

SENATE HEARING SLIP

(Please Print Plainly)

DATE: 10/21/99
BILL NO. SJR 21
OR
SUBJECT Chronic Fatigue Syndrome

Sara Brenner
(NAME)
274 Moland St
(Street Address or Route Number)
Madison 53704
(City and Zip Code)
WI CFS Association
(Representing)

Speaking in Favor:

Speaking Against:

Registering in Favor:
but not speaking:

Registering Against:
but not speaking:

Speaking for information only; Neither for nor against:

Please return this slip to a messenger PROMPTLY.

Senate Sergeant-At-Arms
State Capitol - B35 South
P.O.Box 7882
Madison, WI 53707-7882

SENATE HEARING SLIP

(Please Print Plainly)

DATE: 10/21
BILL NO. _____
OR
SUBJECT SJR
Resolution 21

Raf Fero
(NAME)
1408 Coral St
(Street Address or Route Number)
Sun Prairie WI 53590
(City and Zip Code)
WI CFS Association
(Representing)

Speaking in Favor:

Speaking Against:

Registering in Favor:
but not speaking:

Registering Against:
but not speaking:

Speaking for information only; Neither for nor against:

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Madison, WI 53707-7882

SENATE HEARING SLIP

(Please Print Plainly)

DATE: 10/21/99
BILL NO. Senate Joint
OR
SUBJECT Resolution 21

Nancy Angsten
(NAME)
907 Whispering Pines
(Street Address or Route Number)
Madison 53713
(City and Zip Code)
Wis CFS Association
(Representing)

Speaking in Favor:

Speaking Against:

Registering in Favor:
but not speaking:

Registering Against:
but not speaking:

Speaking for information only; Neither for nor against:

Please return this slip to a messenger PROMPTLY.

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Vote Record

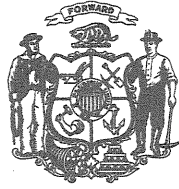
Senate - Committee on Human Services and Aging

Date: 1/18/00
Bill Number: SJR 21
Moved by: Wirch Seconded by: Roessler
Motion: _____

<u>Committee Member</u>	<u>Aye</u>	<u>No</u>	<u>Absent</u>	<u>Not Voting</u>
Sen. Judy Robson, Chair	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sen. Gwendolynne Moore	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sen. Robert Wirch	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sen. Carol Roessler	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sen. Peggy Rosenzweig	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Totals:	<u>5</u>	<u>0</u>	_____	_____

Motion Carried

Motion Failed



Judith B. Robson

Wisconsin State Senator

October 20, 1999
Senate Human Services & Aging Committee
Room 201 Southeast

Testimony: Senate Joint Resolution 21

I am pleased to have this hearing today for Senate Joint Resolution 21. This resolution has a single objective—to increase public attention and understanding of the complex and perplexing illness known as Chronic Fatigue Syndrome, or CFS.

I would guess we all have experienced fatigue in the course of our work or during strenuous workouts. We recover by cutting back, getting more sleep, taking a nap, or slowing down.

CFS, on the other hand, is truly chronic and truly debilitating. To be diagnosed with CFS, a person must be experiencing severe fatigue that has endured six months or longer and has not improved with bed rest.

In addition, the person must have 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;
- post-exertional malaise lasting more than 24 hours.

Because the cause is unknown, the symptoms are puzzling, and there is no effective treatment, the public and many medical professionals are skeptical of CFS.

Serious research on CFS has been ongoing since 1986. The National Institute of Allergy and Infectious Diseases and the Centers for Disease Control and Prevention support research carried out by many distinguished scientists throughout the United States.

In Milwaukee, Dr. Sidney Grossberg has isolated a virus from the white cells of a Madison patient with CFS that may lead to a possible cause. Dr. Grossberg could not be here today, but he supports this effort to educate and inform the public.

Another person who could not be here today is Patricia Jones, the RN Coordinator of the University of Wisconsin CFS evaluation program. She has submitted her remarks, which I am happy to relate to you.

She writes: “Having interviewed 240 plus patients since the program was established in 1996, I can attest to the fact that I’ve learned a great deal about CFS. I began by reading as many articles as possible, but soon realized that I gained much more knowledge from my patients. It was also helpful to discuss the illness and patient scenarios with the few providers who had a good working knowledge of CFS.

“I believe the process of evaluating and providing care and treatment modalities would be greatly enhanced with greater knowledge and understanding of the illness. The old adage of ‘You can lead a horse to water, but you can’t make it drink’ comes to mind. It becomes a very daunting undertaking to assist individuals in need, when these individuals are being discounted and disbelieved by medical personnel. With greater understanding comes knowledge. I believe this resolution should be passed in order to accomplish this goal.”

Today, we will also hear from other people who know CFS as a debilitating disorder. They will speak from experience.

I urge your support for this Resolution.



WISCONSIN CHRONIC FATIGUE SYNDROME ASSOCIATION, INC.

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Sally Albrecht
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January 17, 2000

Senate Committee on Human Services and Aging

Committee Chair: Senator Judy Robson

Committee Members: Senator Gwen Moore, Senator Robert Wirsch, Senator Carol Roessler,
Senator Peggy Rosenzweig

RE: SENATE JOINT RESOLUTION 21 RELATING TO INCREASING PUBLIC
AWARENESS AND ATTENTION TO CHRONIC FATIGUE SYNDROME
AS A SERIOUS AND COMPLEX ILLNESS THAT AFFECTS MANY WISCONSIN
RESIDENTS

The Board of Directors of the Wisconsin Chronic Fatigue Syndrome Association, Inc. would like to express our sincere appreciation for providing a public hearing of Senate Joint Resolution 21. (However, since this was impossible to do for most people disabled with CFS, only two of our constituents were able to present their personal testimony.)

As we await your decision, we hope that you have been able to examine our CFS materials, personal stories, written testimonies, and possibly do some further research on CFS.

We understand the Senate Committee on Human Services and Aging will be voting on Joint Senate Resolution 21 on Tuesday, January 18.

We feel assured that you will concur that Chronic Fatigue Syndrome is a serious public health concern that requires attention and understanding from health professionals and the general public.

Sincerely,

Sara Brenner, President
Wisconsin Chronic Fatigue Syndrome Association, Inc.

cc: WI CFS ASSN Board of Directors
Pat Fero, Director
Sally Albrecht, V.P.
Chris Kraus, Treas.
Karen Upperton, Sec.
William Castagnozzi
Eugenia Gengler
Barbara Gutweiler
Jack Hale
Barbara Hanaway
Roberta Stimac

"I want to get my life back and to be treated with dignity. That means:

1. That information about treatment needs to be disseminated better. Case in point: How come soccer star Michelle Akers can be treated successfully so that she is able to play soccer, and the doctors I go to say there is nothing that can be done. WT

2. The name of the illness needs to be changed so that I am not treated with scorn and contempt by doctors and friends.

3. A much greater effort needs to go into finding a diagnostic marker so that the question of whether I am really sick will go away. Case in point: How about investigating the evidence more thoroughly that red blood cells are misshapen and don't allow blood to flow through the entire body well, causing weakness due to a lack of oxygen? We all know that saline solution infusion helps us. Where is the research to show why?

My name is Genie Gengler. I came down with this disease in October of 1985, 14 years ago. My phone number is 262-241-3430 (June through September) and 520-615-0740 (October through May.)"

My number one concern regarding CFS is the research. More money should definitely be appropriated for this area. The disease is a very devastating one. I've had it for 15 years. I had a gradual onset. For the first 3 years, I was able to function as an *almost* human being. Then I got worse very fast and became bedridden for over a year. Now, after all these years, I can sit up for about 2 hours, and go out if I have the energy, if someone drives. I can't drive, shop, clean the house, lift heavy objects, et al. My whole lifestyle has changed, my career is gone, and my income is very limited on Social Security Disability.

The second concern is that the name MUST be changed ASAP. Besides finding a cause and cure, having such an insane name as Chronic Fatigue Syndrome makes the disease that much more devastating. And, by the way, I am not tired, I am extremely weak. This disease has affected my neurological system immensely. Rest does not help. You try telling someone you have Chronic FATIGUE Syndrome and see their reaction. You'll get comments like, Well, get some rest, take some vitamins, keep positive thoughts, things will get better, go out and exercise and things will be fine, and on and on.

Another concern is for the children with CFS. If it's hard on we adults, it is that much more devastating for children. Who believes them or their parents? Will the schools cooperate? And quite a few of those children have at least one parent with the disease. It is definitely a very hard way of life. They need more understanding and support, and thanks to Pat Fero, at least they get the support they need.

In the back of my mind daily, I have an extreme fear that one of my children, now adults, may develop this disease, especially my 21 year old daughter who is a hair stylist and is exposed to so many chemicals daily. I have a 2 year old grandson that I pray for constantly that he never get this disease, and also that by the time he is older, this disease will have a cause, a cure, and the deep understanding and knowledge of doctors everywhere that this disease does exist.

Thanks for listening.

Sincerely,
Jo Ann Boyle
4361 N. 88th St.
Milwaukee, WI 53222

CFS

My Statement:

Over 9 years ago, I was given a diagnosis of CFS and Social Security Disability. However, the word "fatigue" in CFS has been severely detrimental to my getting any in-depth medical care. Also, my family has not associated or written to me for almost 5 years because they think that CFS, (and the word fatigue), is only a trivial problem and therefore my illness must be imaginary not a real physical illness! Doctors, the public in general, are NOT educated and do not understand how much physical pain, discomfort and disability this causes. I nearly died from gall-bladder/pancreatitis a few years ago because my doctor thought I was complaining only about CFS problems! For 9 years, medical help, understanding and support has NOT been there for me and as a result has caused much suffering. A true nightmare!

Something very big MUST be done, as I understand the numbers of sufferers are growing worldwide.

Lenore Heiman
166A. Brittany Drive
Streamwood, Il. 60107

formerly of
Memorone

My greatest concern, beyond the obvious, is the lack of knowledge in the medical community. I have educated my doctor much more than he has educated me. Recently, because of my CFS/FM connections in my community, I asked my doctor if he was seeing as great an increase in CFS patients in the clinic as I was in our community. His response was alarming. He said, "I am at the point where I am afraid to even diagnose CFS....I feel as though I am sending them away with no hope and I feel helpless to treat them." It is not the job of the patient to educate the Physician, it is the job of the Medical Community and the Government Health Services. This should be a priority of both the CDC and the NIH.

* Chris Kubicek
18811 County Rd. O
Mineral Point, WI. 53565

To Whom It May Concern:

Chronic Fatigue Syndrome is a physiologically debilitating condition. I developed the syndrome over 30 years ago. Both of my children developed the syndrome over 15 years ago, while I was experiencing a catastrophic relapse. Only excellent, exhaustive biomedical research will find solutions and effective management protocols. This requires funding, and the support of the CDC.

Truthfully yours,
Karen Steffenhagen, DVM

608-238-5838
karens@itis.com

CDC

1. Name change -current too demeaning and unappropriate.
2. Adolescent/Pediatric population
3. Medical/Public/ School Awareness

Sally, Watertown, WI

You asked for 2 sentences about something I want them to know about PWCs. it is very simple...

" Find the cause, teach the medical providers, educate the public, find the cure."

We are not lazy, illiterates....these are confused with symptoms of our syndrome....just like excess thirst and urination for Diabetes, excess fatigue for those with Anemia, excess pain with Arthritis...these symptoms never need defending if that is your diagnosis...only if you have CFIDS."

My best to you and safe travels....

Fondly,
Jeanne - WI

I want them to know it's so hard to live with this condition when, on top of everything else, I have to prove to those around me that I really am sick.. And why should they believe? The general image of CFIDS is still a joke. I don't see how we can go forward without belief and a little R E S P E C T.

I feel like my life is on hold. While I've had a kind doctor, he doesn't know what more to do for me.

Julie Crego (CFS/Fibro since 8/94)
5923 Century Avenue
Middleton, WI 53562

Thanks, Pat, for taking the time and energy to go to this meeting. My input is that I think a name change is *essential.* The name "Chronic Fatigue Syndrome" trivializes the illness.

Fatigue is only one aspect of this disease. To call this illness, which has devastated thousands of productive lives, "CFS" is to trivialize it. It is like calling diabetes "Chronic Peeing Syndrome" People with diabetes pee a lot but that is only one aspect of the illness. And to call it that would trivialize it. The name CFS trivializes this disease in the same manner.

I will be looking forward to hearing your report when you get back.

Sincerely,
Helen Dobberpuhl

I would like to change the name of CFS to something that would give the illness more credibility and give it's sufferers more respect. It's difficult enough to be sick, but when you tell people you have CFS, they look at you as if you really don't have an illness. They look at you like you are a quitter and that you are lazy. CFS is a serious and debilitating illness. On May 12, we had a table at Froedert Hospital to inform doctors and visitors about CFS. I saw a few people snicker and laugh as they walked by. CFS is not funny. It is sad that many of us who suffer cannot tell people what we have because we do not want to be looked down on. We are embarrassed by its name and so we are silent.
Faye - Oak Creek, WI

There is a huge problem with public awareness concerning CFS. A name change would help, but I think there is a need to change the public perception of this illness. I saw a movie last night called "Murnford" about a fake psychologist who falls in love with one of his patients. The patient has CFS. Message: CFS is an emotional problem. The first thing the psychologist does is to take her on walks. Message: You just need to push yourself. Without meaning to this movie reinforces a lot of the very messages that we are trying to change. It would be great to have the kind of access to get our own message to people.
Roberta - South Milwaukee, WI

Kevin - 20 onset 14

Ignorance - harder for kids, friends, family, schools, doctors Misconceptions - the name, people think you're taking, or just fatigued, or that it's like aids and that they can catch it from you Labeled - have all the same symptoms for life

Aaron - 18, onset 12

Name - "It's stupid."

"If you go along with what they say, you get so much shit. No one really cares anyway."

"It changes your whole life. Do they know that?"

"No one gives a shit about it anyway."

Bryan - 22, onset 13

Name

Treatment

3 abducts Watertown
WI

Education - both in relation to how it affects, and how no one of importance understands (schools, doctors, etc.)

"I urge the CDC to consider the seriousness of Chronic Fatigue Syndrome. While this disease is not life-threatening it definitely is life-altering. For the majority of people with CFS, this condition is permanent, and without funding to research the cause and an effective treatment, it will remain so. I tried desparately to maintain an active lifestyle for a year and a half after becoming ill. At age 31 I had to "retire" from a career I truly loved. Now thirteen years later I continue to struggle with basic self cares while my goals have become broken dreams. Please help!"

Beth
Sun Prairie, WI

The disease has been with me just 10 years now, making me sicker in stages--not better as some luckier than I have experienced. Do not know if I have reached the bottom yet, knowing someone is always suffering worse than I am, but it feels bad enough to be the bottom--disabled and so weak as to be on the verge of needing help for daily survival.

My feelings toward the CDC, which I trust you to represent well, are deeply rooted negative ones, as deeply rooted as their disregard for what ails me and has ruined any life I understood how to live. My first reading of Ostler's Web, by Hilary Johnson had me sending letters to my elected representatives by Chapter 3, based on the revelations of the unprofessional, casually cruel behavior of CDC scientists and administrators.

I once worked in a national energy lab, doing contract research in transportation (a big energy consumer). Had I performed any of my work so poorly I would have been fired, not just called on the carpet. My work was under constant scrutiny by professionals within and outside my lab, and in the Department of Energy, the sponsor. My work was important, for economic issues--but CDC's research is about life and death, deserving greater attention to the standards of science and, more importantly, to the diligent completion of research tasks raised by primary, that is collected first hand, data on living people. What guided their research and attitude to this disease from the very start was jostling for power within the CDC or the professional community of the particular individual.

The lack of objective, open-minded research is shocking. The blatant and arrogant ignoring of specific Congressional requests is beyond my belief. My 1980's research on the progress of the electric automobile, also requested by Congress, received better attention, and has yielded better results, in the same time as CDC has had with the disease that has felled me.

The apologies and the announced actions are all very good. My own view is that CDC and even parts of NIH will not change until the standard action is taken in such a case as this--put ALL NEW people in the positions involving this disease, people with a demonstrated ability in their technical field and the open-minded approach to research that is essential for effective work to proceed. Researchers cannot take declared stands on the results before the results come in--which is why I insist on open-minded dedicated researchers, not just brilliant ones.

New data should change minds, not fixed minds hunting for data to support those views. Brilliant researchers also develop clever questions to ask, to reveal the needed information to reach a cure, if not just an understanding of what has gone wrong to yield the disease that is so prevalent and so destructive.

A minimum first step is to spend the money on well-designed studies. Simultaneously, working internationally to redefine and re-name the disease within a year is essential. Sweep out the old, bring in the new, and put out some results that show in a hurry.

Sincerely,
Sarah LaBelle
Oak Park, IL 60302

Congratulations to you! You represent the finest Wisconsin has to offer! I know how difficult the travel and all of this is; but you always come thru for all of us. Thanks! I guess I would tell them three things. 1. The totally serious nature of this illness, how it knocks you off your feet and doesn't let up no matter what you or the doctors do. 2. The name change! It would help to address many issues from treatment to respect from family and friends. 3. The disability issue; the length of time ill, unable to work or even function socially. The need for awareness at government levels, including social security disability, CDC, National Health Organizations. We should not be having to do and fund research at grass roots levels. To put it into one word, and you may quote me, and use my name and length of illness (19yrs) diagnosed only (9yrs ago) the thing we want them to know is RESPECT US!!!!!!!
geraldine....

Geraldine Baumgart
1228 W 8th St
Appleton, WI 54914

Pat--I'm not exactly sure what you're looking for, but what occurs to me is that it would be nice if somehow they (CDC) (1) could make CFS more "believable" to doctors, and (2) doctors could be informed of treatment options and things to try, at least to encourage patients.

You can certainly use my name and address if you'd like to. Thanks.

Marianne Abrahamson
N 104 W 6222 Susan Lane
Cedarburg, WI 53012

Message

From: fatigue@pressenter.com (Mimi Trudeau)
Date: Mon, Oct 11, 1999, 8:58pm
To: shoeless-j@webtv.net (Pat Fero)
Cc: hope@ameriga.net (Karen Whitaker), mlowell@ameriga.net (mlowell), letacot@juno.com (Scott Lepley), gufisufi@webtv.net (Larry Burger), isaiah551@webtv.net (Laura Morgan), elliep@citizens-tel.net (Ellie Paulson)
Subject: CDC Input

You carry with you a lot on your shoulders to Atlanta. I've thought at some length about what the citizens of Wisconsin need from the CDC and offer the following ten statements:

1. Proceed with haste with surveillance of children with CFIDS.
2. Proceed with haste with surveillance of minorities with CFIDS.
3. Aggressively build a comprehensive strategy to address the epidemiology of CFIDS and report the results with in a timely, swift manner.
4. Investigate like illnesses that are of apparent neurological/immunological symptomology: ie gulf war syndrome, lyme's disease, post polio syndrome, fibromyalgia, sjogren's syndrome, gel breast implant syndrome, and chemical sensitivity. Make conclusions based on compare and contrast.
5. Develop and implement a suggested plan of treatment.
6. Initiate research to search for answers and hopefully a cure.
7. Conduct international public conferences which will stimulate scientific conclusive response.
8. Assign a proper name and medical coding to the illness(es).
9. Implement a plan for intervention and prevention of same.
10. Strive to keep the public informed every step of the way with press releases, journal articles and public meetings.

Pat, I'm very proud of the work you are doing with Wisconsin CFS Assn. Let me know how I can help.

Mimi Trudeau

You can only fail if you quit trying.