

U.S. Department of Health and Human Services (DHHS)

Chronic Fatigue Syndrome Advisory Committee (CFSAC)

Hubert H. Humphrey Building
Washington, DC

April 4, 2005

MEETING SUMMARY (DRAFT)

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Members in Attendance

Committee Members

- Dr. Charles W. Lapp—*Acting Chair*
- Nancy C. Butler
- Jane C. Fitzpatrick
- Dr. Kenneth J. Friedman
- Dr. Nelson Gantz
- Dr. Anthony L. Komaroff
- Lyle D. Lieberman
- Dr. Nahid Mohagheghpour
- Dr. Roberto Patarca

Executive Secretary

- Dr. Howard Zucker

Ex Officio Members

- Dr. Marc Cavallé-Coll, Division of Special Pathogen and Immunologic Drug Products (DSPIDP), Food and Drug Administration (FDA)
- Dr. Laurence Desi, Sr., SSA, Office of Medical Policy
- Dr. Terrel Hoffeld (substitute), National Institute of Health
- Dr. William C. Reeves, Viral Exanthems & Herpesvirus Branch, NCID, CDC
- Dr. William A. Robinson, Center of Quality, Health Resources and Services Administration (HRSA)

Committee Members Absent

- Dr. David S. Bell—*Chair*
- Staci R. Stevens

Invited Speakers

- Kirk Wagar, Esq., Wagar Murry & Feit P.A.
- Charles McBrayer Sasser, Esq., Sasser Law Firm

1. Call to Order and Roll Call

Dr. Zucker

Dr. Zucker called the meeting to order and conducted roll call.

2. Introduction and Opening Remarks

Dr. Lapp

Dr. Bell was not present at the meeting and Dr. Lapp performed the duties of the Chair.

Dr. Howard Zucker has replaced Dr. Larry Fields as the Executive Secretary of CFSAC. Dr. Zucker is trained as a pediatrician and is now the Deputy Assistant Secretary for HHS, under Dr. Cristina Beato. Dr. Zucker is a pediatric cardiologist, an anesthesiologist, and was the Director of Pediatric Cardiology at Columbia University. He also holds a law degree from Columbia University.

2.1. Review and Approval of Minutes

Dr. Lapp

Dr. Komaroff requested that the word “refused” be changed to “was unable to.” Dr. Desi noted that he was incorrectly noted as making a comment on page 11. The statement was stricken. Dr. Friedman noted that “Howard University” on page 12 should read, “the University of Medicine and Dentistry of New Jersey.” The minutes were approved with the changes.

2.2. Operational and Other Business Matters

Dr. Lapp

It is time for new nominations for CFSAC. Six members will be rotating off of the committee as of September 30, 2005: Dr. Bell, Ms. Butler, Dr. Gantz, Mr. Lieberman, Dr. Patarca, and Dr. Lapp. Nominations must be submitted to Dr. Zucker by 5:00 PM on April 20, 2005.

3. Overview of Disability

3.1. Long Term Disability and CFS

Dr. Lapp

“Impairment” is a medical term and is determined by a doctor, based on AMA standards. Impairment is defined as any alteration of an individual’s health status that interferes with activities of daily living (ADLs). ADLs include:

- Self care and personal hygiene;
- Eating and preparing food;
- Communication;
- Maintaining posture (sitting or standing);
- Caring for the home and personal finances;
- Walking, traveling, and moving about;
- Recreational and social activities;
- Work.

“Disability” is a legal term and is determined by a court or a legal person. Disability is defined as an alteration of an individual’s capacity to meet personal, social, or occupational demands, or regulatory requirements, due to impairment. Types of disability protection include:

- Medical leave;
- Workmen's Compensation;
- Family Medical Leave Act;
- Short-term disability;
- Long-term disability;
- Social Security Disability Income or Supplemental Security Income.

Long-term disability policies are typically described in the Summary Plan Description (SPD). The SPD defines:

- The definition of disability for the purposes of eligibility;
- The amount and duration of benefits;
- Waiting periods;
- Application deadlines;
- Limitations on coverage;
- Type of proof required.

Disability is defined differently than the AMA by most long-term disability carriers. It is generally defined in vague terms, such as, "unable to perform, for wage or profit, all the substantial and material duties of your occupation, and under the regular care of a physician." After two years on disability, the definition will change to "unable to perform any type of job because of illness or injury." Most carriers will provide a lower-cost policy that includes a coordination of benefits policy, which reduces the amount of long-term disability payouts by replacing it with Social Security Disability Income or Workman's Compensation.

There are problems with defining disability concerning CFS. First, the defining symptoms of CFS are all self-reported. Second, there is little objective evidence of the illness itself. Third, many doctors do not have the time to document the patient's functional capacity. Additionally, many doctors do not know how to file for disability benefits.

Many CFS patients are rejected in the disability process for the following reasons.

- A policy may require that a person be disabled from *any* occupation;
- Carriers use independent medical examiners, which are paid by the carriers;
- Functional capacity examinations are frequently used, which are unreliable;
- Peer reviews are conducted by specialists who do not understand CFS or know the patient;
- Field investigations and surveillance result in entrapments;
- Carriers use “delay and deny” tactics.

Many carriers will use a myriad of excuses to delay the application process. They also deny patients because of the following reasons.

- CFS is a self-reported illness;
- There is no limitation of motion;
- CFS is a psychiatric illness;
- All medical remedies and modalities have not been exhausted;
- CFS patients can perform sedentary work.

The Employment Retirement Income and Security Act of 1974 (ERISA) was designed to ensure that people covered by disability plans actually receive the promised benefits. However, the problem with ERISA is that the general public cannot sue for damages.

There are several ways to resolve these issues. First, there needs to be more research to determine better ways of measuring disability. Second, ERISA should be amended. Third, insurers and physicians must be educated on CFS and disability. Fourth, patients should not be required to use the Family Medical Leave Act. Fifth, a broader, universally accepted definition of disability should be established. Finally, insurance exclusions, such as self-reported illnesses, should be disallowed.

3.2. Social Security and CFS

Mr. Lieberman

When a person files a claim for Social Security Disability, the claim is sent to an adjudicator at an Office of Disability Determinations. With a doctor, the adjudicator determines whether the claimant is disabled. If the claim is rejected, the claimant may file a request for reconsideration, to have another doctor and adjudicator review the claim. If the reconsideration is denied, the claimant may file a claim before a U.S. administrative law judge. If the judge denies the claim, the claimant may file an appeal to the Appeals Council. After that, they can file a claim in the U.S. District Court, the court of appeals, and all the way up to the U.S. Supreme Court. At the administrative law level, approximately 53 percent of those cases are approved for benefits.

Traditionally, CFS patients have been denied benefits because benefits cannot be awarded on symptoms alone. In 1999, Social Security published a ruling (99-2P) that specifically dealt with CFS. It stated that since CFS is a diagnosis of exclusion, the lack of clinical findings does not mean that the person is not disabled. As a result of this ruling, there was an increase in the number of allowances for CFS patients. However, these numbers are going down, especially at the lower levels. At these levels, claims are often referred to doctors who have no experience with CFS, though all reasonable efforts must be used to refer the case to the treating physician.

3.3. Obstacles to Obtaining Disability

Mr. Wagar

Mr. Wagar is the managing partner of Wagar Murray & Feit P.A. and limits his practice to representing policyholders against life, health, and disability carriers in both state and federal courts. He is “AV” rated by Martindale Hubbell and is a member of the Board of Governors of the Association of Trial Lawyers of America. He served as a member of the Executive Committee of ATLA in 2003–04, Chair of the New Lawyers Division of ATLA in 2001–02, and Co-Chair of the ATLA Student Trial Advocacy Competition. He served as the Chair of

the Young Lawyers Section of the Academy of Florida Trial Lawyers, as well as a member of the Academy's Board of Directors.

Mr. Wagar started working on CFS and disabilities in 1993. There has been a change in how the courts and carriers treat CFS. However, there has been a backlash because the physicians who perform the functional capacity evaluation are biased or ill trained on CFS.

Title 3 of the ADA states that there has to be equality of goods and services. These rights should be extended to CFS patients. In Florida, there is an attorney's fee statute that states that if a suit against an insurance company prevails, the attorneys are awarded 1.5 times their hourly rate. This often results in the insurance company paying or resolving the claim outside of the court system. As a result, individual cases, that are identical to ERISA cases, are resolved more quickly. Additionally, there are other subjective illnesses, such as migraine headaches, that also suffer from the same disability problems as CFS.

ERISA was conceived in the early 1970s to provide disability and life insurance for everyone. It was to be at the federal level and include an internal appeals process for the carriers. It excluded contractual damages and jury trials. Since 1974, there is now a large deference given to an insurance company, which makes it difficult to win court appeals.

Ms. Fitzpatrick asked about the two-year limitation for mental health.

Dr. Wagar noted that he found only one carrier that did not have the two-year limitation, and that every carrier has a product that excludes CFS or self-reported claims.

Dr. Robinson noted that there are a limited number of physicians that are qualified to diagnose and treat CFS. He asked if there were other avenues to circumvent this problem.

Mr. Wagar noted that there needs to be more clarity for physicians as to what constitutes CFS.

Dr. Gantz asked how the accepted and rejected CFS disability claims differ.

Mr. Wagar noted that they mostly differ in legal strategies. For example, certain judges consistently reject CFS disability cases. Additionally, there are differences in policies. There

are more than 20 definitions of disability, and some cover CFS better than others. Lastly, the credentials of the treating doctor and the vocation of the patient can affect the case.

3.4. ERISA

Mr. Sasser

Mr. Sasser is a well-known disability attorney. His practice is located in Charlotte, N.C., and he has successfully represented CFS patients in matters regarding Social Security and private insurer disability. He graduated with honors from the University of North Carolina at Chapel Hill, where he received his J.D. Mr. Sasser is a member of the American Bar Association, North Carolina Academy of Trial Lawyers, and the American Trial Lawyers of America. He is the former president of the National Organization of Social Security Claimants Representatives. He is nationally recognized for his expertise on ERISA and has lectured extensively on disability law.

ERISA is a federal statute that completely regulates how private insurance companies handle disability cases that are provided by employers. Almost every employee in the United States is covered by ERISA in some fashion. ERISA is different from Social Security disability. It has a different legal process and is not controlled by the same definitions of disability. Since it was passed, it has become one-sided and unfair to the disabled employee.

The principle problem with ERISA is that the insurance companies have no incentive not to deny claims. There are several reasons for this, including:

- The power of a federal court to overturn a carrier's decision is highly limited by the Abuse of Discretion Standard;
- The administrative process of ERISA is very restrictive in terms of evidence, because once the carrier makes a final determination, no other evidence can be submitted;
- Access to ERISA-specialized counsel is limited;
- Benefit awards from court decisions are usually very small and based on the contract amount;

- Few denied claimants actually sue the insurance carriers.

Legislative change is required to correct ERISA's shortcomings, and CFSAC should promote these changes.

Mr. Lieberman asked if carriers that have a two-year limitation for CFS benefits tend to also deny benefits.

Mr. Sasser noted that some deny benefits, some pay for the entire two-year period, and others terminate the benefits before the end of the two-year term.

Mr. Lieberman asked if there were any carrier physicians that determine benefits should be paid because of CFS.

Mr. Sasser replied that he has never seen this to be true.

Dr. Komaroff asked if instruments that define disability and impairment, such as SF36, would help the claimants.

Mr. Sasser replied that these instruments would help claimants during adjudication.

Dr. Patarca asked if there were attempts to change ERISA.

Mr. Sasser replied that there have been attempts to change ERISA. The last attempt, which was unsuccessful, was contained in the Patient's Bill of Rights, proposed by Senators Edwards and McCain. However, the insurance lobby is powerful and has precluded any attempt to change this statute. ERISA also negatively affects employers by limiting the effective payout of the coverage it purchases for its employees.

Dr. Gantz asked if there were suggestions, other than changing ERISA.

Mr. Sasser noted that the administrative aspects of the claims process could be improved. However, the problems with ERISA may not be resolved through regulatory means. It would require legislative change. He added that ERISA is a good example of what privatization of Social Security might look like. CFSAC should propose to the Secretary of HHS recommendations that would promote legislative change.

Dr. Reeves noted that CFSAC is not a lobby group and cannot recommend changes to legislation. He added that continued education is crucial. With respect to the standards, Ruling 99-2P should be revised to include new information on CFS. There are instruments that measure functional impairment, which are internationally validated. These instruments should be added to Ruling 99-2P.

4. Public Comments

Ottely English

Ms. English's friend, Judy Rodriguez, had CFS at the age of 48. She would spend 12 to 14 hours a day in bed and has been misdiagnosed with depression and other things. After 1.5 years, she was diagnosed with CFS. At that time, she stopped working and spent much of her time with physicians. Ms. English added that if there was a drug for CFS, it should be fast tracked.

Dr. Mary M. Schweitzer

In an online discussion forum, *Disinissues, Disability Insurance Issues*, many participants discuss the problems with ERISA—it rewards carriers that unjustly deny benefits. There is an estimate 560,000 CFS patients, of which one-fourth cannot work full time. However, there are only 500 patients with CFS currently under Social Security Disability Insurance (SSDI). Even if SSDI covered 5,000 CFS patients, there are still 135,000 patients without SSDI.

There are considerable geographic variations in the number of people accepted under SSDI. It is suggested that these variations are due to the political and social culture in which these cases are reviewed. In other words, if the local perception of CFS was negative, the patient's claim was more likely to be denied.

Another problem is that 90 percent of patients with CFS are women. Women often cannot apply for SSDI in the first place because they are more likely to have remained outside of the workforce. These women tend to turn to AFDC for assistance. AFDC has been replaced by TANF (Temporary Aid to Needy Families). TANF provides benefits for only five years, and

one-half of female-headed households in TANF have either a disabled mother or a disabled child who must be cared for by the mother.

Dr. Beverly Bugos

Dr. Bugos noted that the vast majority of the CFS community would prefer the name “ME/CFS.” She is on SSDI. However, it was not until she got a lawyer on her second attempt that she was able to get on SSDI. She also needed her lawyer to get her long-term disability insurance from Prudential, where she received benefits for two years. Prudential ended the benefits, claiming that the disability was due to a mental disorder. All of her doctors disagree with that decision.

Dr. Bugos now has a second disability lawyer, Ben Glass, who has an article on his website called, *14 Ways to Guarantee that Your Long-term Disability Insurance Claim is Denied and You Lose in Court (Avoid Them and You May Have a Shot at Winning Your Claim)*. Dr. Bugos reiterated the need for patient representation at CFSAC meetings. She recommended that CFSAC bring Jill McLaughlin on as a consultant, and she asked for statistics regarding SSDI acceptance rates for CFS cases.

5. Summary and Recommendations Updates

5.1. Subcommittees

5.1.1. Education

Dr. Patarca noted that Dr. Desi made available to CFSAC the adjudicator training tapes for CFS. There is also a meeting scheduled with Dr. Robinson at HRSA on pediatric CFS.

5.1.2. Research

Dr. Friedman noted that the state of Vermont is considering legislation to reproduce the New Jersey State CFS manual. There will be a meeting on May 12, which is CFS Awareness Day,

to promote this legislation. The legislation has been drafted, and testimony before the state legislature is required before a vote.

Dr. Mohaghehpour suggested that this should be a nationwide effort—all states could provide funding to make this manual available in all states.

5.2. Ex Officio Members

5.2.1. Food and Drug Administration

Dr. Cavaillé-Coll

The reorganization of the Office of New Drugs is on schedule and will take place in July and August, as the different divisions move to a new campus in White Oak, Maryland.

5.2.2. Social Security Administration

Dr. Desi

Dr. Bill Anderson has retired and Mr. James Julian is the new office director. The listings that SSA uses to make allowance decisions are out-of-date, which takes 10–15 years to update. The current business process is to update these listings more frequently. Once the major overhaul is completed, the listings will be tweaked on a five-year cycle.

5.2.3. Health Resources and Services Administration

Dr. Robinson

HRSA will meet with Dr. Patarca and Ms. Staci Stevens to discuss education.

5.2.4. National Institutes of Health

Dr. Hoffeld

The proceedings of the conference co-sponsored by the Office of Research on Women's Health and the Arthritis Institute can be ordered on the NIH website. The RFA is currently in the process of obtaining institute sponsors, and the program announcements were renewed last year. For the next round of reviews, there are three times as many applications, compared to two weeks ago.

Dr. Lapp asked Dr. Desi for statistics on the number of people diagnosed with CFS and the number of allowances. He added that he would recommend that CFSAC begin to look at the issue of miscoding grants as CFS-related.

5.2.5. Centers for Disease Control and Prevention

Dr. Reeves

The Georgia study is half completed and they are beginning to work on the registry. They have gathered four teams to an integrated approach to describe the systems biology of CFS from the Wichita study. There will be a three-day meeting at the Cold Spring Harbor laboratory to discuss the outcomes of that analysis.

CDC has two published studies on adolescent CFS. The first study, "The Prevalence of Chronic Fatiguing Illnesses Among Adolescents in the United States", published in 1997 in the *Journal of CFS*, is an amalgamation of three studies: Physician Surveillance Study (1991–93), School Nurse Survey (1993), and Metropolitan Population Survey (1994).

The Physician Surveillance Study included 500 physicians in four cities. They were asked to prefer all patients 12 to 60 years of age with unexplained chronic fatigue or un-wellness. All participants received a standardized interview and questionnaire. Their medical records were reviewed, and a physician review committee reviewed these materials for exclusions, using the 1988 case definition. The study found 23 adolescents (rate: 9/100,000) and 350 adults (14/100,000) with unexplained chronic fatigue. Seven of the adolescents (3/100,000) and 130 of the adults (6/100,000) had CFS confirmed.

The School Nurse Survey involved a telephone survey of all middle and high school nurses, which cared for 41,600 students in Reno and Wichita. The nurses were interviewed concerning students with chronic debilitating fatigue or un-wellness. Of the 41,600 students, 23 adolescents had chronic fatigue (0.06%) and 10 were diagnosed with CFS (0.02%).

The Metropolitan Population Survey involved a random-digit-dial telephone survey of 8,004 households in San Francisco. The survey showed no children between two and 12 with chronic fatigue; five adolescents (466/100,000) and 292 adults (1,894/100,000) with chronic fatigue; and one adolescent (0.1%) and 33 adults (0.23%) with CFS-like illnesses.

The second study, "Chronic Fatigue Syndrome and Other Fatiguing Illnesses in Adolescents: A Population-based Study," published in 2004 in the *Journal of Adolescent Health*, was based on the Wichita study. During the study, they attempted to give everyone that had a CFS-like illness a clinical evaluation. Thirty-one adolescents were identified with a CFS-like illness and 11 participated in the clinical evaluation. Of the participants, none had CFS, three had exclusions, and eight had unexplained chronic fatigue. The study also showed that the highest risk of CFS and CFS-like illnesses were among the 40 to 59-age group.

The current CDC study involves CFS in metropolitan, urban, and rural Georgia. The study included a CFS pilot regional registry, which is in its early stages. The objective of the registry is to identify and follow large numbers of adults and adolescents with CFS. The registry will help to describe the natural history of CFS; identify well-characterized subjects for intervention trials; compare CFS in the population; and develop a brain tissue bank.

The registry feasibility study is being conducted in Bibb County. Its referral sources include physicians and school nurses, complimentary and alternative medicine providers, and self-referrals. Referred individuals will be patients between the ages of 12 and 59, who have unexplained fatigue not improved by rest, or un-refreshing sleep, or unexplained problems with concentration or memory, or join/muscle pain, or thought to have CFS.

In summary:

- A lot is known about the epidemiology of CFS;
- The prevalence of CFS is in the adult population;

- The impact of CFS has not been well studied on kids;
- The basic characteristics in kids are the same as they are in adults;
- Comorbidity is essentially the same between kids and adults;
- Most kids get well;
- The risk factors for kids are unknown.

Dr. Patarca asked if incidence follows prevalence.

Dr. Reeves noted that prevalence is the number of people in the population with the disease at any one time. Incidence is the new cases in a period of time and is unknown among adolescents. The incidence of CFS is extremely low. The average duration of illness is five to six years, and there are few new cases.

Dr. Patarca asked if there are other international studies.

Dr. Lapp noted that the Japanese had a school-based study.

Dr. Friedman commented that making the New Jersey CFS scholarship program nationwide could improve data collection efforts among adolescents.

Dr. Komaroff noted that there was a putative outbreak of CFS in children 12 and younger in Northern Nevada and California in the mid-1980s. He asked if other putative outbreaks have been reported to CDC.

Dr. Reeves noted that new outbreaks have involved adults only. Though CFS does occur in kids, the risk in kids is very low. As a result, population-based studies are costly; registries are less costly alternatives to capture the same types of data.

Dr. Lapp asked about gender and socio-economic data in children.

Dr. Reeves responded that there is not enough data for children to do these analyses.

Dr. Lapp asked if there was any work on a case definition for pediatric CFS.

Dr. Reeves noted that the core symptom complex is the same in children and adults.

Dr. Lapp asked if CDC was studying which symptoms are most common among children.

Dr. Reeves commented that he is not aware of anything rigorous that has looked at this question. However, they are preparing for publication an empirical study of the core symptoms of CFS in 32,000 patients from 22 different sites in 15 countries. The study showed that the core symptom complex is the same regardless of culture or language in those who are seen in primary care and community care settings. Those in specialty and tertiary care settings have no standard symptom complex, which varies by the type of tertiary care setting.

Ms. Fitzpatrick asked if anything was happening with the CDC training program with CFIDS.

Dr. Reeves noted that the program is moving along nicely. They can begin to measure outcomes and have hired an educational assessment analyst. He offered to provide more information at the next meeting. They are also beginning a larger public awareness campaign to raise public and healthcare provider awareness.

Ms. Fitzpatrick asked if they have acted on CFSAC's recommendation to reinstate staff.

Dr. Reeves noted that they have the FTEs—one filled, one in the process of being filled, and two others that are being advertised.

6. Public Comment

Dr. Lapp

Dr. Lapp noted that they were unable to obtain an advocacy group to present at this meeting. As a result, he asked an advocacy group to advertise on the Internet that CFSAC was looking for stories of problems people have had with disabilities. In one week, they received 1,600 responses. Of those, seven were willing to provide testimony. Most of those who were unwilling cited confidentiality agreements and fear of retribution. Five did provide testimonies, which are presented in a handout called, "Testimony from Patients and Advocacy Groups."

The majority of complaints dealt with long-term disability (LTD). One person testified that:

An economic war via terrorism is being waged upon disabled LTD claimants. A clear pattern of illegal practices pervades numerous LTD carriers. These archetypes have expanded exponentially to constitute a concealed, shared methodology or modus operandi practiced by almost all LTD carriers.

The most common methodologies include:

- Denying claims, regardless of merit;
- Delaying payment of claims;
- Dropping claims;
- Not providing the rules or governing plan document;
- Deliberately obfuscating the standard of proof;
- Habitually ignoring pertinent, objective medical evidence;
- Paupering claimants and forcing them to chose between paying for legal representation or paying for medication and medical care;
- Delaying a lawsuit filing to further pauper the claimant.

Other problems in the LTD system include:

- Not rehiring the CFS patient when the patient is denied LTD;
- The “secondary gain” myth;
- Changing the diagnosis to mental illness under duress;
- Independent medical examiners with no active clinical practice in treating CFS;
- SSDI offsets;
- Confidentiality agreements.

A testimony regarding ERISA involves a successful drug representative earning a five-figure salary. He and his wife were disabled by CFS and FM several years ago. He was approved for LTD, which was terminated within a few months for no good reason. His appeal was denied. He filed an ERISA suit in federal district court, which was denied. He then appealed to the

federal circuit, which refused to overturn the denial without a full hearing, which he can no longer afford to pursue. Currently, he and his wife survive on Social Security benefits. He stated:

Of course there is the resulting loss off all my health, prescription, and life insurances...disability retirement pension, and LTD incomes, having to spend my entire six figure retirement savings to live on, and the stresses of not being able to afford or obtain all the healthcare services we need without multiple chronic medical conditions.

Regarding SSDI, one person noted that her case was “buried at the local level for approximately” five months. She inquired about her case progress, but calls went unanswered. She appealed to the Baltimore office of the SSA, which took a week to “exhume” the records. An adjudicator was assigned, but obtained only one of the many medical records that she was required to disclose on her original application. The record was not supportive, so the adjudicator gave greater weight to an independent examination that was contracted by SSA, ignoring her treating physician’s records. She was denied benefits and is appealing again.

Other complaints include the time it takes to receive benefits and the time for appeals. Others noted that SSDI employees are uneducated about CFS and conclude that CFS is not a legitimate disease. Another complaint was that the SSDI application was too difficult to complete.

Another patient returned to school in 1995 to obtain her second Ph.D. She was paid a stipend by the university, which did not pay into Social Security on her behalf. She became ill with CFS, but was able to complete her Ph.D. However, she was unable to work. When she applied for Social Security benefits, she found that too much time had elapsed since her last Social Security payment for her to qualify.

Dr. Desi noted that this woman might qualify for SSI, if not SSDI.

Dr. Reeves asked Ms. McCleary, as a patient advocate, what she thinks CFSAC can do to help with disability issues.

Ms. McCleary commented that the Social Security law was written when work was more physical. However, today's work is more intellectual and cognitive. This shift has not been recognized in Social Security laws and policies. CFSAC has an opportunity to make sure that this is reflected in Social Security and LTD policy. Physicians also need to be educated on how to document disability.

Dr. Desi noted that there are some technological advancements coming to ease the Social Security application process. Applications can be submitted in-person, over the Internet, and by phone. Records will become electronic. Regarding documentation, training videos are being provided to primary care and family practitioners to make them aware of the process.

Rebecca Artman

Ms. Artman is from Florida. It took her two years to complete the SSDI process. However, there were some positive aspects of the process. The people that she worked with were friendly and understanding, including her boss and HR representative, and the Social Security representative.

At the beginning of her illness, Ms. Artman was referred to the Mayo Clinic for treatment by her family practitioner. All of her 401K savings went to this clinic, which was unable to correctly treat her illness. She was eventually referred to Dr. Paul Cheney, who was able to correctly diagnose and treat her illness.

Northwestern Mutual Life (NMF) is her LTD carrier. It took NMF almost a year to approve her claim, and she has been collecting benefits for about five years. However, she is continually required by NMF to comply with various requests, such as new paper work or physician visits.

Additionally, it was difficult to acquire state aid. When she applied, the forms were eight pages long and difficult to complete because of the illness. At her appointment, she was told that assistance was not available because she owned a car. She sold her car to pay medical expenses and reapplied. She was then told that she did not qualify for aid because she did not have a decision on her SSDI. After being approved for SSDI, she was told that she still did not qualify because she was receiving SSDI. However, the social worker told her that if she had a child, she would then qualify for aid.

Ms. Artman also attempted to return to school. She met with the disability office and was told that she qualified to take tests outside of the classroom. She enrolled in class and was subsequently told that she no longer qualified to take tests outside of the classroom. She noted that there needs to a consistent measure for disability.

7. Wrap Up and Adjournment

Dr. Lapp recommended holding the next CFSAC meetings on June 27 and mid-September.

Ms. McCleary noted that from February 9 to 11, the Japanese government sponsored a conference in Osaka called “The International Conference on Fatigue Science.” Researchers gathered from 13 countries to discuss CFS and fatigue in general. The Japanese government has provided funding for this effort to continue through the year 2007, and it is interested in establishing Centers of Excellence. She recommended that HHS should participate in these efforts.

Ms. Fitzpatrick recommended inviting someone who is involved with the current trends in physician education for the next meeting.

Dr. Friedman requested that CFSAC review the new recommendations from the last meeting.

Dr. Gantz suggested examining the SSA criteria (Ruling 99-2P) for diagnosis.

The meeting was adjourned.