

**CFSAC Testimony of Pat Sonnett
October 2010**

I. INTRODUCTION

My name is Pat Sonnett.. I have had Chronic Fatigue Syndrome and Fibromyalgia since January of 1986, and have previously testified by phone before this Committee. I once again thank each of you for your service on this Committee and to the CFS/ME community.

II. THE HUMAN TOLL

While I have presented testimony to this Committee on a number of occasions, I am having a very hard time putting my thoughts on paper this time because I find myself becoming very emotional each time I sit down to begin the writing process. Every other time I've talked about the physical and emotional toll this illness has taken on the patients including the loss of jobs, abandonment of friends and family, financial ruin, fear of the future, ignorance and sometimes even ridicule by the medical establishment, the desperate search for diagnosis, treatment and a cure for this disease.

Having had CFS for almost 25 years, I personally know people whose spouses have left them because they just couldn't cope with the illness any longer. I know people who have had to move into homeless shelters because there was nowhere else for them to go. I know people who have suffered dire health consequences because of being given medication and treatments that caused a severe CFS relapse and they have had to go into nursing homes to recover. I know of someone who went to the emergency room with chest pains and when she told the treating physician she had CFS, he didn't pay attention to anything she said after that and sent her home where she suffered a heart attack that evening. Even today I spoke with someone who was at Mayo Clinic for treatment and the physician just grinned when she told him she had to be careful with certain types of medication because she had CFS. He then admitted that he didn't really "believe" in CFS. Even after 25 years, over 5000 CFS publications, and the recent discoveries of the XMRV and MLV retroviruses connected to CFS, not much has changed for CFS patients.

Today I want to address the devastation CFS has taken on those who have friends and loved ones who have been stricken down with this illness, and those who are the primary caregivers for CFS patients. We have a tendency to push this group of people into the background but they are often the ones on the front lines of the battlefield, fighting for the patients who are too weak to fight for themselves. I want each of you to imagine what it would feel like if you were in their positions.

A. The Parent of a Child with CFS

I want you to imagine how it feels to be the mother or father of a child who is too sick to attend school or develop any friendships. How do you help your child make a life for himself when he's confined to bed and you can't even find a pediatrician with any knowledge of CFS to be able to treat him? You become the caregiver, the teacher, the outside world for your child.

In the process, any plans you had for your own future and career fall by the wayside. Your dream becomes one of hoping to see your child get well. Finances become difficult if you previously had two incomes and now have only one, and medical bills continue to climb. As days turn into months and months turn into years with no changes, you worry about what will become of your child if something happens to you and you can no longer care for him.

Young children grow into adults who still require your constant care which you continue to give because you love your child. You mourn deeply the losses he feels for not having had a childhood, not being able to look forward to marriage and a family, not being able to work to support himself.

The working spouse had hoped to retire at some point and you had looked forward to spending your retirement years doing things you always wanted to do. The realization is that there will be no retirement because you have no money left for retirement and you still have a son to care for who remains too ill to care for himself.

Being the parent of a child with CFS becomes even more difficult when there are other children in the household who need your love and attention as well. How can you divide your time when there is no time left to divide? How do you show your other children that they are equally loved?

B. The Parent Who Has CFS

Now I want you to imagine what it feels like to be a young mother or father who has CFS and also has young children to care for. You consider yourself fortunate if you can keep them fed and bathed but there's very little left over to give to your children because you can barely care for yourself. Your children may have a grandparent or aunt or uncle who is able to spend time with them and take them to their sports and other activities, but you are forced to miss out on a part of their lives that you so much want to be involved in. You are forced to develop a relationship with your children through "being" rather than "doing." It can be enough, but you dreamed of so much more when you decided you wanted the joy of having children.

C. The Husband or Wife of a Spouse With CFS

Now I want you to imagine what it feels like to be the husband or wife of a person with CFS, a husband or wife who believes CFS is a real devastating illness, a husband or wife who takes your wedding vows very seriously and loves your spouse enough to stand by them regardless of what their health situation is. You want desperately to make them better, but you've been to every specialist you can think of and tried every treatment recommended and nothing has helped. You know that all you can do is to continue to give them hope and encouragement that one day they will overcome this disease.

You make an effort every day to let them know they are loved and appreciated for even the small things they say and do. You love them for who they are, not what they can or can't do. You laugh with them and you cry with them and reassure them you'll always be there for them. But even as you do all these things, you still worry that there may come a time when you won't physically be able to care for them on your own.

D. The Sibling of Someone With CFS

Now I want you to imagine what it feels like to be the sibling of someone with CFS. As a child, I'm sure you feel badly that your sibling is ill and can't play with you and the other children like other siblings can. You probably also resent your sibling because his illness likely requires that you give up any extra-curricular activities and your parents aren't able to spend as much time with you as they would if your sibling weren't ill. You probably also feel some guilt that you are healthy while your sibling is ill and also feel some guilt that you resent your sibling at times even though his illness isn't his fault. As an adult sibling who understands about CFS, you feel sadness that your sibling is ill and you feel helpless to do anything to make it better for them. You probably spend as much time as possible with them but know it's not enough because you have your own family to care for and your own life to live. You want to share your life with them but you also hold back somewhat because you don't want to make them feel worse than they already do about the things they're missing out on.

E. The Friend of Someone With CFS

Finally, I want you to imagine what it feels like to be the friend of someone with CFS. You've known each other for years; you grew up together; you've shared your deepest secrets and your dreams for your future. Your friend comes down with CFS and you know that nothing will ever be the same again. Your friend doesn't feel well enough to spend as much time with you or talk with you on the phone. You know that when you make plans to do something together, you may get a call at the very last minute saying she's too sick to make it and your heart breaks because you know it's true. You develop other friendships but continue to cherish the one you still have. You keep in touch if only for a few minutes at a time. You make her promise to let you know when she feels like she can get together, even if it is at the very last minute, and you make every

effort to see her when she's up to it. You continue to share your life and your joy knowing she wants the very best for you just as you do for her. You don't shut her out of your life and you don't let her shut you out of hers. You give her the time and the space she needs but you don't allow her to shut out the world around her. If she's having a pity-party day, you join in, bring chocolate, and help her do it up right, but you let her know she only gets to do it for the day and tomorrow you're going to help her do something special for someone else so she can help someone have a special day. You help her understand she is still needed and has value. Above all else, you remain her friend.

F. How You Can Help Your Friends and Loved Ones

If you find yourself in any of the above categories, you still have power to help your friends and loved ones. You have the power to become involved in CFS Advocacy. You can speak out on their behalf. You can write letters, send emails, and make phone calls to those in power who can bring about change. You can educate your other friends and family members, neighbors and physicians.

III. CONCLUSION

CFS/ME continues to devastate the lives of not only the patients, but family members and friends of those patients as well. Medical history will likely reflect upon these last 25 years of CFS as an era filled with ignorance, shame and neglect on the part of the government agencies whose very purpose is to protect the public. We have lost a generation to CFS and this is a travesty that must be corrected. Don't let the mistakes of the past carry forth into the future. As members of the Chronic Fatigue Syndrome Advisory Committee, I respectfully request that you use whatever influence you have to bring about the changes needed to give CFS patients and their loved ones an opportunity to at least be able to look forward to a future. No one can return the lost years, but perhaps there can be hope for the years that remain.

IV. ACTIONS REQUESTED

In light of all the new information that has surfaced and the XMRV and MLV studies that have recently been released, I request that the following actions be taken immediately:

- Designate CFS/ME as a public health priority.
- Set aside \$100 Million Dollars for CFS/ME research.
- Establish and provide funding for five CFS/ME regional centers of excellence which include facilities for pediatric treatment.
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- Provide CFS/ME clinicians with the means necessary to begin testing patients for XMRV and MLV.
- Commence clinical trials now.

This is not the type of testimony I am accustomed to writing, and probably not the type of testimony you are accustomed to hearing; but I feel strongly that we all need to be reminded that CFS is not just about facts and statistics. The facts and statistics often miss the reality that there are other lives involved besides just the CFS patients themselves. CFS shows no more mercy for the other people whose lives it destroys than it does for the patients.

Sincerely,

Pat Sonnett