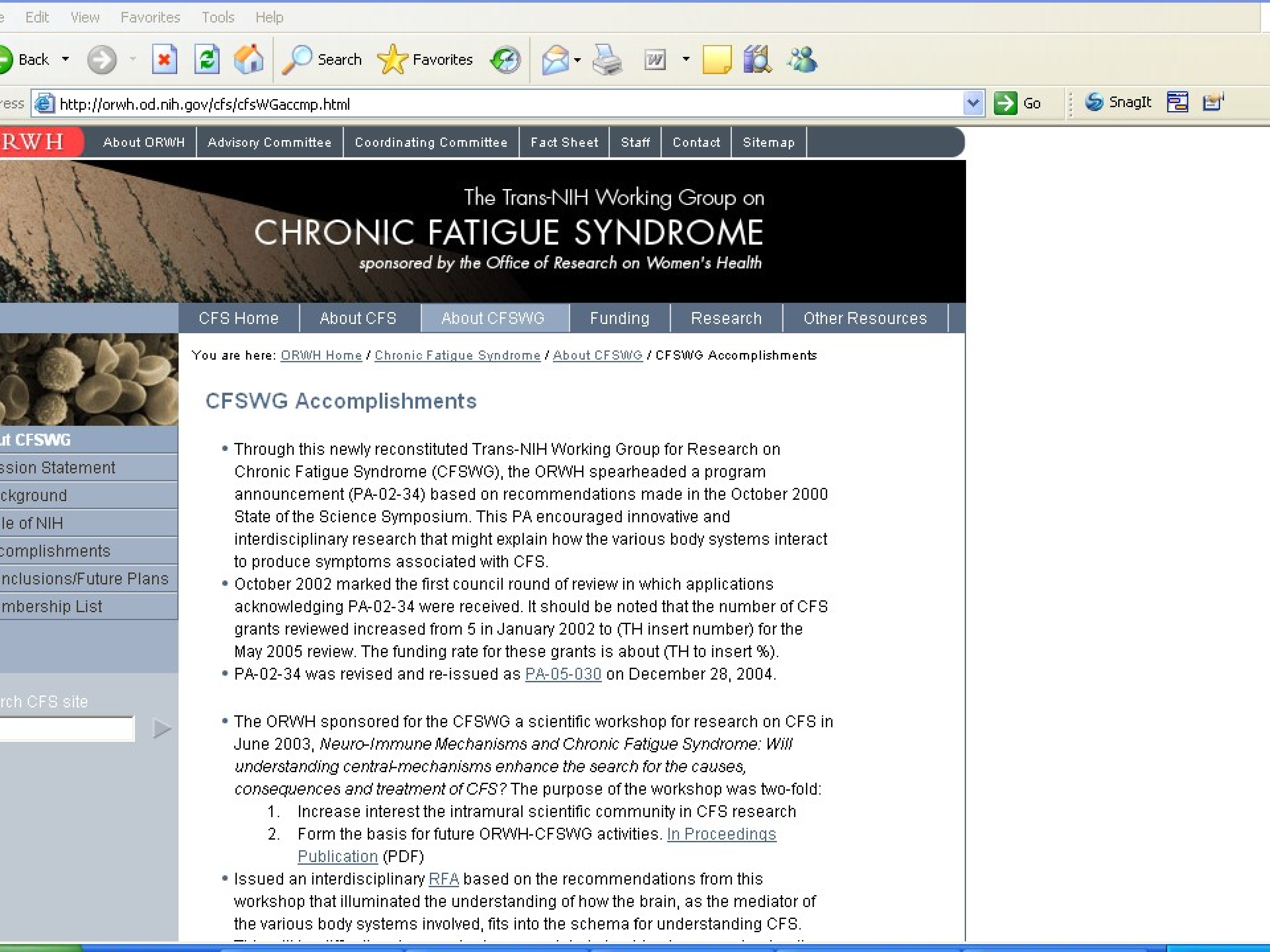
- Symptoms of CFS are variable in severity and not homogenous making acceptable research in clinical diagnostic criteria difficult

Trans-NIH working group Chronic Fatigue Syndrome (CFS Specific Funding):

- Pathophysiology and treatment of Chronic Fatigue Syndrome with regrant opportunities including neuro-immune mechanisms of Chronic Fatigue Syndrome

NIH Scientific / Research components:

- Office of Research on Women's Health
- Office of Behavioral and Social Science Research
- National Institutes in Alcohol Abuse and Alcoholism
- National Institute of Arthritis and Musculoskeletal and Skin Diseases
- National Institute of Environmental Health Science
- National Institute of Neurological Disorders and Stroke.

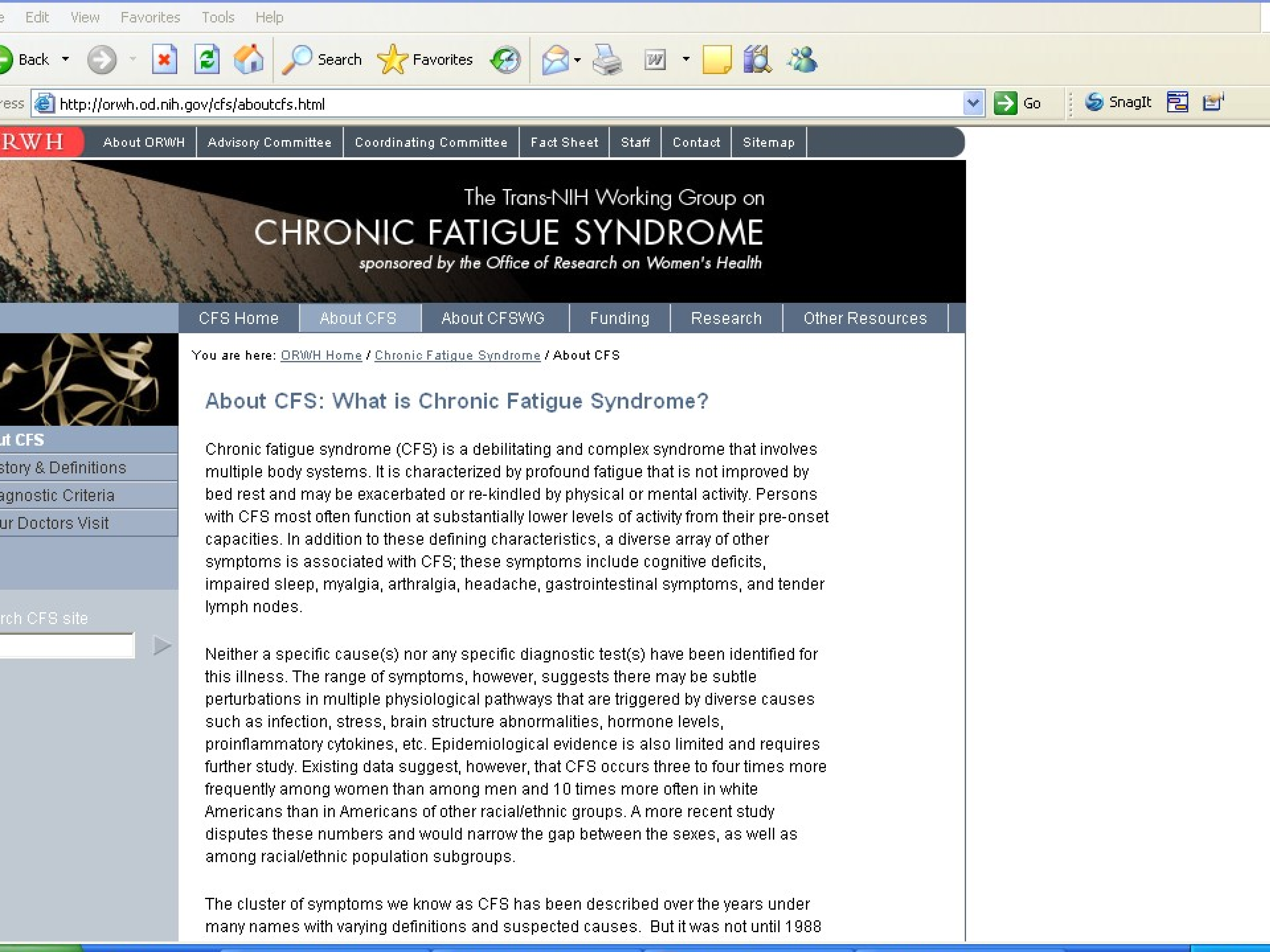


You are here: ORWH Home / Chronic Fatigue Syndrome / About CFSWG / CFSWG Accomplishments

CFSWG Accomplishments

- Through this newly reconstituted Trans-NIH Working Group for Research on Chronic Fatigue Syndrome (CFSWG), the ORWH spearheaded a program announcement (PA-02-34) based on recommendations made in the October 2000 State of the Science Symposium. This PA encouraged innovative and interdisciplinary research that might explain how the various body systems interact to produce symptoms associated with CFS.
- October 2002 marked the first council round of review in which applications acknowledging PA-02-34 were received. It should be noted that the number of CFS grants reviewed increased from 5 in January 2002 to (TH insert number) for the May 2005 review. The funding rate for these grants is about (TH to insert %).
- PA-02-34 was revised and re-issued as PA-05-030 on December 28, 2004.

- The ORWH sponsored for the CFSWG a scientific workshop for research on CFS in June 2003, *Neuro-Immune Mechanisms and Chronic Fatigue Syndrome: Will understanding central-mechanisms enhance the search for the causes, consequences and treatment of CFS?* The purpose of the workshop was two-fold:
    1. Increase interest the intramural scientific community in CFS research
    2. Form the basis for future ORWH-CFSWG activities. In Proceedings Publication (PDF)
- Issued an interdisciplinary RFA based on the recommendations from this workshop that illuminated the understanding of how the brain, as the mediator of the various body systems involved, fits into the schema for understanding CFS.



http://orwh.od.nih.gov/cfs/aboutcfs.html

The Trans-NIH Working Group on
CHRONIC FATIGUE SYNDROME
sponsored by the Office of Research on Women's Health

You are here: ORWH Home / Chronic Fatigue Syndrome / About CFS

About CFS: What is Chronic Fatigue Syndrome?

Chronic fatigue syndrome (CFS) is a debilitating and complex syndrome that involves multiple body systems. It is characterized by profound fatigue that is not improved by bed rest and may be exacerbated or re-kindled by physical or mental activity. Persons with CFS most often function at substantially lower levels of activity from their pre-onset capacities. In addition to these defining characteristics, a diverse array of other symptoms is associated with CFS; these symptoms include cognitive deficits, impaired sleep, myalgia, arthralgia, headache, gastrointestinal symptoms, and tender lymph nodes.

Neither a specific cause(s) nor any specific diagnostic test(s) have been identified for this illness. The range of symptoms, however, suggests there may be subtle perturbations in multiple physiological pathways that are triggered by diverse causes such as infection, stress, brain structure abnormalities, hormone levels, proinflammatory cytokines, etc. Epidemiological evidence is also limited and requires further study. Existing data suggest, however, that CFS occurs three to four times more frequently among women than among men and 10 times more often in white Americans than in Americans of other racial/ethnic groups. A more recent study disputes these numbers and would narrow the gap between the sexes, as well as among racial/ethnic population subgroups.

The cluster of symptoms we know as CFS has been described over the years under many names with varying definitions and suspected causes. But it was not until 1988

EXAMPLES OF INTERNATIONAL ORGANIZATIONS

- International Association for CFS / ME
- Alison Hunter Memorial Foundation
- CFS – Japan
- ME Research UK
- Irish ME Trust

IACFS/ME
International Association for CFS/ME

- Presidential Letter
- Member Login
- Member Directory
- Search
- Case Definitions
- ME/CFS Diagnosis in Adults
- ME/CFS Pediatric Case Definition and Health Questionnaire
- FDA Approved Drugs
- Research Studies, Trials, Grants and Scholarships

SAVE THE DATE
Next IACFS/ME International Conference
March 12-15, 2009
Reno, Nevada

Click Here For More Info

SAVE THE DATE
Infections in CFS,
HHV-6 Foundation-IACFS/ME
Satellite Conference
June 22-23, 2008, Baltimore, Maryland

Click Here For More Info

View January 2007 Conference Summary
by Anthony Komaroff, M.D.
Professor of Medicine, Harvard Medical School

IACFS/ME
Join us
IACFS/ME Membership

Members GET INVOLVED

Donate to the IACFS/ME
Click here to make a donation

History of IACFS/ME

- Founding goal to bring together researchers, clinicians, health care workers and support groups to foster discussion, research, treatment and education.
- Internationalization – 2005 IACFS/ME became international adopting current name of IACFS/ME.
- Goals focus on educational projects for professionals and nonprofessionals.
- Award programs for outstanding clinicians and researchers.
- Sponsors semi-annual research conference.

IACFS/ME MISSION

- To promote, stimulate and coordinate exchange of ideas related to CFS, ME and FM research, patient care and treatment.
  - Reviews research and treatment literature to develop guidelines for scientist, clinicians and patients.
  - Conducts or participates in local, national and international conferences to promote and evaluate new research
  - IACFS/ME International Conference, March 12-15, 2009 Reno, Nevada.

Leadership IACFS/ME
Board of Directors

- David S. Bell, MD / Editor
- Lucinda Bateman, MD / Secretary
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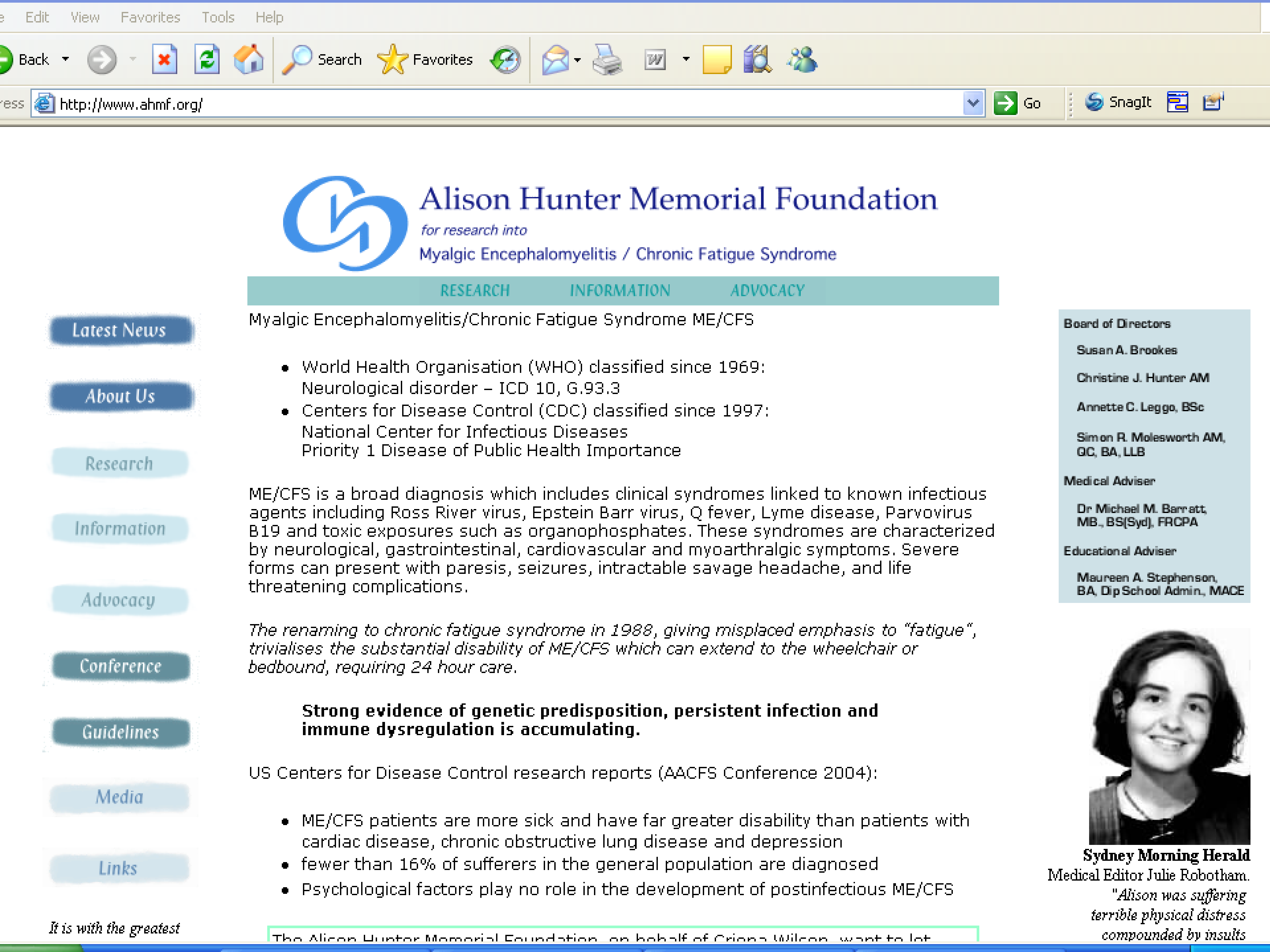
IACFS is in the developmental phase of treatment guidelines using their board members and outside consultative opinion



Alison Hunter Memorial Foundation

for research into

Myalgic Encephalomyelitis / Chronic Fatigue Syndrome

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome ME/CFS

- World Health Organisation (WHO) classified since 1969:
  Neurological disorder – ICD 10, G.93.3
- Centers for Disease Control (CDC) classified since 1997:
  National Center for Infectious Diseases
  Priority 1 Disease of Public Health Importance

ME/CFS is a broad diagnosis which includes clinical syndromes linked to known infectious agents including Ross River virus, Epstein Barr virus, Q fever, Lyme disease, Parvovirus B19 and toxic exposures such as organophosphates. These syndromes are characterized by neurological, gastrointestinal, cardiovascular and myoarthralgic symptoms. Severe forms can present with paresis, seizures, intractable savage headache, and life threatening complications.

The renaming to chronic fatigue syndrome in 1988, giving misplaced emphasis to "fatigue", trivialises the substantial disability of ME/CFS which can extend to the wheelchair or bedbound, requiring 24 hour care.

Strong evidence of genetic predisposition, persistent infection and immune dysregulation is accumulating.

US Centers for Disease Control research reports (AACFS Conference 2004):

- ME/CFS patients are more sick and have far greater disability than patients with cardiac disease, chronic obstructive lung disease and depression
- fewer than 16% of sufferers in the general population are diagnosed
- Psychological factors play no role in the development of postinfectious ME/CFS

The Alison Hunter Memorial Foundation, on behalf of Criona Wilson, want to let

It is with the greatest

Board of Directors

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Educational Adviser

Maureen A. Stephenson, BA, Dip School Admin., MACE

Sydney Morning Herald
Medical Editor Julie Robotham.
"Alison was suffering terrible physical distress compounded by insults

Alison Hunter Memorial Foundation

- Supports personalized individualized treatment by patient subset.
- Scientific evidence on etiology, pathogenesis and treatment again is underfunded and poorly organized.
- The medical community, health professionals, patients and families should be encouraged to work together to increase funding and research patient impact.
- Early diagnosis and aggressive therapy can alter outcome.
- The patients have responsibility for their activity, diagnosis and treatment.
- Mental activity, as well as physical exertion may worsen symptoms.

- Emphasizing broad diagnosis with attention to post infectious etiologies including Ross River virus, EB, Q fever, Lyme disease and Parvo B19
- Supports research of syndromes characterized with neurological gastrointestinal, cardiovascular and myoarthalgic symptoms.
- Building upon base of strong evidence suggesting genetic predisposition, persistent infection, and immune disregulation as the pathogenesis of the disorder.
- The patient is oriented with respect to emphasis on the great disability of patients suffering immensely of CFS.
- Lack of appropriate diagnosis and management in Australia.

- Lack of appropriate diagnosis and management in Australia.

- Lack of primary and tertiary care centers for diagnosis and treatment.

CFS Chronic Fatigue Syndrome and related illness

CFSNJ CFS Network JAPAN

慢性疲労症候群・疲労関連疾患情報

TEL. 090-3716-0642

Japanese Edition **English Edition**

WELCOME TO CFS NETWORK WEB PAGE

CFS (Chronic Fatigue Syndrome) /CFIDS/ME/FMS

- CFIDS (Chronic Fatigue and Immune Dysfunction Syndrome) -

-ME (Myalgic Encephalomyelitis) -*and related disorder.*

FATIGUE : Japanese Research & Information

265755

Welcome

ME Research UK is a national charity funding biomedical research into Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (also known as ME/CFS). Our principal aim is to commission and fund high-quality scientific (biomedical) investigation into the causes, consequences and treatment of ME, but we also have a mission to 'Energise ME Research'.

Our in-house team is involved in identifying potentially important biomedical projects, publishing scientific papers on biomedical aspects of the

Vitamin D status

New research in Dundee investigating vitamin D status and its association with cardiovascular function in patients with ME/CFS.

London Marathon Heroes

Robert Ogden, Madhi Choudhury and Ian Bottomley finished the Flora London Marathon within 13 minutes of each other, all 3 raising money for ME Research UK. Read more about their and other friends' fundraising achievements.

Identifying gene SNPs

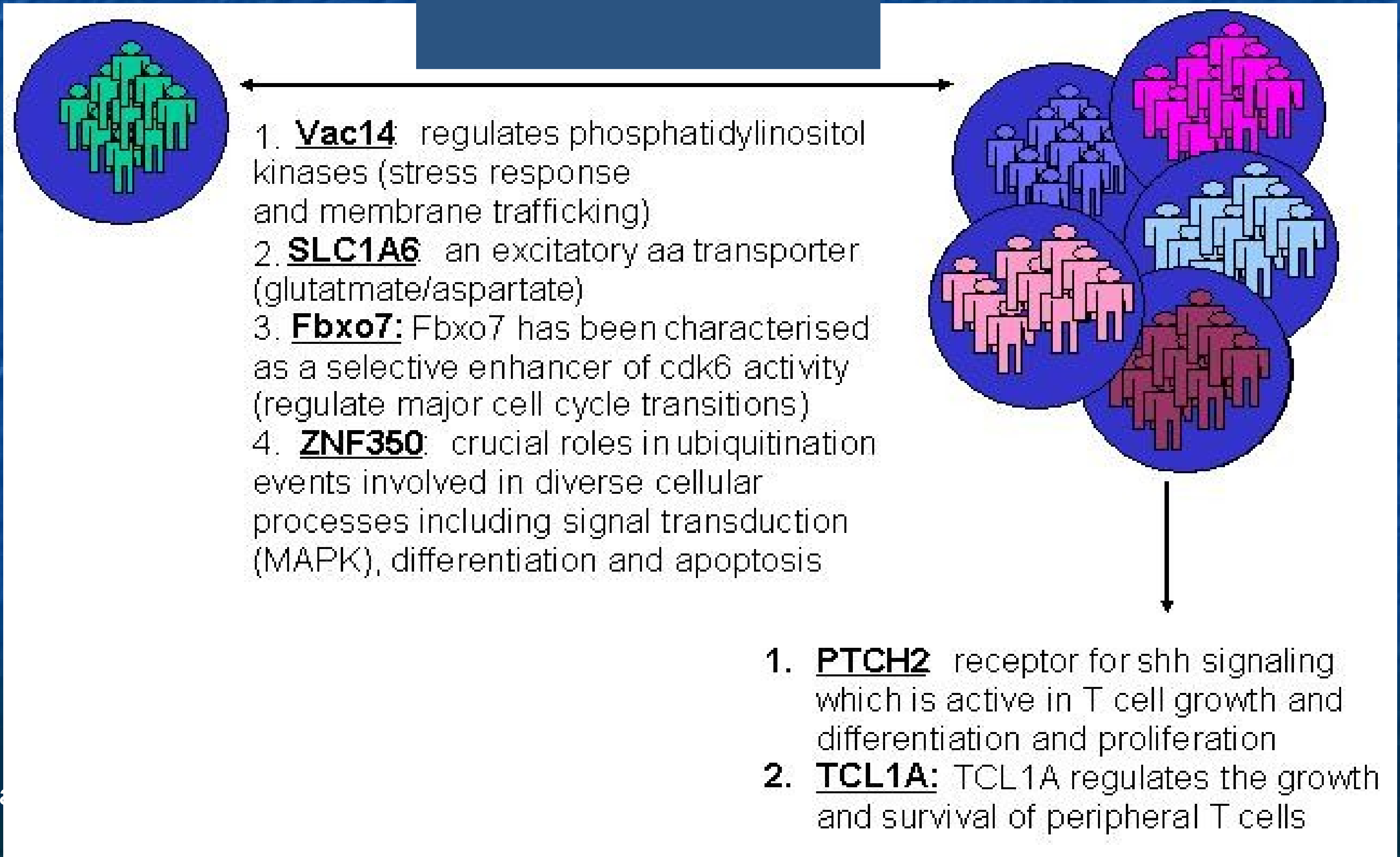
Dr Jonathan Kerr's group at St George's University of London will shortly begin the

ME Research UK

- Is a national charity funding basic biomedical research into causes, consequences as treatment of ME.

- Committed to identifying and funding biomedical projects, publishing scientific papers, and producing high quality professional review.

Gene Expression Differentiates Subgroups of People with CFS



1. **Vac14**: regulates phosphatidylinositol kinases (stress response and membrane trafficking)
2. **SLC1A6**: an excitatory aa transporter (glutatmate/aspartate)
3. **Fbxo7:** Fbxo7 has been characterised as a selective enhancer of cdk6 activity (regulate major cell cycle transitions)
4. **ZNF350**: crucial roles in ubiquitination events involved in diverse cellular processes including signal transduction (MAPK), differentiation and apoptosis

1. **PTCH2**: receptor for shh signaling which is active in T cell growth and differentiation and proliferation
2. **TCL1A:** TCL1A regulates the growth and survival of peripheral T cells

Ca

Support New Horizons International Research Conference

- Support basic research; i.e. Dr. Jonathan Kerr, St. George University London, genetic subsetting and SNPS as signature for ME/CFS

Welcome to the Home Page of the Irish M.E. Trust.

The Irish ME Trust was established in 1989 for the purpose of trying to alleviate some of the hardship which was being experienced by ME sufferers throughout the country.

We provide information and a counselling service to those affected as well as targeting individual problems on behalf of sufferers. We aim to create awareness in the general public and the medical profession as to the plight of ME sufferers in Ireland and to generate funds for the purpose of promoting research into the illness.

Please explore the menu buttons on the left for various information regarding the condition of ME / CFS.

This website will be added to over time.

Please feel free to contact us at **info@imet.ie** with any comments or observations you may have in relation to this website.

Irish ME Trust:

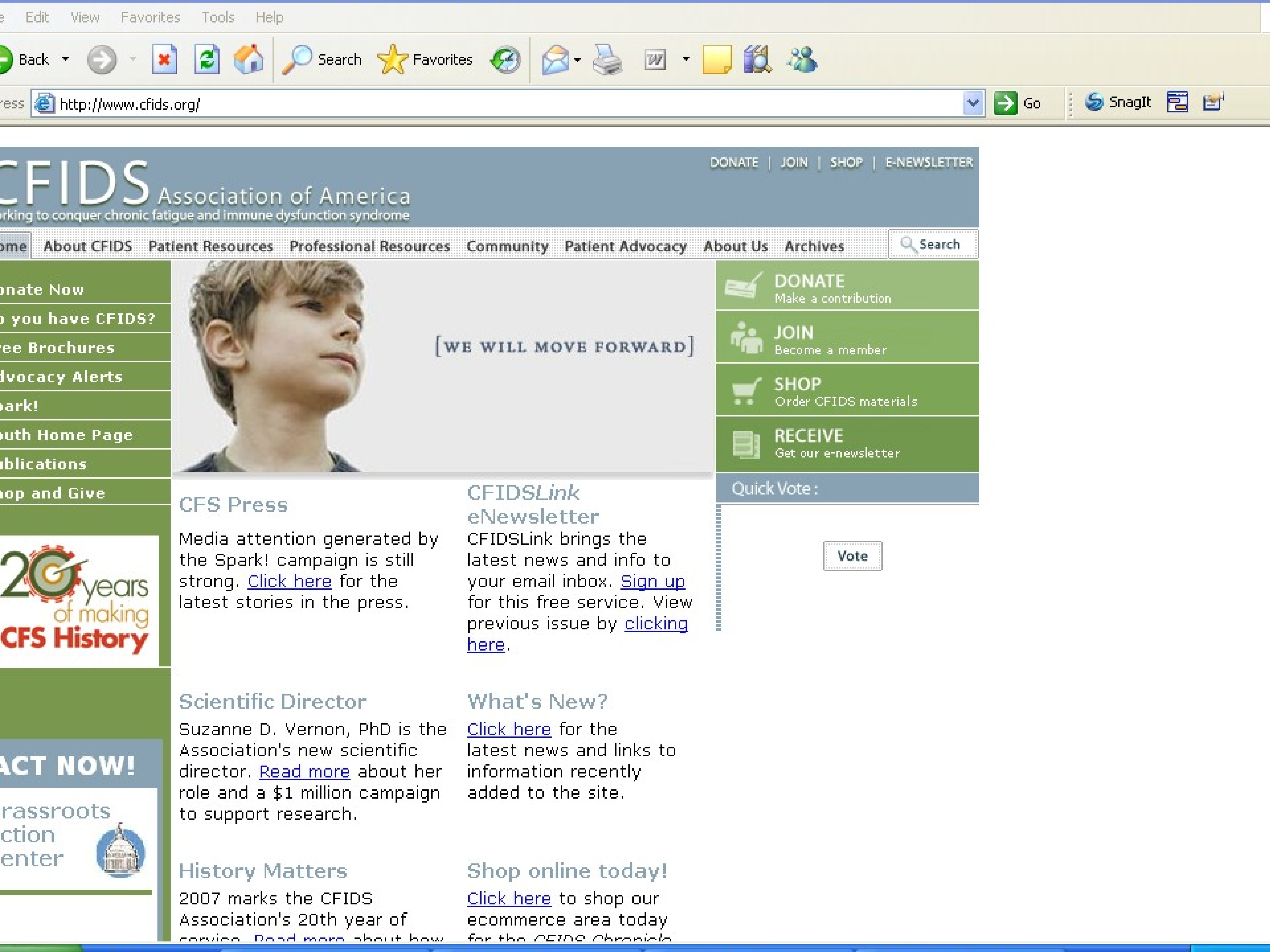
- Mission to alleviate hardship experienced by ME suffers
- Provide information and counseling services.
- Sponsor educational programs and research projects.

US PRIVATE ASSOCIATIONS/ FOUNDATIONS/ INSTITUTES

- Chronic Fatigue and Immune Dysfunction Syndrome (CFIDS)
- Co-Cure ME/CFS
- WP Institute for Neuro-Immune Disease

- AIM
- Informatics

Chronic Fatigue and Immune Dysfunction Syndrome Association of America (CFIDS)



CFS Press

Media attention generated by the Spark! campaign is still strong. Click here for the latest stories in the press.

CFIDS*Link* eNewsletter

CFIDSLink brings the latest news and info to your email inbox. Sign up for this free service. View previous issue by clicking here.

Scientific Director

Suzanne D. Vernon, PhD is the Association's new scientific director. Read more about her role and a $1 million campaign to support research.

What's New?

Click here for the latest news and links to information recently added to the site.

History Matters

2007 marks the CFIDS Association's 20th year of service. Read more about how

Shop online today!

Click here to shop our ecommerce area today for the *CFIDS Chronicle*

History of CFIDS Association

- Founded in 1987 to stimulate high-quality CFS research
- Improve the ability of health care professionals
- The organization has invested more than $25 million in education, public policy and research and is the largest charitable funder and advocate of CFS research in the U.S.
- Year long commemoration of the Association's 20 years of service

CFIDS Association of America

- Congressional Activities:
  - Annual appropriations advocacy to stimulate research funding
  - Participates in congressional advocacy for legislature.
  - Disseminates information with respect to advocacy and nation issues.

CFIDS Association of America, Leading US Organization for Advocacy:

- Broad spectrum of activities including sponsoring scientific research.
- Physician and patient education
- Local and federal advocacy.

National Concerns:

- Practitioner and patient-based demand for evidence-based guidelines for provider education
- 3500 publications without clear-cut guidelines
- Few recognized experts
- Few complete data sense
- Extremely small number of recognized experts

Failure to diagnose:

- Estimated 80% of CFS/ME. The patients were unable to find expert providers
- Global inexperienced similar
- Inadequate training remains largest obstacle for patients
- Research and diagnostic protocol secured by individual scientist study population.
- Models for other diseases with respect to diagnostic and treatment algorithms.

CFIDS Association of America

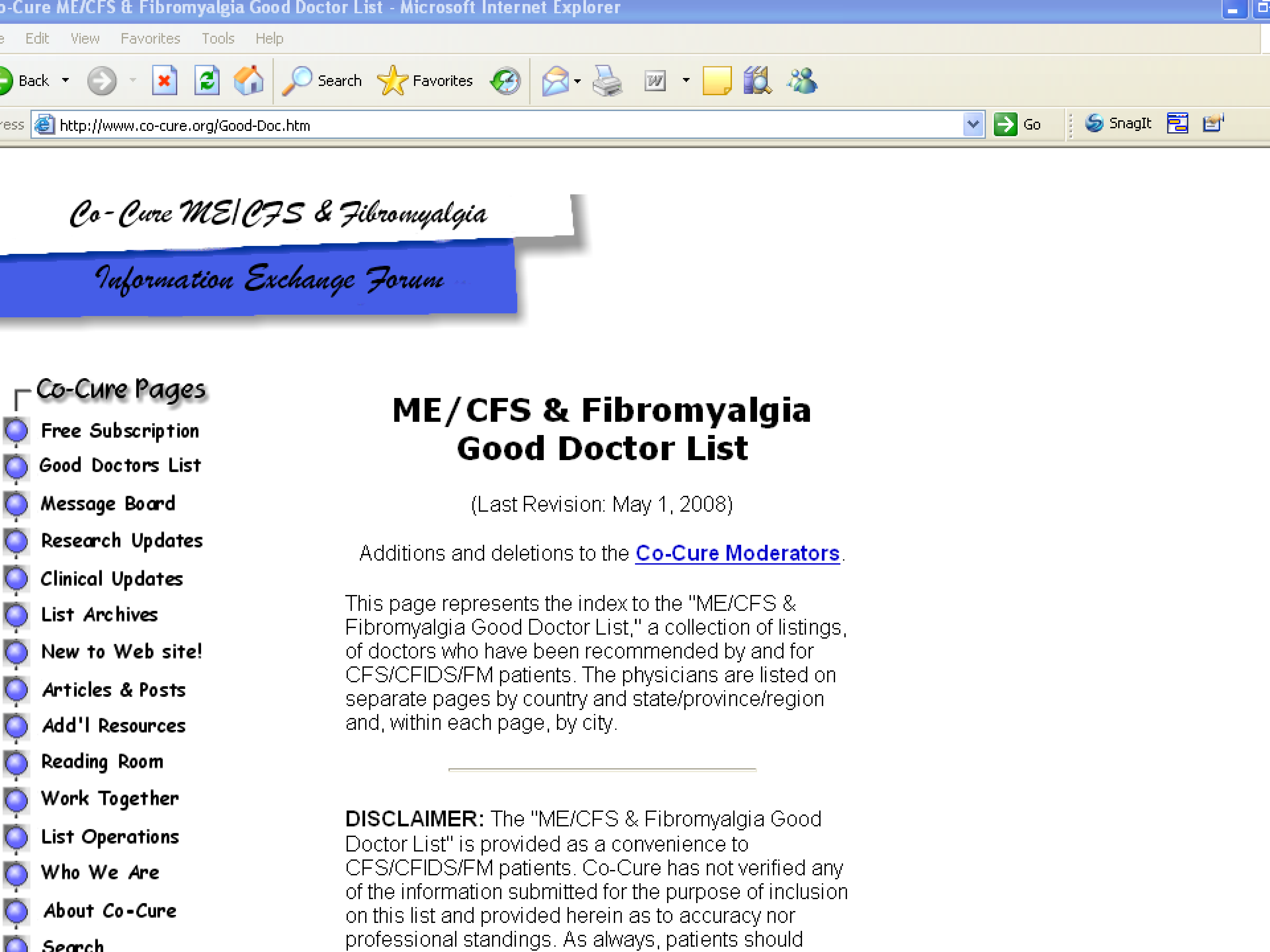
Congressional Activities:

Annual appropriations advocacy to stimulate research funding.

Participates in congressional advocacy for legislature.

Disseminates information with respect to advocacy and national issues.

Co-Cure ME/ CFS



ME/CFS & Fibromyalgia Good Doctor List

(Last Revision: May 1, 2008)

Additions and deletions to the Co-Cure Moderators.

This page represents the index to the "ME/CFS & Fibromyalgia Good Doctor List," a collection of listings, of doctors who have been recommended by and for CFS/CFIDS/FM patients. The physicians are listed on separate pages by country and state/province/region and, within each page, by city.

DISCLAIMER: The "ME/CFS & Fibromyalgia Good Doctor List" is provided as a convenience to CFS/CFIDS/FM patients. Co-Cure has not verified any of the information submitted for the purpose of inclusion on this list and provided herein as to accuracy nor professional standings. As always, patients should

Co-Cure ME/CFS and Fibromyalgia (Cooperate and Communicate for Cure).

Patient sponsored organization maintaining list of referral doctors, research updates, clinical updates, and educational information.

WHITTEMORE PETERSON INSTITUTE

Whittemore Peterson Institute For Neuro-Immune Disease

WHITTEMORE PETERSON
INSTITUTE FOR NEURO-IMMUNE DISEASE

EXECUTIVE TEAM:

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Medical Director: Daniel L. Peterson, MD
Research Director: Judy A. Mikovits, PhD
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WPI Rationale

- One in 300 US citizens suffers from ME/CFS
- One in 750 suffers from MS
- One in 158 boys suffers from autistism
- One in 150 suffers from fibromyalgia
- Neuro Immune diseases are on the rise

Our Mission

- To facilitate and advance patient care
- Research the pathophysiology of neuro-immune diseases
- Develop therapeutics, diagnostics and prevention strategies for this spectrum of diseases

A Unique “Center of Excellence” Model

- A comprehensive outpatient medical and translational research center dedicated to: patient care, basic research, education and drug development for a spectrum of neuro-immune diseases.

- A ‘First of its Kind” Institute dedicated to Neuro-Immune Disease. Integrating: patient treatment, basic and clinical research, and medical education.

The Center for Molecular Medicine

The CMM houses three unique entitites:

- University of Nevada Biomedical Research
- Whittemore Peterson Institute
- Nevada Cancer Institute

Integrative Mission:

To reveal the mechanisms of chronic diseases and to develop novel treatment strategies

- Patients go through extensive immune and neurological testing to determine the extent of their immune dysregulation and nervous system involvement. Brain scans determine levels of brain inflammation and rule out other diseases such as MS and cancer.

- Testing for pathogens such as human herpes viruses, fungi and bacteria determine the types of infections that are actively causing disease which leads to more effective treatment.

- Finally, a comprehensive treatment plan is written defining each patient's specific treatment protocol. Personnel will be on hand to discuss various legal, medical, nutritional and environmental issues that may relate to their new diagnosis. This protocol will guide the medical treatment of each patient whether they stay at the Institute or go back to their personal physician.

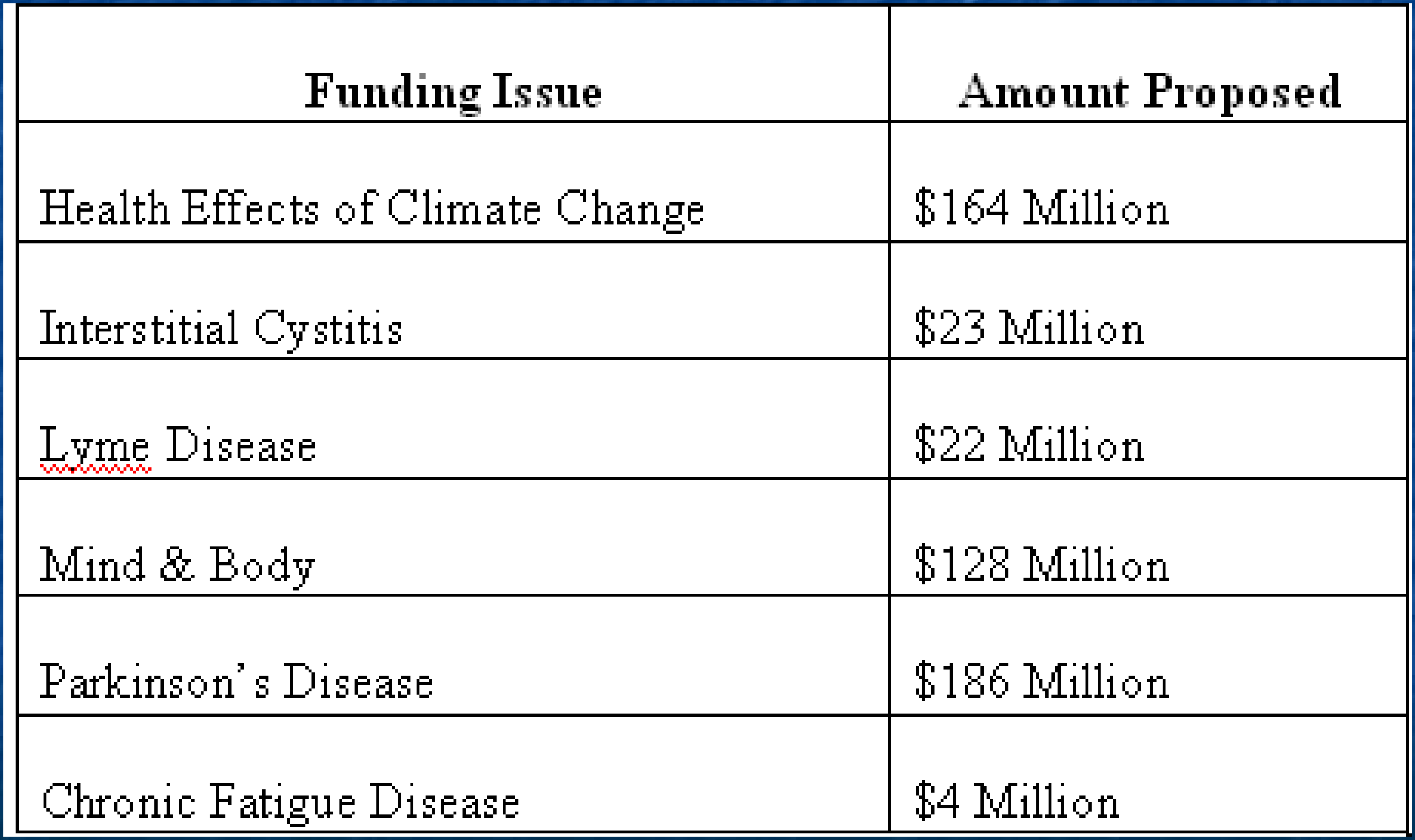
Current WPI Research

- Gene expression profiling on ME/CFS
- Virus expression profiling in CFS
- Clonal T cell receptor gamma rearrangements and MCL development
- Chromosomally integrated HHV6 (CI HHV6)
- Cytokine and proteomic profiles by antibody array

Major Problems

- Inadequate funding
- Uncoordinated efforts

NIH – Estimates of Funding for Various Diseases, Conditions, Research Areas



Funding Issue	Amount Proposed
Health Effects of Climate Change	$164 Million
Interstitial Cystitis	$23 Million
Lyme Disease	$22 Million
Mind & Body	$128 Million
Parkinson's Disease	$186 Million
Chronic Fatigue Disease	$4 Million

CLINICAL COMPONENTS

WHITTEMORE PETERSON
INSTITUTE FOR NEURO-IMMUNE DISEASE

Whittemore Peterson
Institute For Neuro-Immune Disease

TREATMENT:

- Complex diseases require a comprehensive plan. Often this plan includes using a combination of drugs that will modulate a dysfunctional immune system, suppress viral or other pathogens, and address nutritional deficiencies and hormonal imbalances.

EDUCATION:

- Due to the complexity and serious nature of these diseases, patients require doctors with special skills and knowledge in immunology, neurology and virology. An eductional concept to develop specialists in neuro-immune diseases through a systematic educational process that will include medical education, student interns, graduate internships and fellowships in this area of medicine is under development

Current Funding

- 5 million dollars: Private pledge
- 4.5 million dollars: Nevada State Legislative support
- 1.5 million dollars: Federal government (research and clinical equipment)
- 1 million dollars: Private donations

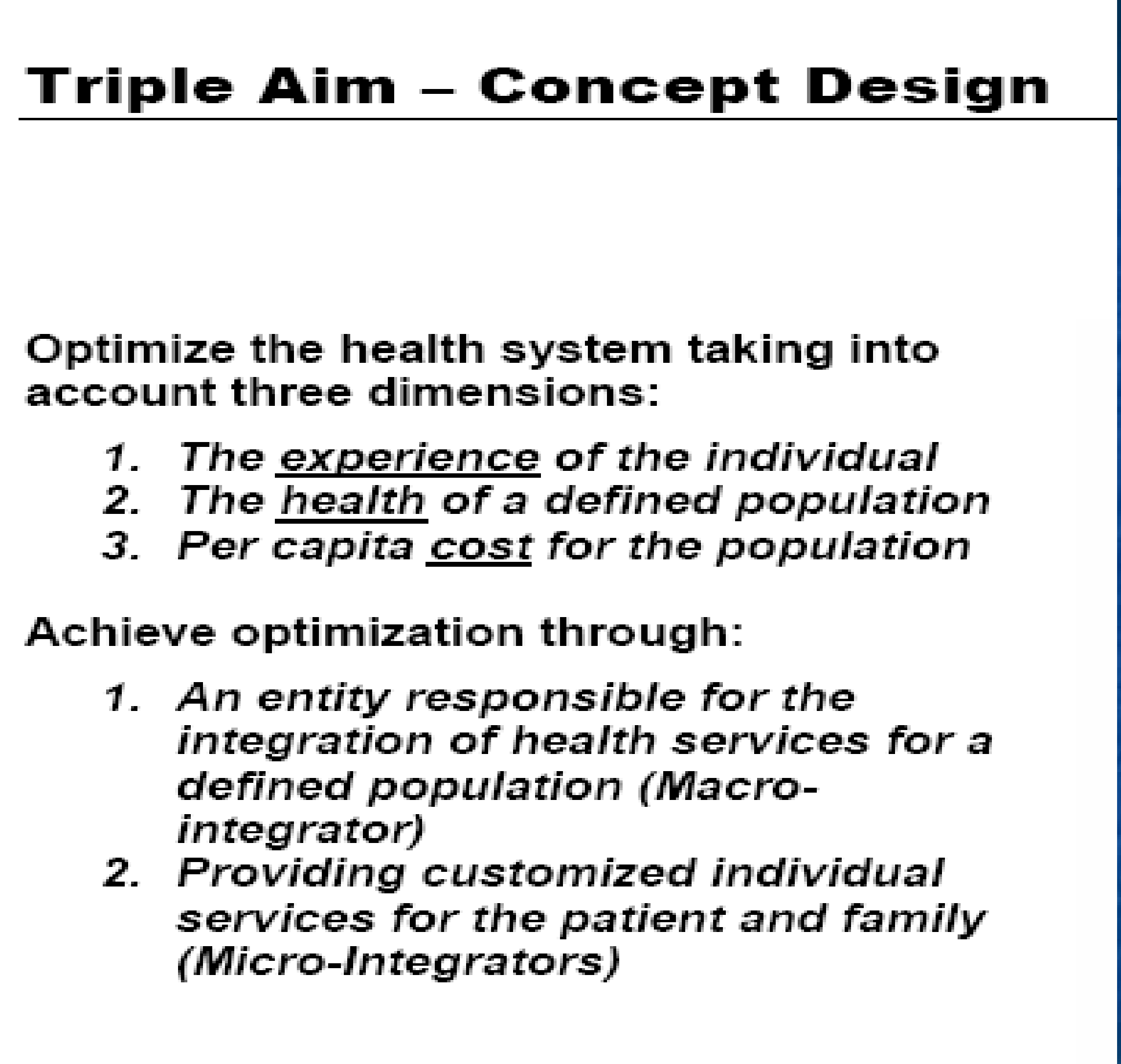
North and East Elevations

WHITTEMORE PETERSON
INSTITUTE FOR NEURO-IMMUNE DISEASE

WPI/CMM Site Plan

WHITTEMORE PETERSON
INSTITUTE FOR NEURO-IMMUNE DISEASE

AIM RESEARCH



Triple Aim – Concept Design

Optimize the health system taking into account three dimensions:

1. *The experience of the individual*
2. *The health of a defined population*
3. *Per capita cost for the population*

Achieve optimization through:

1. *An entity responsible for the integration of health services for a defined population (Macro-integrator)*
2. *Providing customized individual services for the patient and family (Micro-Integrators)*

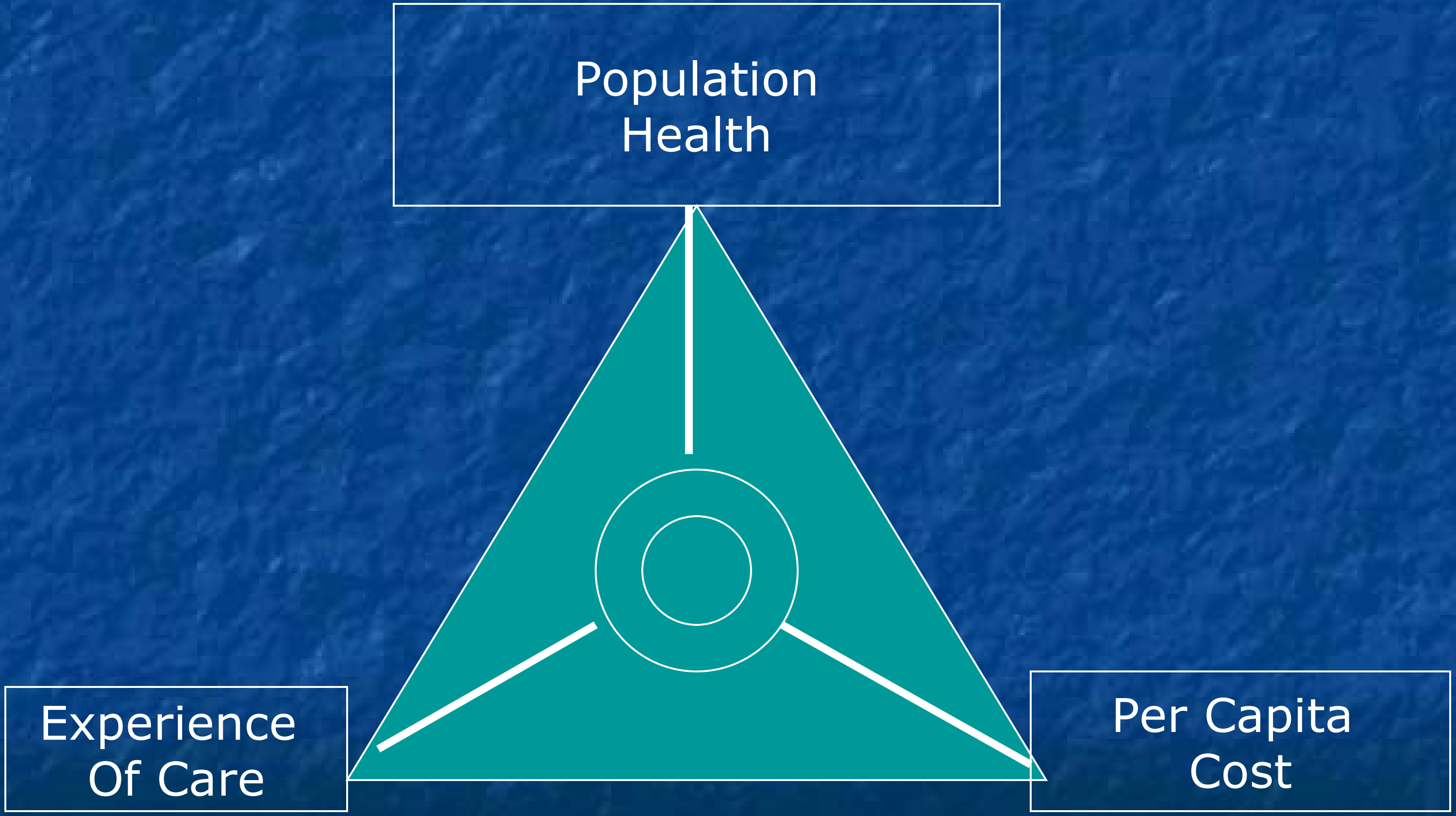
Institute For Healthcare Improvement

Aim model for revision of health care in the United States focusing on patient-oriented and directed health care to achieve conceptual model. Requires extrapolation, requires emphasis on patient as primary consumer, recipient and benefactor from health care.

I. Model must extrapolate to society at large

III. Model must be cost effective

The "Triple Aim"



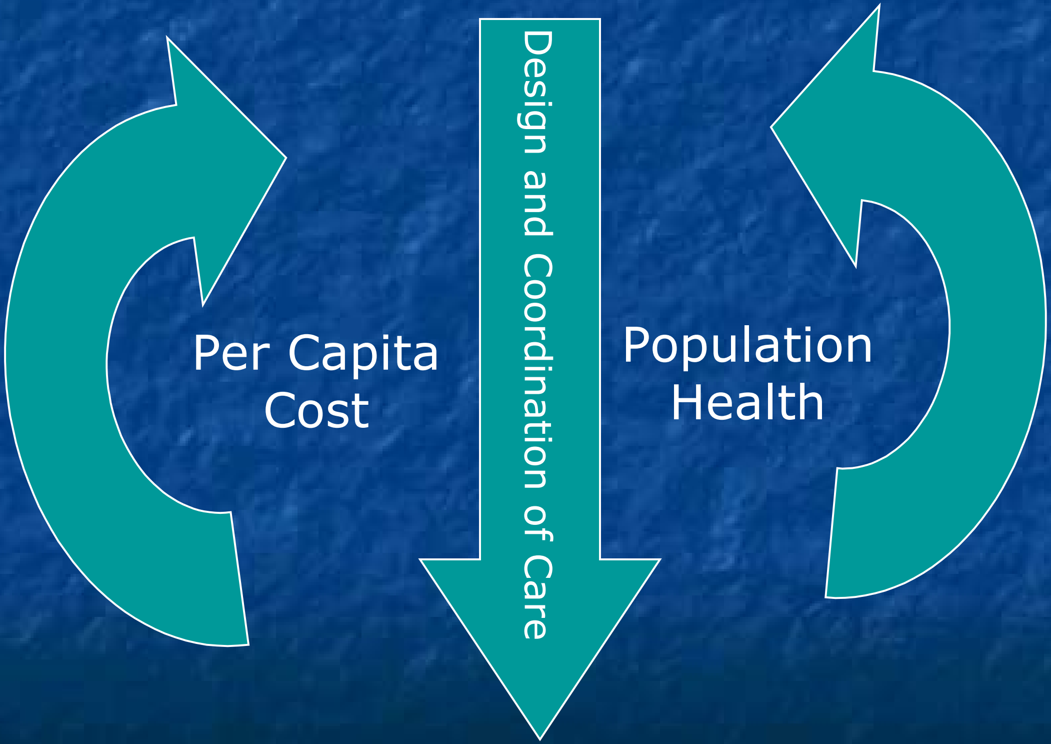
Population Health

Experience Of Care

Per Capita Cost

Triple Aim Model
Can We Begin with the Individual and Scale Up?

Act with the Individual and Family
Learn from the Population



Design and Coordination of Care

Per Capita Cost

Population Health

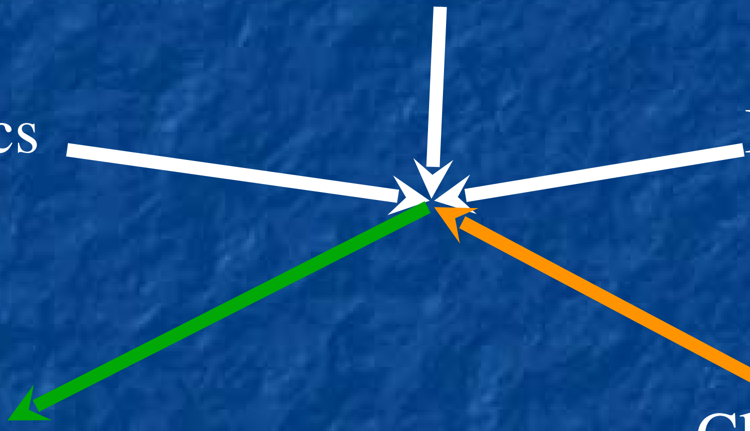
Individual Experience

INFORMATICS

Overview of Informatics

- Applications
  - Host-response signatures
  - Informatics-based surveillance
  - Clinical trials and therapeutic monitoring
  - Utilizing large-scale databases and genomic nosologies

Informatics new paradigm: Convergence



Databases

Genomics

Biotechnology

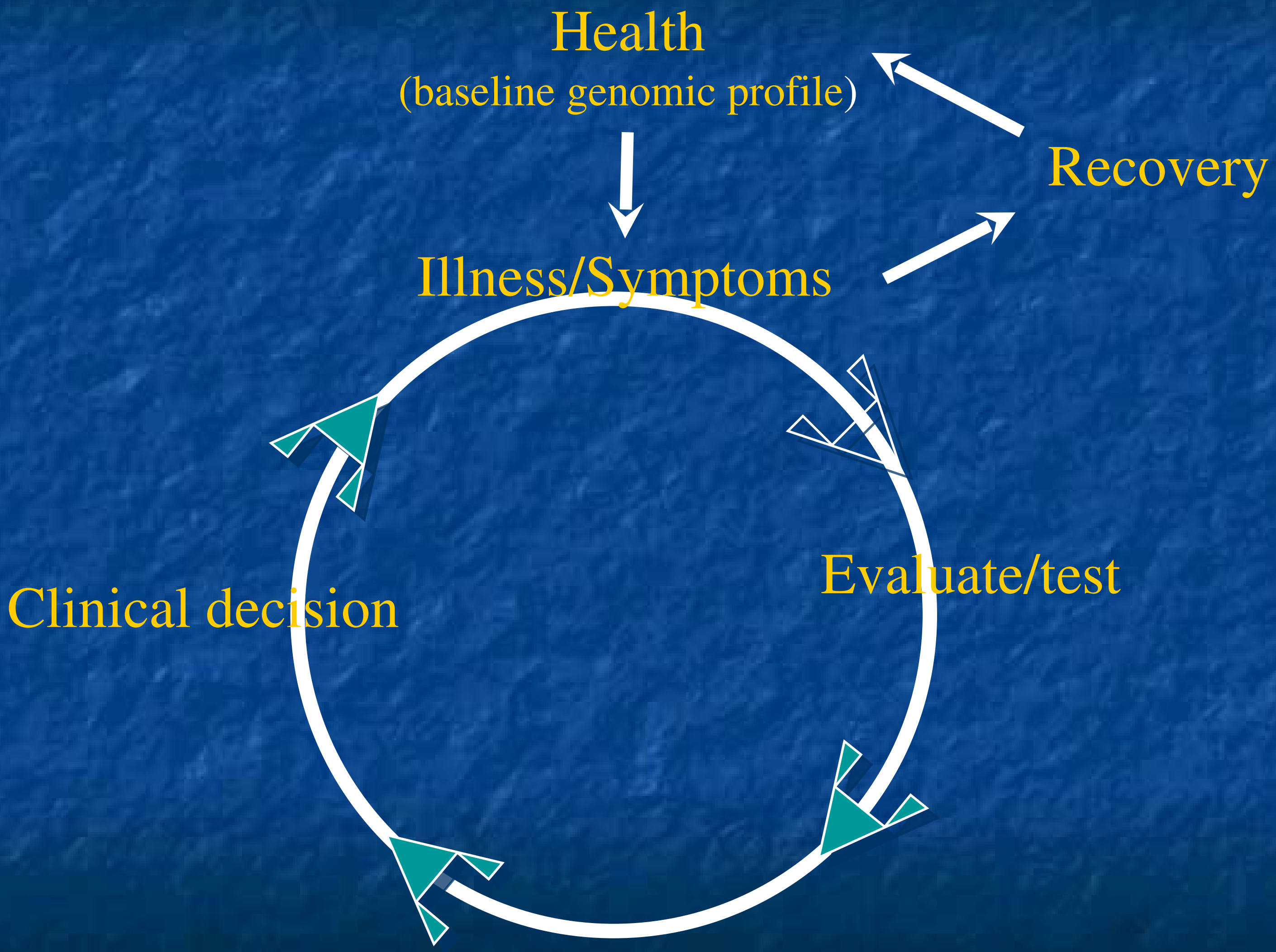
Individualized
diagnostics and therapy

Clinical Medicine

Mining Summary

- Large scale population screening is possible even between heterogeneous health care systems
- Direct provider feedback is a highly effective mechanism for tailoring abx treatment
- Microbial resistance rate reduction requires inter-system screening
- Best interventions remain to be proven

Clinical Care Paradigm



Health
(baseline genomic profile)

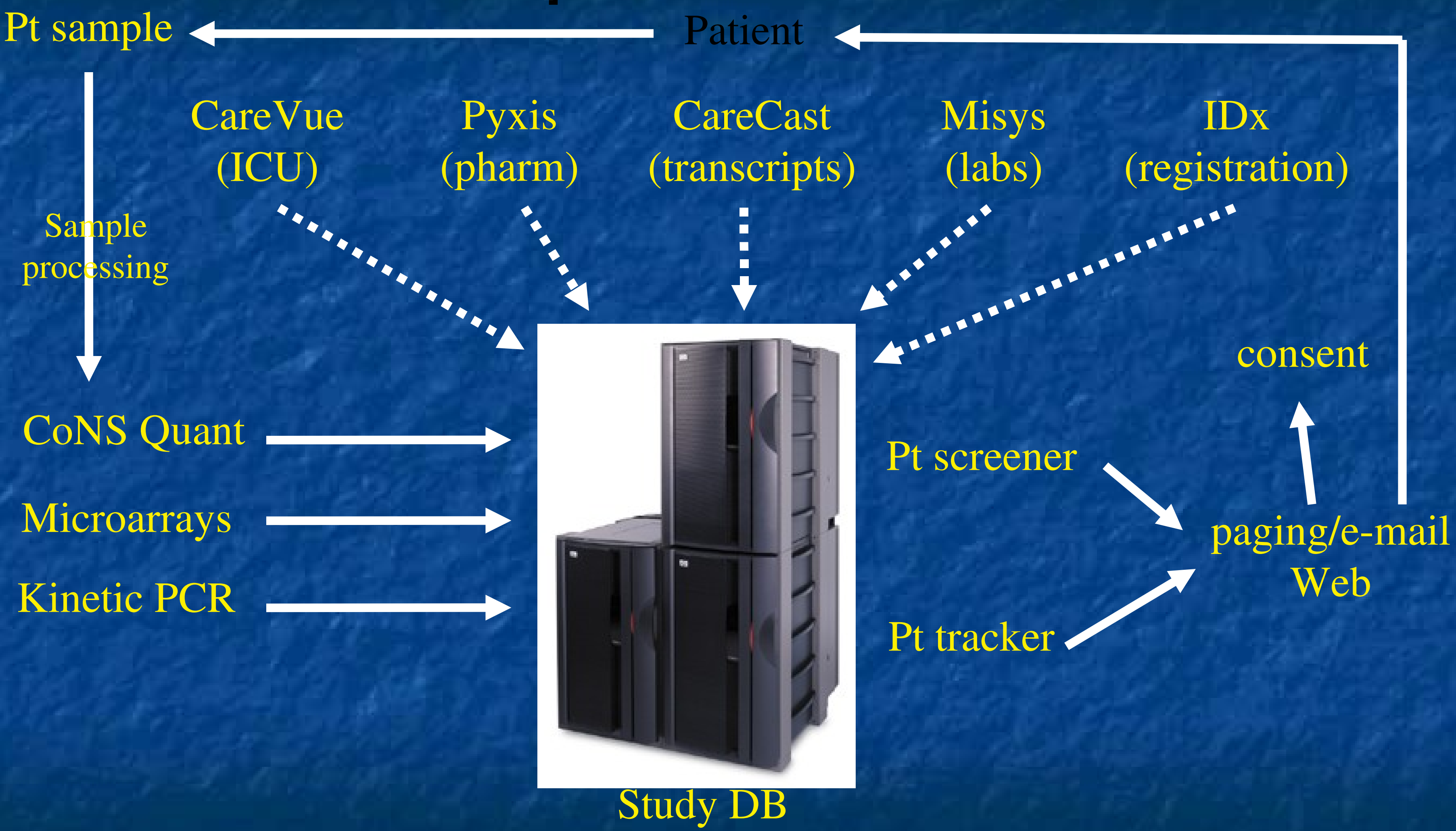
Recovery

Illness/Symptoms

Evaluate/test

Clinical decision

Host-response Data Flow



Pt sample

Patient

Sample processing

CareVue (ICU)

Pyxis (pharm)

CareCast (transcripts)

Misys (labs)

IDx (registration)

consent

CoNS Quant

Microarrays

Kinetic PCR

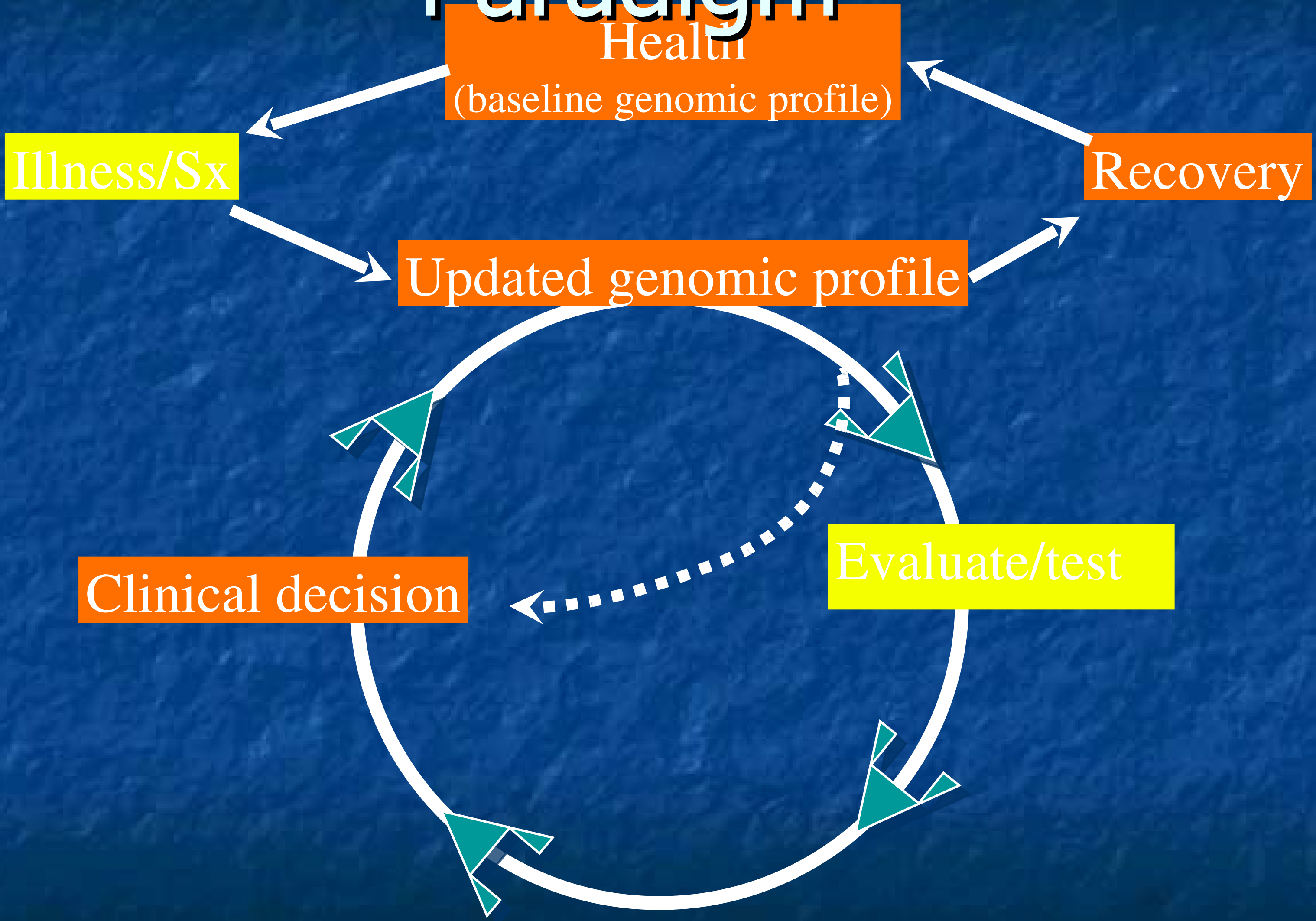
Pt screener

paging/e-mail
Web

Pt tracker

Study DB

Improved Clinical Care Paradigm



Health
(baseline genomic profile)

Illness/Sx

Recovery

Updated genomic profile

Clinical decision

Evaluate/test

- We welcome collaboration with similar institutes, health care organizations, and government bodies internationally including Sweden and the Scandinavian countries.