ME/CFS Overview and History

Media Articles - Overview

April 23, 2014
The Last Word on Nothing
Why Are Doctors Skeptical and Unhelpful About Chronic Fatigue Syndrome?
By Julie Rehmeyer


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January 30, 2014
NPR
Does Chronic Fatigue Syndrome Need a New Name?
By Miriam E. Tucker


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January 27, 2014
BuzzFeed
How “Chronic Fatigue Syndrome” Obscures a Serious Illness
By David Tuller

http://www.buzzfeed.com/davidtuller/chronic-fatigue-syndrome

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January 3, 2014
Al Jazeera America
Chronic Fatigue Syndrome Activists Launch “Uprising” From Their Beds
By Nicole Grether


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November 20, 2013
Huffington Post
The Most Prevalent and Devastating Disease Your Doctor Has Never Heard Of
By Jennifer Brea

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July 27, 2013
Yahoo Voices
Chronic Fatigue Syndrome: More Than Just Being Fatigued
By Darcy Chappel


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All In The Mind? Why Critics Are Wrong To Deny The Existence of Chronic Fatigue
By Sonia Poulton

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January 12, 2012
Discover Magazine
A Tale of Two Viruses: Why AIDS Was Pinned to HIV, But Chronic Fatigue Remains a Mystery
By Vincent Racaniello


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December 2, 2011
Slate
Stolen Notebooks and a Biochemist In Chains
By Julie Rehmeyer


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November 23, 2011
Virology Blog
Chronic Fatigue Syndrome and the CDC: A Long, Tangled Tale
By David Tuller


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March 7, 2011
The Wall Street Journal
Health Blog
Chronic Fatigue Syndrome in the Spotlight
By Katherine Hobson


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March 5, 2011
Wall Street Journal
The Puzzle of Chronic Fatigue Syndrome
By Amy Dockser Marcus

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March 4, 2011
The Wall Street Journal
Video: Rural NY Town Become Chronic Fatigue Laboratory


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November 28, 2010
Newsweek
Validation in a Virus?
By Claudia Kalb


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May 21, 2010
Mail & Guardian (South Africa)
The Trouble with ME -- No End to a Tiring Debate
by Sarah Boseley

http://mg.co.za/article/2010-05-21-the-trouble-with-me-no-end-to-a-tiring-debate

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September 24, 2009
ABC News
Feeling Chronically Fatigued?
By Dr. Donnica Moore

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July 17, 2007
The New York Times
Chronic Fatigue No Longer Seen as “Yuppie Flu”
By David Tuller


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PrimeTime Live
CFS and the CDC’s Failure to Respond
By Nancy Snyderman

http://www.youtube.com/watch?v=A0x9_Q8qbo&feature=share

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Chronic Fatigue Syndrome - 2011
Jose G. Montoya, M.D.
Associate Professor of Medicine
Division of Infectious Diseases
Stanford University, Palo Alto, California
http://www.youtube.com/watch?v=Riybtt6SChU

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CFS Update
Stockholm Presentation - 2011
Daniel Peterson, M.D.
Incline Village, Nevada

http://vimeo.com/30430680

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CFS Update
North Carolina Presentation - 2013
Paul Cheney, M.D.
Asheville, North Carolina


**Media Articles - Osler's Web**

Osler’s Web is a comprehensive history of the emergence of the disease that the CDC ended up naming “Chronic Fatigue Syndrome.” It covers the time period between 1980 and 1996.

Hillary Johnson
Osler’s Web: Inside the Labyrinth of the Chronic Fatigue Syndrome Epidemic
Backinprint.com
2006

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National CFIDS Foundation
Hillary Johnson Talks About Chronic Fatigue Syndrome and Her New Book, Osler’s Web

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Myalgic Encephalomyelitis Society of America
Chronic Obfuscation
By Maryann Spurgin

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April 21, 1996
The New York Times
Feeling Rotten
Osler’s Web: Inside the Labyrinth of Chronic Fatigue Syndrome
By Philip J. Hilts


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What If They Found a Disease and Nobody Cared? ‘Yuppie Flu’ Victim Traces How Researchers Dismissed the Debilitating Syndrome
By David Perlman

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Boston Globe
Behind the Puzzle of Chronic Fatigue
By Michael Kenney

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+Kenney%2C+Globe+Staff&pub=Boston+Globe+
(pre-1997+Fulltext)&edition=&startpage=87&desc=Behind+the+puzzle+of+chronic
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The New York Times
Genetics and Stress are Found Linked to Fatigue Disorder
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syndrome%22&st=nyt

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San Francisco Chronicle  
From Skepticism to Science:  
After 20 Years, Chronic Fatigue Syndrome May Finally Be Getting Some Respect and Cutting-Edge Science  
By Dorothy Wall  
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For Chronic Fatigue, Placebos Fail the Test  
By Nicholas Bakalar  

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Time  
Neurotic or Misunderstood?  
By Daniel Williams  
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San Francisco Chronicle  
New Research Debunks Chronic Fatigue Syndrome
By Dorothy Wall

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February 21, 2000
The New York Times
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A Postmodern Plague
By Howard W. French


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March 16, 1999
The New York Times
When Symptoms are Obvious, But Cause is Not
By Jane E. Brody

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The New York Times
Personal Health
By Jane E. Brody


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October 21, 1994
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Clearing Up Confusion on Fatigue Syndrome
By Jane E. Brody


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December 4, 1990
The New York Times
Chronic Fatigue Syndrome Finally Gets Some Respect
By Lawrence K. Altman


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November 19, 1990
The Baltimore Sun
“Yuppie Flu” Tied To Immune System: Blood Test May Identify Chronic Fatigue Syndrome


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November 12, 1990
Newsweek
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July 28, 1988
The New York Times
Health
Personal Health
By Jane E. Brody


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July 28, 1987
The New York Times
Fatigue “Virus” Has Experts More Baffled and Skeptical Than Ever
By Philip M. Boffey


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June 7, 1986
Los Angeles Times
160 Victims at Lake Tahoe: Chronic Flu-Like Illness a Medical Mystery Story
By Robert Steinbrook


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Charlene, a 35-year-old married mother of two, wept with relief when she learned she had chronic Epstein-Barr virus (CEBV). “I’d been sick off and on for over two years and no one could tell me what was wrong. One doctor thought I had hepatitis, another sent me for an eye test, still another prescribed tranquilizers and suggested counseling. At last what had been plaguing me had a name.”

Yet her diagnosis, like that of thousands who claim to suffer from CEBV, has generated a tremendous amount of controversy within the medical community. Some doctors believe CEBV is a genuine ailment, while others regard it as a buzz word for hypochondria. Still others consider it a catch-all diagnosis for symptoms that can’t be explained, as had been the case with low blood sugar, iron-poor blood, and thyroid disorders in the past.

According to medical definitions, Epstein-Barr is a herpes virus, similar to chicken pox, genital lesions and cold sores. It is closely related to infectious mononucleosis in the United States and Western Europe, Burkitt’s lymphoma (a tumor of the jaw) in Africa, and cancer of the nose and mouth in Asia.

“The Epstein-Barr virus is present in the white blood cells in over 90 percent of the American population,” explains Dr. Ronald Glaser, chairman of the Ohio State University Department of Medical Microbiology and Immunology in Columbus. The virus is believed to be transmitted by saliva. “Usually it remains dormant until the immune system weakens, causing it to proliferate.”

And unlike mono, which strikes during adolescence and college years, CEBV affects adults. “During the first three to six weeks of incubation, patients show few or no symptoms,” states Dr. James Jones of the National Jewish Center for Immunology and
Respiratory Medicine in Denver. “The illness takes hold, may worsen, then reaches a plateau, waxing and waning at seemingly unpredictable intervals.”

Victims of the disease, dubbed the “yuppie flu,” are primarily women, health professionals and high-level executives in their 30s and 40s. The symptoms, they say, range from partially to completely disabling, cutting them off from their jobs, recreational activities and loved ones.

“The disease took over my life,” Charlene asserts. “I ran a counseling program for 13 years and had to quit. Whenever I have had spells, I’m forced to hire a babysitter to help care for my kids. I love my career and my family, but I’m too sick to handle them full-time.”

Also nicknamed the “Raggedy Ann Syndrome” because sufferers feel as if they’ve had the stuffing knocked out of them, CEBV first received national attention in 1985 after an outbreak of a mysterious illness in Incline Village, near Lake Tahoe.

According to an account in Hippocrates magazine, two local doctors, Paul Cheney and Dan Peterson, began seeing an uncommonly large number of patients with persistent, flu-like symptoms.

The patients tested negatively for mono, so Cheney and Peterson did some research, coming upon articles on CEBV in a medical journal. They then ordered a recently developed diagnostic test from a commercial laboratory. The results showed high levels of antibodies to the virus in sufferers. Thus, a syndrome was born -- or perhaps reborn.

Because the outbreak appeared to be clustered in the Lake Tahoe area, the Centers for Disease Control (CDC) sent two researchers to investigate. Their highly publicized report in May 1986 questioned not only the validity of the lab test but pointed out that healthy people also had high antibody counts.

The findings led many physicians to assume that CEBV was a fraud, even though more and more cases kept surfacing. “There’s a large element of ‘me, too’ in this,” says Ohio State’s Glaser. “Once news of a disease reaches the media, people start thinking they have it if they’re tired or depressed.”

However, “not everyone who is sick is imagining this,” he insists. “Many are truly ill. They have clinical symptoms to prove it. And well-adjusted people who lead vigorous,
active lives don’t suddenly become too ill to lift their heads. Something is out there. We just don’t know exactly what.”

The CDC is currently compiling a standard clinical diagnosis for Chronic Fatigue Syndrome for use by all doctors. “We’ve had similar outbreaks since the 1930s,” explains Carlos Lopez, chief of the Herpes-Virus Division there. “The scientific literature has described something like it for the past 50 years.” It has also been known as Royal Free disease, epidemic neuromyasthema and myalgic encephalomyelitis.

Lopez hopes the definition will serve as a unifying force in identifying the syndrome. “Our investigators were looking at one specific virus, Epstein-Barr (in Incline Village). What we’re now dealing with is a series of symptoms, possibly resulting from a number of viruses.”

Other causes might be infectious agents, or the body’s inability to respond to infection, toxic materials, stress or other psychological reactions, or a combination of these factors.

And research is beginning to uncover a few things. Dr. Robert Gallo of the National Institutes of Health, who also first identified the AIDS virus, recently discovered a new herpes virus (HBLV) which may be involved in Chronic Fatigue. Researchers are currently trying to isolate HBLV in patients who already have the syndrome.

Preliminary results of a study by David Purtilo of the University of Nebraska Medical Center link Chronic Fatigue with viruses known to cause sore throat (adenoviruses). And Ohio State’s Glaser is studying diagnostic “markers” associated with the Epstein-Barr virus and nasopharygeal (nasal) carcinoma. He hopes to find an antibody that will serve as a common denominator in diagnosing some cases of the syndrome.

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May 7, 1987
Sierra Sun
Study on Fatigue Illness Determined "Inconclusive"
By Jean Lamming
Federal medical researchers who studied the chronic fatigue outbreak in Incline Village in 1985 published a report on their work in a national professional journal May 1.

The Centers for Disease Control (CDC) epidemiologists wrote that their study of 134 of North Shore and Truckee patients revealed that Epstein-Barr virus is not necessarily the culprit in the fatigue syndrome. The report, however, falls far short of providing any conclusive answers for victims of the fatigue illness.

Doctors Gary Holmes and Jon Kaplan report in a five page lead story in The Journal of the American Medical Association today, that other known and unknown viruses should be suspected.

The CDC investigators also report that the tests used to diagnose the syndrome in the practices of Incline internists Paul Cheney and Daniel Peterson yield inconclusive information.

However, the journal report, which circulates to 300,000 physicians, does not pioneer any new information, according to one of the doctors who asked the investigators to come to Lake Tahoe.

"It's not very useful to me," Peterson said Wednesday. "It's two years old. It doesn't say anything," he said.

Epstein-Barr virus, (EBV) was the first agent the Incline Village internists suspected when cases of the mysterious fatigue started to mount in their practice in 1985.

EBV, a virus in the herpes family that causes mononucleosis, had been linked to cases characterized by chronic-fatigue, sore throats, aches, and other cold-like symptoms by a national researcher that year.

Today it is implicated in new reports across the country as the root of an illness that has emerged as a nationwide phenomenon in the last year.

But by 1986, Peterson and Cheney had decided that a new virus or bacterial agent was probably involved or totally to blame.

In October of 1986 they joined forces with the National Cancer Institute (NCI) to prove that a new virus in the herpes family, HBLV, was the cause. AIDS co-discoverer
Dr. Robert Gallo and his NCS lab had isolated a new herpesvirus HBLV, in 1986. Lake Tahoe patients had tested positive for it.

Peterson said he expects a more provocative report on the Lake Tahoe and Truckee cases and the illness to be published this month, with his name on the list of authors.

Packaged with the CDC report in The Journal of the American Medical Association today was a report on chronic fatigue by Harvard researchers who have been working with Cheney, Peterson, the NCI and others on cases from Lake Tahoe and other areas. That article also reports that EBV cannot be said to cause the chronic fatigue. But results of the Harvard study, which was set at Brigham and Women's Hospital in Boston, show that a mild fatigue syndrome could be common in medical practices.

The goal of the study was to determine the number of patients in a large practice that complained of chronic fatigue.

Doctors Dedra Buchwald, John Sullivan and Anthony Komaroff found 21% of the 500 unselected patients they studied suffered from an illness similar to what has been labeled chronic EBV or CEBV. However, they, like Holmes and Kaplan, found that there was no evidence to implicate EBV as the cause and that tests that measure the immune reaction to EBV infection had to be carefully interpreted.

In fact the Harvard article reports that the test results could point to an infection by another virus that also reactivated a latent EBV infection.

Most people carry EBV in their immune system by the time they are teenagers.

The CDC also reports that Holmes and Kaplan tried to define the scope of the North Shore outbreak. Because there was a high proportion of patients who lived outside of Incline, the total number of patients treated reflected an epidemic in Incline Village when in reality the patient profile entailed a much larger geographic area.

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March 6, 1986
Sierra Sun
Doctors Admit to Mystery of Malady
No new answers were revealed concerning the so-called Tahoe malady during a February 27 panel discussion at Sierra Nevada College, Incline Village.

Drs. Paul Cheney and Anthony Komaroff presented a synopsis of the disease and the results of the week-long studies by three doctors from Harvard University.

Komaroff and his colleagues, Drs. Dedra Buchwald and Nick Fiebach, spent the past week in Incline Village poring over patients files in an attempt to locate correlating factors.

What has been most noticeable about the disease is that it seems to occur within certain circles of people, although many individuals have it who do not associate with other people affected by it.

The clusters have been detected in two groups of teachers, one group from Tahoe-Truckee High school and the other from North Tahoe High School, a local girls basketball team; and a group of Hyatt casino employees. Cheney said that the people contracted the disease at least a year ago, and that no new clusters have been found.

For whatever reasons Incline High School has been relatively unaffected by it; there have been few complaints from the teachers there.

Cheney said he thinks reasons Incline Village High has not been affected as much as the other schools are its circulating air system, large windows and overall good ventilation and airiness, as compared to internal circulation. The conditions of the buildings with poor ventilation is referred to by the doctors as the sick building syndrome.

Although no one can confirm why some contract the Epstein-Barr virus and others don't, the doctors agree on a few points.

First, they believe it is not really a new disease but one reactivated after lying dormant for years. Both believe that 90 per cent of all people come in contact with this disease at some point of their lives, usually before the age of 10.

When the virus is first contracted it may or may not affect a person. The effects could show up as acute mononucleosis or a cold or remain latent for the duration.
The biggest question facing the doctors is what reactivates the disease.

Komaroff said the thinks the activator is some other virus that has passed through a community of people.

Other possibilities mentioned include household items such as tung oil, which is used in a variety of glues and varnishes, and certain foods such as vinegar from China that has been contaminated with tung oil.

Basically, both doctors believe another virus triggers the EBV and environmental conditions may only amplify the situation rather than cause it.

As far as the degree of contagion is concerned, although it is contagious in some capacity, Cheney said he didn't think it was highly communicable or otherwise he would have it by now.

Despite the length of the illness and the despair that goes with being ill for a long period, there seems to be some hope.

Very few new cases have been recorded in Dr Cheney's and Dr Dan Peterson's offices. And some people seem to have recovered from it, although, as Komaroff warned, it might seem to have gone away and then come back again.

Both doctors agreed that the best way to treat the disease is to keep an optimistic attitude in spite of its antagonistic nature, and that those who have tended to be over-stressed and therefore ill should pace themselves better.

Although no one can safely say that a typical patient exists, Komaroff said, most of the patients are women between 25 and 40, have been athletic or in good health in the past, and seem to be in higher economic standing.

But the Tahoe malady doesn't seem to follow this pattern, as the highest number of people affected by it have been the basketball team, teachers and casino workers.

Cheney said that the degree of infection is much higher that the number of people sick with it because the spread of it appears to be over.

"The threat to public health has been diminished to almost near zero." Cheney said during a telephone interview later.
Cheney said that through the three types of tests that have been conducted there is strong evidence of the presence of Epstein-Barr virus. The EBV infection is not necessarily mono itself, although it can be a contributor to the common strain of mononucleosis.

"The question of this virus is the primary problem or the secondary problem." Cheney said.

"If it's primary then maybe it's because it's a new strain. If it's secondary the maybe we can find out what the primary problem is," he said. "If it's secondary we have to be more cautious. That's why Dr. Komaroff is here."

Cheney said the tests used to detect the Epstein-Barr virus include sample tissues of patients and serologies. Also a new test has found antibodies that are directed toward EBV in a patients blood.

Komaroff and his colleagues returned to Boston this week with samples, which they intend to study using the new test.

Their findings will be released in a few months. Until then all doctors involved will be searching for the answer to whether the EBV is a new virus or a reactivated virus, yet Cheney believes the patients who already have the disease are not facing any new complications.

Copyright 1986, Sierra Sun

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December 20, 1985  
North Lake Tahoe Bonanza  
Basic Symptoms May Be Sign of Epstein-Barr Virus

SUMMARY: Headaches, Muscle spasms, Swollen glands, Slight fever, Dizziness. The symptoms of one of the least diagnosed but still widespread illnesses begin here and add up to chronic Epstein-Barr virus.

Most people are exposed when they are children to this herpesvirus that hides in the white blood cells. The symptoms are similar to those of mononucleosis, but the
diagnosis is psychologically important to its sufferers. Though research is being done and doctors are hopeful of a cure, the victims turn for now to self-medication.

Fifteen years ago, W.H. thought she was coming down with something going around. Her throat was sore, her arms felt bruised and she was tired. Really, really tired. But then, she had been working 12-hour days as a social worker, and she knew she was run-down.

After about a month of a growing list of symptoms - headaches, muscle spasms, swollen glands, slight fever, dizziness - she went to her first doctor. He told her it was just the flu, and she should take it easy.

She went back to see him, a month later, still complaining. "But they (the symptoms) were worse, you know, I was unable to get out of bed because my muscles were so weak." she says. And she had some numbness around her face and in her fingers. This time the doctor said it was probably stress. She asked him to run tests. He ran tests, and he said she was as healthy as an ox. And she went to another doctor.

And another doctor, and another. She couldn't concentrate well, and she was so tired. "I was getting real depressed." she says.

Generally she felt like leftover pizza. She quit her job and stayed in bed. "There wasn't one doctor that whole time who did anything more than pat me on the head, inferring it was psychosomatic." Finally, two years ago, W.H. was diagnosed as having chronic Epstein-Barr virus.

There are stories of sufferers who have been placed in mental institutions or who have tried suicide.

One young woman was diagnosed by psychiatrists as "a manipulative child" after she told her parents she was too tired to leave her bed. On the psychiatrist's advice, the girl was forced to go to school. She was found in the street, asleep in the pouring rain.

Even if Epstein-Barr virus is diagnosed, there is no cure, and currently no medically accepted treatment. Ninety percent of those who get it have it for life.

Epstein-Barr is a herpesvirus that hides in the white blood cells of the body, suppressing the immune system when activated. Although there is "no evidence that this disease leads to a more serious illness." says Dr. James Brodsky of Chevy Chase, Md. it is
associated with Burkitt’s lymphoma, nasopharyngeal carcinoma, lupus and rheumatological arthritis.

To date, most doctors are not knowledgeable enough to look for it, and most laboratories are not sophisticated enough to detect it. Because the disease is seldom diagnosed, it is considered extremely rare, although some researchers believe there may be as many Epstein-Barr sufferers as there are people with multiple sclerosis.

"The patter we connect with this virus is that of mono." says Dr. James Jones of the National Jewish Center for Immunology and Respiratory Disease in Denver. The disease's symptoms have been misdiagnosed as infectious mononucleosis, except that mono is considered a short-term, nonrecurring illness. When fatigue, swollen glands and muscle aches persist in the Epstein-Barr virus patients, the physicians treating these persons for mono either are dumbfounded by the symptoms' longevity or consider the disease psychosomatic. As early as 1948, Dr. Raphael Issacs of New York wrote that 25 of his patients had symptoms for infectious mononucleosis for more than a year. Not until 20 years later was the virus re-examined by Drs Werner and Gertrude Henle of Philadelphia.

The mono connection was not gratuitous. Many of the people with the virus have had mono. The antibody test that finally was developed, thanks to the Henles, measures the active Epstein-Barr virus in the blood.

Most people are infected with the virus - which mimics a case of the flu or a cold - as children and recover from it. The virus then lies in the body, held in check by the immune system.

Most standard blood samples will contain a measure of the virus. But for those whose immune system for unknown reasons has proved to be less than efficient in checking the virus, these antibody levels increase.

But the antibody test is not foolproof for identifying all persons with the disease. "I'm pretty sure we don't have a good test for all people," says Dr. Irena Brus of Beth Israel Hospital in New York.

For some, the disease comes and goes. For other, like W.H., it remains constant. There is some evidence that it gets less severe with time. Many of the symptoms may disappear. "I'm much better than I was," says W.H. "but, my God, I wouldn't wish what I
went through on anybody."
The fatigue "a pronounced, an unusual and nauseating fatigue," says Brus. In some persons, lasts a lifetime.

Epstein-Barr disease has been called the "yuppie flu" because it tends to afflict urban professionals older than 30, especially women. It is thought that this demographic profile exists because of the rash of infectious mononucleosis that has occurred in the past 20 years. In reality, "It's an extraordinary, ubiquitous disease," says Jones, one of the principal researchers into its treatment and possible cure.

Some victims get mono and just never get better. When these people go back to their doctors, their blood tests for mononucleosis are negative. But nothing else in their disease has changed. For those who have had mono years before an then get Epstein-Barr virus, the symptoms are similar. "Looking back on it now, " says W.H. whose spleen had been removed before the virus was diagnosed, "I practically gave the doctor the answer. I told him, 'The only time I ever felt this bad was when I had mononucleosis in 1968.'"

The diagnosis is psychologically important to the sufferers, especially those who have been undiagnosed for years. "Every doctor I went to in the last 10 years just rolled their eyes," says C.J., whose symptoms of sore throat, swollen glands and fatigue were cyclic, coming every fall.

The disease varies greatly from individual to individual. When E.A. became sick with hepatitis five years ago, it seemed to trigger the disease. "But I've gone through every possible symptom of it you can. I've had it all."

For five months of it, she says, "I couldn't talk, couldn't breathe, couldn't walk." Several sufferers had to quit their jobs, find part-time work or go on welfare. W.H went back to work part-time two years ago, when she began feeling better. "But I brought on my own relapse by doing too much," she says.

Jones says he believes "the depression is a primary part of the illness." Considering the chronic nature of the disease, the difficulty in ever getting diagnosed and its debilitation, that depression is a symptom is not surprising. "It isn't my own depression," says C.J. "You know how you can tell about your own body after you reach a certain age? I'll tell you what's depressing, though: feeling like I'm older than my grandmother. And she's dead."
Like infectious mononucleosis, the "kissing disease," the Epstein-Barr virus is carried in the saliva. But it's considered only moderately infectious. Theories on what triggers it range from genetic susceptibility to immunological abnormality.

One of the more interesting theories implicating tung oil, a furniture sealant. Tung oil, a rat poison in the Orient, is an active ingredient in paints, waxes, polyurethane, putty and caulk. In laboratory experiments, tung oil, a known carcinogen, has reactivated the latent virus.

D.E, who has had the virus chronically for two years, says, "I restored an old house, and somewhere in there I got mono and then this. I like the tung oil idea. I like it a lot better than thinking I'm genetically faulty."

Sherwyn Williams has agreed to look into the removal of tung oil from its products. Research to locate an effective treatment for the disease is being done at several institutions. At the National Institutes of Health in Bethesda Md, Dr. Stephen Straus is conducting a double-blind study using acyclovir, a drug proved effective against herpes simplex. Subjects in the study are given either the drug or a placebo and then monitored for improvement.

Another double-blind study using intramuscular doses of gamma globulin was done by Dr. Richard DuBois of Atlanta, who says the blood protein indicated the therapy was more effective than placebo. By next spring, results on acyclovir and intravenous gamma globulin should be available.

With no remedy in sight, many of the virus sufferers become self-medicators. W.H. calls herself "the home-remedy quack person," having read nearly everything in the years that she's had the disease. In the beginning, she says, bee pollen gave her some energy back. She tried megadoses of Vitamin C intravenously. Then she took the adrenal glands of baby pigs a couple of times a week. "That didn't help me, but it helped some people."

There's also something called the transfer factor, which is a blood product made of centrifuge-spun blood. W.H. has had the mercury removed from her teeth and replaced with gold on the chance that mercury poisoning has something to do with chronic Epstein-Barr virus.

There is optimism in the medical community about someday finding a vaccine for Epstein-Barr. "One of the crucial problems of finding a cure," says Brus, "is, Why do
some people have chronic Epstein-Barr virus? What makes the latency? Is it a change in the immune system? Is this virus an innocent virus? Until these questions are answered, we cannot find a cure unless by serendipity."

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Thursday, October 24, 1985
Tahoe World, Page 14A
At Least Six Were Affected: Truckee Teachers Recount "Malady"
By Barbara Barte

Irene Baker, one of about a dozen local teachers who have been diagnosed as having chronic mononucleosis, is exasperated with doctors who dispute the findings of the two Incline Village doctors who have diagnosed 90 local cases.

"I know that I'm sick and I think it's more than coincidence that five teachers who share the same prep period have the same symptoms," Baker said Tuesday.

She spent most of the summer in bed and has not been able to return to her teaching job at Tahoe-Truckee High School this year. Her daughter, Laura, was also sick but has gotten better, she said.

Baker said at least six other Truckee teachers -- Andy Antonucci, Gerry and Janice Kennedy, Karen and Michael Cosgriff, and Jan Showalter -- have similar symptoms and the same diagnosis, as do three North Tahoe High School teachers.

Symptoms are "fatigue and killer headaches, sore throat, swollen lymph nodes, pain in the spleen area and the inability to stand up for more than a short period of time," she said.

While she has all the above symptoms and most share the fatigue and bad headaches, not all have the other symptoms. Most were sick all summer, some have returned to teaching full- or only half-time, and some are still not able to work.

"Eventually, everyone ended up at Peterson and Cheney's office," she said, referring to Incline Village doctors Daniel Peterson and Paul Cheney, who have been criticized by other doctors for their chronic-mono diagnoses.
"I don't think Peterson and Cheney are off-base," said Baker, "and what bothers me is that these doctors who are being so critical haven't seen patients with these symptoms, or, if they have, they haven't listened to them.

"One teacher was told she just had an allergy, and she was so sick. Others are told they're depressed. I had gone to Peterson and recommended him to other teachers.

"Peterson and Cheney believed we were sick. That's why they got all these patients. All of us showed negative on a mono spot test, but not on an E-B panel." (See other story for a description of the controversial Epstein-Barr test)

Since becoming ill, Baker has been finding out what she can about chronic mononucleosis and has learned that there isn't much research on the disease.

She has learned, however, that she is not alone, as someone sent her a list of 200 names from a national support group.

Since reading a paper by a Wisconsin doctor who believes he had a latent mono virus reactivated by the toner in his copy machine, she wonders if two copy machines in the teachers room could be at fault.

Cheney says that certain drugs and chemicals can cause latent mono infection to become active again. So can other illnesses, such as cancer and rheumatoid arthritis.

In fact, he says, the tiredness associated with these diseases my be due to reactivated mono.

"Phorbol esters used in copy machine toner, the tung oil in many furniture polishes and in certain glues and varnishes and even in some houseplants may reactivate the mono virus that is latent in 90-percent of adults," says Cheney.

While this may be the cause of a few local cases, however, he says he is more inclined to believe a reactivation was triggered by another virus last winter.

"I wouldn't want people to go around unplugging their copy machines," he says. "If it is a common chemical, how come it caused problems this year and not last year? It was more likely a virus."
If reactivation is caused by a chemical, he said, "a lot would depend on the concentration, ventilation, and a lot of other variables."

Cheney agrees with Dr Gary Holmes, a viral-disease researcher from the Center for Disease Control in Atlanta who is investigating the Tahoe-Truckee cases, that chronic mono is not easily transmitted from person to person.

"Ninety percent of all adults are immune to it because we already have the latent virus," says Cheney, "but I believe that something happened last winter to reactivate the virus in many people."

He says that, because the virus that causes mono is a member of the same family as the herpes virus, a mono treatment is being studied using a new drug for herpes.

"Results are still pending but may be in by mid-winter," says Cheney.

Although the CDC researcher who investigated Cheney and Peterson's findings says he doesn't believe there is an outbreak of chronic mono in the area (see story) and other local doctors also dispute the claims, Cheney says he is convinced at least 90 local people had a mono virus reactivated last winter.

He has seen no new cases since late summer and says "This thing has a beginning, a middle, and an end."

Irene Baker and some other locals are still waiting for an end to their illness, though.

"It's all I can do to go to the doctor, maybe stop at the store, and get back to bed." she said Tuesday. "I just talked to Karen Cosgriff (who is back teaching half-time) and she was going to go lie down."

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