Talking Point

2007 Issue 1 Official Journal of the M.E./C.F.S. Society (SA) Inc.

Your Society

forget-ME-not

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ME/CFS Society (SA) Inc.

The ME/CFS Society (SA) Inc. is a non-profit organisation (Registered Charity 698) which aims to:

- promote recognition and understanding of the disease among the medical profession and the wider community
- provide information and support for people with ME/CFS and their families

Patron

Her Excellency Marjorie Jackson-Nelson AC, CVO, MBE, Governor of South Australia.

Membership

Annual membership is from July 1 to June 30, and includes subscription to the magazine *Talking Point*. Membership rates for first-time members are as follows (GST included):

New Members (cheaper rates apply for renewal):

Single membership..... $35
Single Concession..... $25
Professional..... $50
Family $40
Family Concession $35
Overseas – as above plus..... $10

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Talking Point

Talking Point is the official journal of the ME/CFS Society (SA) Inc. It is published quarterly, and is financed primarily by member subscriptions.

Talking Point Subscriptions:

Professionals:	$35
Persons with ME/CFS:	$22
Overseas (Asia-Pacific):	$32
Overseas (Rest of World):	$38

Management Committee 2007/2008

The Society is directly administered by a voluntary committee elected at the Annual General Meeting.

President: Peter Cahalan
Vice-President: (vacant)
Honorary Secretary: Peter Mitchell
Treasurer: Richard Cocker
Management Committee Members: Lynda Brett; Adrian Hill; Melanie Cocker; Emma Wing

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Note: It is our policy to ignore anonymous correspondence.

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Wednesdays 10am to 3pm (subject to volunteer availability).
Our email address is: sacfs@sacfs.asn.au.
Our Web site address is: www.sacfs.asn.au.
Our youth Web site address: www.sayme.org.au.

Donations

Donations are an important source of income for the Society and are welcome at all times.

All donations of $2.00 or over are tax deductible and a receipt will be issued.

Disclaimer

The ME/CFS Society (SA) Inc. aims to keep members informed about research projects, diets, medications, therapies etc.

All communication both verbal and written is merely to disseminate information and not to make recommendations or directives.

Unless otherwise stated, the views expressed in *Talking Point* are not necessarily the official views of the Society or its Management Committee and do not imply endorsement of any products or services (including those appearing in paid advertisements) or treatments

Always consult your medical practitioners before commencing any new treatments.

Notice to Vendors

The ME/CFS Society (SA) Inc. does not permit direct marketing of products to our members. This includes distributing promotional literature, providing demonstrations of products or approaching members at any of our events.

If you have information about products which you wish to bring to the attention of the Society, you should direct it to the Information Officer GPO Box 383, Adelaide 5001.

In particular, you should note that members give their contact details to the Society in trust and misuse of those is a breach of confidentiality. Any use of member information for direct marketing will be investigated and dealt with appropriately.

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ME & You, ME/CFS Society of NSW Inc., Suite 204, 10 Help Street Chatswood NSW 2067.
Emerge, ME/CFS Society of Victoria Inc., 23 Livingstone Close, Burwood Vic 3125.
Queensland ME Quarterly, Queensland ME/CFS Syndrome Society, PO Box 938, Fortitude Valley Qld, 4006.
ChaMEleon, ACT ME/CFS Society, Shout Office, Collett Place, Pearce ACT 2607.
ME/CFS News, ME/CFS Society W.A. Inc., c/- WISH, PO Box 8140, Perth, WA 6000.
The CFIDS Chronicle, CFIDS Association, PO BOX 220398, Charlotte, NC28222-0398, USA.
Perspectives, Myalgic Encephalomyelitis Association, Stanhope House, High Street, Stanford le Hope, Essex SS17 OHA, UK.
Country Network, Journal of the Northern Rivers ME/CFS/FM Support Assoc. Inc. PO Box 6024 Lismore NSW 2480.

Talking Point – 2007 Issue 1

The Official Journal of the M.E./C.F.S. Society (SA) Inc

From the President

*By **Peter Cahalan**, President ME/CFS Society (SA) Inc.*

As you will see from the items below, the Society has started 2007 at a strong pace. We're feeling buoyant about this year's program of activities and hope that you'll be joining us in a number of them.

Here goes.

Our international panel of speakers on 25 March

You will by this time have received a flyer – in fact a sheaf of them – for the public meeting. As I write we have just had confirmed that Dr Dan Peterson, famous US medical campaigner for people with ME/CFS – will join the other three speakers. They are Prof Abhijit Chaudhuri and Dr Malcolm Cooper of the UK and Prof Kenny De Meirleir of Belgium and the USA. Prof De Meirleir spoke to us as the sole international expert attending a forum of experts in Adelaide in July 2005. And now, for this second Adelaide forum of experts, our guests from overseas have risen to four.

As you will see from the flyer, the four are all eminent people who figure frequently in the literature of ME/CFS research and in the political controversies that swirl around it. It asks a lot of people who might be feeling quite ill to come out on a Sunday night to a meeting. But we hope that many of our members and their families and friends (including the sceptical ones) can make it to Norwood Town Hall. The time is 7 pm by the way. If you have another time in your head from any previous communications – forget it. It's 7 pm.

It is not cheap to put on the event. Hiring the hall, printing and posting leaflets and other costs will take us over the $2000 mark. For that reason we have to charge. Members will get in for a lower price than non-members. We took that decision because we are working hard to make membership something to be really valued. We have just gone through our e-bulletin lists for example and found a lot of people who have not been paid-up members for some years. We're not critical of them in any way. But we want to encourage more people to join. As I write we are at the 250 mark and want to make it to 300 by 30 June. So if you know any past members who want to come on the night – I suggest you get them to join beforehand.

To return to the experts. They're here in Adelaide for a meeting with a group of Australian researchers to discuss a range of matters. The Alison Hunter Memorial Foundation has organised the event and put a huge amount of effort into wooing these eminent persons to Adelaide. Our Society has acknowledged that by agreeing to defray some of the costs of the forum.

You will have a chance to hear outcomes of the forum, we hope, some weeks afterwards. We hope to have a meeting on Saturday afternoon 21 April with several local experts who will be attending the forum. We did this last time and people appreciated it. We'll confirm that when we know if we have the speakers. You'll be able to get a DVD of the public meeting by the way. We'll let you know the cost and other details later.

Seminar program for 2007

You'll read elsewhere in this issue that we are already well into stride with the organisation of a series of lectures for this year. We weren't able to get too far last year with it. In one case one potential speaker failed to respond to emails and telephone calls from three successive members of the committee over some months. Which nicely stuffed us around!! This year we've had more success. That's thanks to our member Lorenzo Pizza who took on the task of pursuing potential speakers until they begged for mercy. He tells us that it

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hasn't been as hard as that. And so we look like having about five lectures in addition to the big meeting. The program aims to traverse a range of issues and I hope that you'll do all that you can to get to all or some of them.

Incidentally, as a result of a poll of members who get our e-bulletins, we're slightly varying the times of the lectures. Some members get quite tired in the afternoon and would prefer morning meetings. The great majority however indicated that it's the other way around for them and they find it hard to get started early. We'll bring one or two lectures back earlier and see what happens to attendances. This is not an easy one to resolve but we are trying to honour the needs of all our members where we can.

The Multiple Chemical Sensitivity Campaign

Just before Christmas we took the MCS Report Clock off our website after, as I recall, it had reached around the 540 day mark. We did so because, finally, the Health Department convened a first informal meeting of the MCS Reference Group which was a key recommendation of the parliamentary report of July 2005. It was informal because the Department had not then received nominations from the Local Government Association for its two representatives. As I write (in mid-February), and as far as I know, those nominations still haven't been received. And the chance of the first official meeting being held in February, as the Department indicated at the December meeting, is looking pretty slim.

It's instructive to compare this disappointingly slow progress with what has happened elsewhere. The MCS campaign team – Peter Evans, Debra Paior and myself- have had good success on several fronts:

- **Catholic schools.** We held a fourth meeting for the year with the Catholic Education Office by going to a parish school and reviewing with staff how the school was operating as a safe environment or not for chemically sensitive staff and students. It was a real success and brought out a number of practical issues which the CEO will be addressing in new policies and procedures on building new schools and on refitting and maintaining schools. We found that one of the teachers at the school – St Joseph's Hindmarsh – was reactive to some chemicals and so the staff were to some extent aware of the issues we were raising.
- **Hospitals.** Through personal contacts Peter Evans and I found ourselves invited to address the management team of the Gawler Health Service. After the dull inertia of the central health bureaucracy it was utterly refreshing to be met by a group of people who were sympathetic, interested and willing to participate in any pilot projects which might be set up to explore how our hospitals can become safer for MCS persons.

We've now set up an MCS email group under the Society's banner so that Peter, Deb and I can communicate more efficiently with those members with an active interest in the MCS campaign. We must keep the pressure up on the government at all levels, using the parliamentary report as our point of leverage. But to do that we need as many people as possible coming on board to harass politicians and bureaucrats. We invite you to join us. Just let the Society know and we'll add you to the list.

Now I think that will do for this *Talking Point*. We're committed to getting it to you regularly this year and we're hoping to see its standard of production improve after some of our recent issues were on the dull-looking side. Meanwhile our editor Peter Scott, in his other role as webmaster, has been working on changes to our website to make it even more user-friendly. For reasons that we can't quite fathom, our readership has risen to new highs and we're getting almost 500 visits a day. It's a great tribute to Peter's work and to the support he gets from Jenni Gay, Peter Mitchell and others who regularly feed him material.

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Alison Hunter Memorial Foundation
for research into
Myalgic Encephalomyelitis / Chronic Fatigue Syndrome

ME/CFS SOCIETY (SA) INC • Forget - ME - Not •

ME/Chronic Fatigue Syndrome:

The breaking news from around the world

Sunday 25 March 2007 at 7 pm
Norwood Town Hall

175 The Parade, Norwood (bus stop 9)

Speakers:

- **Dr Abhijit Chaudhuri (UK)**
- **Prof Kenny De Meirleir (Belgium)**
- **Prof Malcolm Hooper (UK)**
- **Dr Daniel Peterson (USA)**

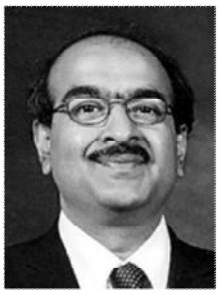
For everyone interested in Myalgic Encephalomyelitis / Chronic Fatigue Syndrome – this is a once-only opportunity to hear a panel of the world's leading medical experts on Myalgic Encephalomyelitis / Chronic Fatigue Syndrome explain the latest advances in research and treatment.

Admission: ME/CFS Society members: gold coin donation
Non-members: $5

For further details contact the ME/CFS Society on mobile 0431 990 492 or 8410 8929 (Wednesdays) or at sacfs@sacfs.asn.au. (Website: www.sacfs.asn.au)

Many people with ME/CFS are chemically sensitive. Please therefore avoid or minimise the use of fragrances. Please also refrain from smoking before the meeting or near the venue.

About the speakers:



Dr Abhijit Chaudhuri (UK) Consultant Neurologist at the Essex Centre of Neurological Sciences. Dr. Chaudhuri was appointed as a Senior Lecturer and Consultant Neurologist in July 2000. Research on fatigue in common neurological disorders is the main theme of Dr. Chaudhuri's work. He takes special interest in myalgic encephalomyelitis (ME). His other areas of interest include multiple sclerosis, neurological infections and adult neurometabolic diseases. He has been widely published on a number of medical diseases and conditions. He has recently collaborated with Dr John Gow on the genetic biomarkers for CFS - what they have termed "the gene signature" for ME/CFS

Prof Kenny De Meirleir (Belgium). MD, Ph.D. His vast experience includes roles as Professor of Physiology, Pathophysiology and Medicine, Vrije Universiteit, Brussels Belgium; Professor of Physiology and exercise physiology and Professor of Medicine at the University of Brussels. His research activities in Chronic Fatigue Syndrome date back to 1990. Winner of the Solvay Prize and the NATO research award. He has been director of one of the world's largest CFS clinics for almost two decades. This is Prof De Meirleir's second vist to Adelaide: he was also here in 2005.

Prof Malcolm Hooper (UK) Malcolm Hooper is a British biochemist and Emeritus Professor of Medicinal Chemistry, University of Sunderland, U.K, Malcolm Hooper has been one of the most outspoken advocates for ME/CFS patients and those who research the physiological foundations and progression of this disease. His studies of the similarities (and differences) between the disabling illnesses of Gulf War Syndrome (GWS), Multiple Chemical Sensitivities (MCS) and ME/CFS, and his perseverance in advocating for the physiological basis of these illnesses, have allotted him a place of honor within the ME/CFS international community.

Dr. Daniel L. Peterson (US), affiliate of the Sierra Internal Medicine Associates in Incline Village, Nevada; ME/CFS researcher and clinician; a board member of the American Association for Chronic Fatigue Syndrome; and member of the International Chronic Fatigue Syndrome Study Group. He was one of the first doctors to recognise the illness in the US, treating the famous Lake Tahoe cases of ME/CFS in the early 1980s. Dr Peterson was honoured with the Pioneer Spirit Award from IACFS conference 2007.

Arthritis SA

1ST April 2007

Arthritis SOUTH AUSTRALIA

April Pain Day

You would be a fool to miss it!

Arthritis SA Presents

A Public Pain Symposium

A "joint initiative" of Arthritis (SA), the Australian Pain Society and the Decade of the Bone and Joint and to launch Arthritis Awareness Week 2007, Arthritis SA will present a Public Symposium on CHRONIC PAIN titled

Challenging the Burden of Pain

An innovative approach to pain management through arts, photography, music and monologue

Date: Sunday, 1 April 2007

Time: 12.30 pm—4.00 pm

Location: University SA
City East Campus
Room H2–02
Basil Hetzel Building (Enter off Frome Road)
ADELAIDE
www.unisa.edu.au/about/campuses/cemap.asp

⇒ **Spaces are limited**

⇒ **Bookings essential by 23rd March 2007**

ADMISSION:

⇒ **$15.00 (AF SA Members)**

⇒ **$20.00 (General)**

⇒ **$30.00 (Health Professionals)**

All bookings to be made through
Arthritis SA
Reception 08 8379 5711
(Free call) 1800 011 041

How I learned to stop worrying and love my wheelchair

*By **Jesse Kaysen**.*

My body began falling apart a decade ago and I had to quit even part-time paid work. Many joints, muscles and tendons hurt, so I am never comfortable sitting in a 'standard' chair. I'm dizzy and tend to fall over. My body can't tolerate exercise or repetitive motion; a stroll around the block requires an hour's rest, while leafing through a magazine puts my hands out of commission for half a day. My brain, thankfully, developed a rapid-forgetting technique so I'm not overwhelmed by chronic pain. Unfortunately, this also means I may forget my topic in mid-sentence. After years of doctors saying that it was all in my head, they now call it 'fibromyalgia' or 'chronic fatigue syndrome'.

And so I've been led to change many aspects of my daily life. The first big change was denial, guilt and self-doubt. I was sure that if I only developed a more positive attitude I'd get better. Now I'm realising this negative perspective results from our society's attitudes. In feminist consciousness-raising groups, I learnt that women share guilt, self-blame and learnt helplessness because we share growing up in a society where female is not 'normal'.

I've come to understand that the American way of health adds to the pain of illness and disability: that 'disability' is, like 'femininity', a notion compounded of biology and society. Gallons of ink have been used to debate the correct terminology – I call myself 'disabled' or 'sick'. (Euphemisms like 'differently abled' or 'physically challenged' sugar coat my experience.) But it is not just a word game because it is hard to put on a filthy, tattered coat when you can't hide your shivering.

I denied I was disabled because I did not want to accept the stereotypes that ride along with the label – and who would want to call themselves incompetent, worthless or imprisoned? It seemed easier to pass as 'normal', even if that meant never being comfortable with who I was. At the personal level any change, even a positive one, is hard to accept. Many of the changes associated with disability and chronic illness are no fun at all. In my case I didn't want to develop a new body image, to feel pain, to relearn certain activities or to modify my pace. All these reluctances add up to a powerful engine of personal denial.

In addition to these interior messages there are social ones as well. The most basic is if you're sick, get better or die. If you're disabled or sick it's your job to 'overcome' it. The American individualist ideal is relying on oneself.

In the popular imagination disability and illness are defined as a struggle. Totally invisible in the past, the few media images of disability we now see are the 'overachievers' – almost all male. We know that 'superwoman' is a convenient myth that keeps us so busy juggling work and family that we don't have time to analyse where society can be changed.

Disability rights activists speak of the parallel burden of the 'supercrip' – rolls in a marathon, dresses like Geena Davis, works 50 hours a week and never gets nasty when discriminated against. Gracefully accepting changes in one's body is, well, weak.

However, some of us don't have that capacity to live at the edge of our limits. CFS/ME has robbed me of precisely the ability to spring back. Our 'be all you can be' society gives greater approval to the walking fool than the rolling sage. My denial made me a walking fool; it prevented my taking advantage of useful tools and services that in fact minimise the functional limitation of disability.

Thanks to years of activist effort, as well as smart politicking by legislators with personal experience of disability, America is becoming easier to use from a wheelchair.

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CFS/ME definition – 2002 Oxford Concise Medical Dictionary

When one looks up the new sixth edition 2002 Oxford Medical Dictionary under Chronic Fatigue Syndrome, ME, Myalgic Encephalomyelitis or Myalgic Encephalopathy you are referred to CFS/ME. It reads as follows:

CFS/ME – The approved name for the condition formerly known as Chronic Fatigue Syndrome, myalgic encephalomyelitis (or encephalopathy) or postviral fatigue syndrome. It is characterised by extreme disabling fatigue that has lasted for at least six months, is made worse by physical or mental exertion, does not resolve with bed rest, and cannot be attributed to other disorders. The fatigue is accompanied by at least some of the following: muscle pain or weakness (fibromyalgia), poor co-ordination, joint pain, recurrent sore throat, slight fever, painful lymph nodes in the neck and armpits, depression, cognitive impairment (especially an inability to concentrate), and general malaise. The cause is unknown but some viral conditions (especially glandular fever) are known to trigger the disease. Treatment is restricted to relieving the symptoms and helping sufferers to plan their lives with a minimum of energy expenditure. Graded physiotherapy and cognitive behavioural therapy may be helpful in some cases.

How I learned to stop worrying and love my wheelchair (continued)

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I now celebrate July 17, 1993 as my 'independence day' because that's when I got my power wheelchair. It makes such a difference in my life. I now have a custom-fit, comfortable place to sit. I can go to restaurants or movie theatres without worrying about what sort of chair I'll find there. Snug and relaxed I have more energy to bring to daily tasks. The less effort I spend walking, the more energy I have to think. I can again accompany my husband and dog on long walks around the neighbourhood. Now I can travel the ten blocks to the bus stop, roll on the lift and travel independently. I can go back to my favourite place on earth – the library – easily transporting pounds of books in the bag that hangs on the back.

Perhaps the most interesting change is how others see me; I have a visible disability and strangers more easily accept that I may not do things just like they do. Of course, some folks see the wheelchair as confining me, rendering me incapable of speech, independent thought, or any place in society. But my chair no more confines me than my eyeglasses obstruct my vision. I hope and work for the day when everyone who needs this remarkably useful tool can have it.

Reprinted with permission from Emerge*, Spring 2006.*

Is there a pot of gold at the end of the murky CFS/ME rainbow?

*by **Ursula Kielewska**.*

We all know that as CFS/ME sufferers we feel like an eighty year old with a hangover. However, after we go through the torrent of emotions that CFS/ME inflicts on us we may also have acquired an emotional maturity that is commensurate with our frail elderly form.

The prolonged and debilitating nature of CFS/ME, delayed diagnosis and frequent misdiagnosis, lack of prognosis and medical treatment, frequent ridicule from doctors and lack of understanding from family, friends and work colleagues all contribute to the emotional roller coaster that each CFS/ME sufferer is forced to endure. But by experiencing intense and varied emotions we can gain a new perspective on life which can serve us well during the illness as well as when we recover. But first let's look at some of the varied shades of the decidedly murky emotional rainbow that CFS/ME brings on:

Denial:
I'm really fine. If I keep pushing on and ignoring it, it will go away. I can't spend my life in bed, I've just got to get on with it.

Fear and Despair:
What if I never get better? What if this is going to be my life? Or what if I get a bit better, resume life (buy a house, have kids etc…) and then relapse and have to go through all of this again?

Frustration:
I used to be a winner – now I am a snivelling bedridden invalid. I've been robbed of my twenties by a disease for which there is no cure. Weddings, engagements and parties pass me by. I used to be the first on the dance floor and the last off. Now I can only manage to write a 'best wishes' card.

My personal and career plans have been scuttled and replaced with long periods of 'nothingness'. I see people with less ability getting promoted. I see my friends get married. I can do neither.

Doctor No 3 examines me after looking at a barrage of normal blood test results. "Let me guess," I sigh, "There's nothing wrong." "Should there be?" he replies and writes a referral to a psychiatrist.

Recrimination of self and others:
If only I hadn't kissed the boy at that monkey magic party those many years ago, I wouldn't have contracted glandular fever. If only doctor No.1 hadn't misdiagnosed it for tonsillitis I wouldn't have gone to Vietnam. If only I hadn't gone to Vietnam with glandular fever I wouldn't have contracted CFS/ME. If only doctor No.2 had realised I had CFS/ME when I got back I would have done the right things to get better. If only.

Anger:
I can't believe that I let this happen? Why the hell did I feel pressured to go travelling overseas with a friend when I didn't feel well? How dumb am I?

I can't believe the stupidity and carelessness of doctors. I think I'll get my medical records off doctor No 1 and sue the b*****d for negligence. I can't believe that doctor No 2 didn't believe in CFS/ME and thought I had depression. What a moron. I can't believe the insensitivity of doctor No 3.

I can't believe that my boyfriend's mum freaked out and thought I had depression 'just like her mother' and was openly anxious about the life he'd have if we stayed together. What a stupid and insensitive thing to do.

I can't believe some people say that CFS/ME

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"sounds like fun" because you can "skip work and chill out at home". I feel like slapping them, only I don't have the energy. So instead I file their names under 'I' for ignorant insensitive imbecile.

Guilt:
For letting down my boss and work colleagues who are carrying my load; for continually calling up work and postponing my return; for not being able to pay the rent and having to terminate my lease; for not being able to help out around the house and impersonating a giant slug; for cancelling social appointments; for continually leaving my partner partnerless.

Sadness:
When I had to cancel my lease and move out of the apartment that my boyfriend and I called home. It looked so bare without our furniture. (Was this the end? Would distance and illness drive us apart?); when I have to refuse wedding and engagement invitations; when I look at old photos. (The girl in the photo looks so happy and full of life. Her smile is so wide. Her eyes are so confident and full of hope.)

Loneliness:
It's 3pm. It's another three hours before anyone comes home. My cat is curled up and sleeping on her tattered chair. I pat her furry little head. I need her more than she'll ever know.

Humiliation:
When I went to Centrelink to apply for the sickness benefit, I pathetically took my law degree part of my identification documents to show that I was not 'one of them'.

The first time I purchased antidepressants at the Chemist (on my new healthcare card), I felt like a crazy unemployed woman. I wanted to tell the pharmacist that I wasn't depressed but had CFS/ME and tablets were part of an effort to rewire my brain so when I got stressed I wouldn't automatically get sick. But I stood there awkwardly and handed over the money because I didn't know what else to do and I don't like defensive people.

Hope:
When my temperature stabilised or when my headaches went away; when the muscle aches subsided or when I regained the coordination to be able to drive again; when I read about a new potential treatment for CFS/ME or hear about a doctor who might know something. It's a ray of light that brightens my day.

It does indeed look like a long walk through the valley of suffering but it is precisely because the emotional journey through CFS/ME is so difficult that sufferers acquire such emotional strength and fortitude and eventually learn to accept life for what it is. The challenges and emotional difficulties that most CFS/ME sufferers face in a relatively short period of time are experiences that most people would encounter over the course of a lifetime, or not at all.

So take heart from the works of Nietzsche who believed that difficult situations can, through careful cultivation by a person who has both knowledge and faith, bear beautiful fruit. Buddhists came to a similar conclusion saying that wisdom only comes through suffering. If these philosophical approaches are correct then CFS/ME sufferers are very wise indeed! Here are some lessons that I have learnt through having CFS/ME.

1. **Rethink your purpose and priorities:** You have the opportunity to think seriously and deeply about what you want to do with your life when you get better. Most people are caught up in jobs or relationships that are not very fulfilling. It's what happens when you get onto a certain course in life; obligations pile up and soon there's no turning back. You are up to your neck in it and you would have to be very mad or very brave (or both) to ditch it all and try something new.

   Well, you are in the position to remodel your life after CFS/ME. You have nothing to lose by

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changing course and starting again because you have already lost everything. Providence has taken away what you had; now it's your choice as to whether you want to take it back or start anew. Perhaps you were in the wrong job or not doing enough of what you really love. Make a list of what is important to you and what drives you in order of priority. Make a vow to pursue these things when you get better. Life is too short to be doing what other people expect of you.

2. **Adopt new values:** Through your experiences you have probably learnt that life is about relationships and experiences, rather than the acquisition of 'things'. This is a very liberating realisation as our society is clearly geared towards the acquisition of wealth and with that value set come a lot of pressures that we subconsciously put on ourselves. After suffering through the punishments of CFS/ME you should be free of this onerous outlook on life. Now, doesn't life seem easier than it did before?

3. **The simple life:** You now understand the joy of simple things. You don't need promotions or awards to feel good about yourself and life. You have been forced to extract joy from watching autumn leaves falling from the trees, from observing the tranquillity of your cats sleeping and from watching parrots bathe in the bird bath. These are simple, everyday events that go unnoticed by most as they hurry on doing what must be done.

4. **Perspective:** You will not be perturbed by life's small problems that most people get tangled up in. Once you've dealt with CFS/ME most of life's problems will seem insignificant. You will probably observe others' angst over administrative problems with wonder and some bemusement.

5. **Patience:** Used to getting things straight away? Not any more. CFS/ME teaches you to wait patiently for progress. Not only that, but impatience is severely punished. When walking five minutes too long can land you in bed for a week, you fast acquire monk-like patience. It's a very cruel but very effective form of teaching.

6. **Humility and Kindness:** The experience of physical frailty and the subsequent reliance upon the charity of others for survival is a humbling experience and one that brings home the fragility of every human's existence. Furthermore, I suspect that all CFS/ME sufferers have been touched by someone's kindness and charity in their hour of need and, as a consequence, value these attributes more than they would have prior to CFS/ME.

7. **Determination:** CFS/ME either turns you into an emotional wreck or forces you to acquire steely resolve. I suggest the latter. Since you can't transplant yourself into a new body, the only solution is to develop a plan for recovery and march on despite setbacks (which are likely to be numerous). Even though it's like trying to get from one end of a mine field to another without a map, you quickly learn what improves your condition and what compromises it. So figure out an approach which you are comfortable with and don't be disheartened by setbacks – they are just part of the illness (unfortunately improvement is rarely linear). This experience will give you the steely determination to tackle any problem that life will throw up in future.

These are just some of the lessons that I have learnt through having CFS/ME. I am sure there are many more that have been, and will be, discovered. But, whatever realisations you have, it is important to note them and hold them close to your heart as they are a gift that you can extract from an otherwise unpleasant experience and keep with you for the rest of your life.

So make an effort to at least harvest some fruit from the twisted and gnarled tree that is CFS/ME. Keep it safe and eat it wisely.

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Talking Point – 2007 Issue 1

The Official Journal of the M.E./C.F.S. Society (SA) Inc

Mental "self-help" and CFIDS

*By **Mary Schweitzer**.*

How do you talk about mental "self-help" without descending to the level of "if you THINK like a well person, you will BE a well person"?

(Sort of reminds you of *The Music Man*, when the con artist band director came into town with the "Think Method" – the players would "practice" their nonexistent instruments by "thinking" they were playing.)

When a male doctor says you could get better by changing your perception of pain, you might try kneeing him in the balls and then ask him how his perception of pain is.

Back to reality: my doctor practices a type of behavior adjustment therapy that makes sense and RESPECTS the degree to which we are really sick. That is, you try to keep track of your activities and crashes, and learn what it is that sends you into a downward spiral or a crash. If you can find your upper bound activity level – that is, the activity levvel that you can generally sustain day to day without bringing on a crash, then you live within that constraint and you can regain a sense of independence and control over your body and the disease.

Every once in a while you push the envelope to see if you've improved any – usually it happens because there's something you want to do. so I go to Florida, do more things than usual, see what makes me crash (if anything). Well, I did crash. But I did find out that I can do A LOT if I am in an electric motor scooter, and I can also ride pretty long distances in the car if I use the backseat and a pillow and lie down the whole way. Conversely, the times I accidentally had to walk further than I had planned brought on a retaliation the next day – I did a lot of unwilling and unintentional walking Wednesday, and Thursday I was in a lot of pain and spent the whole day in bed. (But that was okay – I had planned that day "off", so to speak.)

In other words – the doctors who would have you "will" yourself to be better by pretending you're not really that sick are absolutely wrong. It's like asking someone with a broken leg to walk without a limp. I think when they are talking about perceptions of pain, they mean their own perception of your pain, and it makes them uncomfortable to have to realize how much pain/discomfort/illness you sustain every day. So they want you to pretend that you are not really that sick, which will make THEM feel better.

As opposed to my own doctor, Marsha Wallace in Washington, who has said (and I am so grateful for that) publicly that patients with CFIDS and fibromyalgia are the bravest people she knows.

Now, WITHIN those limits imposed by our serious physiological illness, if you can find ways to – as another doctor put it – to THRIVE, to STILL have a life – that's good for you. That has to make you better.

But the process starts with recognizing your limits, accepting them, living within them – and then learning to enjoy and appreciate life in spite of them. (If you go into remission, you'll find out.)

Which is why Internet has been a godsend for me. Here, I am not an invalid, somebody who makes other people uncomfortable. I am just … me. Surrounded by other "just me"s for whom I have respect and affection. Being able to be honest about my life, not having to hide it, to pretend I'm okay when I'm not – and then to move on – THIS is healthy.

Reprinted from Listening to CFIDS.

Spacing out at the mall

*By **Mary Schweitzer**.*

I get spacey in crowds – but since I can't drive (my confusion is too strong), I never go anywhere by myself. So… I just relax and go with it. That is, lots of people pay to get a buzz on; I get one for free. I really need a "keeper" with me, though – when my family left me early at the All-Star Game preliminaries in July (they went down to a party downtown that would have been too much for me, and I said I'd just enjoy sitting and watching the stuff at the Vet), if it wasn't for the kindness of strangers, I think I would have left my pocketbook in ten different places. When I first began using a handicapped parking tag, my daughter was mortified that I would just walk out of the car and walk into wherever we were going. So, at the suggestion of someone on this very list, I bought myself a cane ($6.59 for a cheap wooden one at the drug store). It was just going to be a prop – but I learned quickly that I really needed it – I loved it.

First, my balance isn't very good. At home, I can touch furniture or walls to stabilize myself. (My golden retriever thinks she helps out by sticking to my side, but instead I have to be careful not to fall over her – but I love her for the thought) Well, that was one of my problems in public – I was really afraid I would fall – I would get bumped and lose my balance, or I would encounter an unexpected drop in the pavement or a step everybody but me saw. With the cane, I was no longer afraid of falling. That helped immensely.

I also found that when people see me with the cane, they give me space. Most people will try not to bump into you if you have a cane (and when they do, everybody glares at them; lots of fun.) So, I could create my own little safe place within the crowd.

Finally, though, I just don't walk very much in those situations (I can't walk much anyway). At a sports event, my husband drops me off at the entrance nearest my seat (they are really nice about it – the Olympics was the only place that was lousy about accommodation) and goes and parks, and the rules are I just walk right down and sit down. Then when he and the kids get back, someone can go get me something to eat. (I can go to the restroom on my own…) That works very well.

At the mall, I use a wheelchair. They provide wheelchairs for free at our local malls, but, unfortunately, they are not motorized. So I have to have a babysitter, which is not always easy. Even if I can get the handicapped bus to pick me up and TAKE me to the mall, I can't get around the mall because I can't use a wheelchair on my own. But the local Acme has a motor scooter that works great. I love it. Little kids want to know how come I get to ride the little car – and before their parents drag them away with an alarmed look on their face, I say – because I'm lucky. (If the parents let them stick around long enough, I explain I have a medical problem that makes it hard for me to walk, but then I get to ride this thing and it's fun. My brother grew up in a wheelchair; I am not shy about this at all. Kids have no problem with it – they nod and understand. It's the parents who get embarrassed…)

One reason you may be getting dizzy at the mall is that you are unaware of how long you just stand around there. A secondary solution that some of us use is to get the wheelchair, push it (which helps with the balance), and then sit in it when you are looking at things to buy or you have to wait in line.

And if people glare at you when you stand up, you can always use my favorite line, borrowed from good friend Rona on the left coast – "It's a miracle! I can walk!"

As for me, most of my holiday shopping is spent walking the catalogs.

Reprinted from Listening to CFIDS.

IACFS Conference report

The 8th International IACFS Conference on Chronic Fatigue Syndrome, Fibromyalgia, and Other Related Illnesses was held in Florida on 10-14 January 2007. It was hosted by P.A.N.D.O.R.A., the Patient Alliance for Neuroendocrineimmune Disorders Organization for Research and Advocacy.

The Conference was divided into two sections: one for Patients; and one for Professionals.

The following, by ***Cort Johnson****, is the first half of a four-part report on the IACFS Conference. Part I and Part II are dedicated to the Patient Conference. (This report is entitled* Phoenix Rising Special Edition: A Layman's Guide to The 2007 P.A.N.D.O.R.A. International IACFS Patient Conference – January 10th-12th, Fort Lauderdale, Florida*.) Part III and Part IV, dedicated to the Professional Conference, will appear in the next issue of* Talking Point*.*

Part I: Politics, Advocacy and the Media / Dr. Teitelbaum and D-Ribose / Ask the Experts

The patient conference was an overwhelming success. It has always been a kind of poor sister to the professional conference but this time with its strong program and top-notch speakers the patient conference was a success in and of itself. According to people who'd been to the patient conferences in the past the attendance for this one was double or triple that of the preceding conference. The credit for this success must go to Marly Silverman, Rebecca Artmann and the rest of the P.A.N.D.O.R.A. volunteers.

One of the most encouraging aspects of both IACFS conferences was the availability of the participants. Virtually everyone I talked to, from officials at the National Institutes of Health (NIH) to the Centers of Disease Control (CDC) to the CFIDS Association of America (CAA) to the CFS researchers and physicians present willingly gave their time to discuss CFS issues. Gratifyingly they almost all appeared to be impressive, highly competent individuals.

Of course, not all was positive – there were ups and downs in both the patient and professional conferences and these will be reported. These overviews are liberally supplemented by my inputs; i.e. they include information not given in the talks.

Politics and Advocacy

The patient conference started off, appropriately, with perhaps the most important issue facing CFS patients – the politics and advocacy of CFS. What the federal government does or not does not do regarding CFS has enormous implications for CFS research, disability and treatment. Kimberly McCleary the President and CEO of the CFIDS Association of America (CAA) underscored this point in her talk.

Kimberly McCleary, President and CEO of the CFIDS Association of America:
Empowerment Within the CFS Community

Kimberly McCleary very dramatically demonstrated the importance federal dollars play in CFS research by showing a chart that overlaid the CFIDS Association of America (CAA) contributions to CFS research with those of the federal government. While the CAA has at times been able to marshal as much as $450,000 for CFS research even at its peak it's spending is dwarfed by federal funding rates that are from 10 to 30 times higher. There is no simply no substitute for effective advocacy at the federal level. First we take quick look at the agencies involved in CFS research.

The NIH: The subject of CFS research and the NIH is a complex one that will be covered in a

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future paper. Suffice it to say, though, that the CFS program at the NIH is a matter of concern. While the two officials in charge of CFS research at the NIH, Vivian Pinn and Eleanor Hanna, were able to get the institutes to sign off a special grant (an RFA) that supplied funding for five major new CFS research projects there are no new programs in the works and the outlay on CFS research is still at near record lows. (The RFA funded seven grants, five of which were focused directly on CFS.). The RFA notwithstanding, the NIH has been approving about 1 or 2 new CFS grants a year for the past four years. The Office for Research into Women's Health (ORWH) did get the services of Dr. Hanna when it took over the CFS research program in 2001 but it hasn't received any new funds for CFS initiatives and had to raid its other programs to get the $2 million dollars it needed to cofund the 2003 neuroimmune grant initiative (RFA).

Later in the Professional Conference, Pat Fero, the founder of one of the oldest CFS support groups, the Wisconsin CFIDS Association, presented data indicating numerous abnormalities regarding CFS research funding including significant over reporting of CFS funding and including non-CFS projects under CFS research.

In the last five years the ORWH has dramatically changed the focus on CFS in the NIH and is now interested in funding only multi-dimensional studies that attempt to explain CFS in a mechanistic fashion. It is unclear whether the CFS research community, never exactly robust, has managed to adjust to the ORWH's new focus. Dr. Hanna and others assert that they are willing to fund more studies than they have but that researcher input to the agency is low and generally does not meet the criteria for multi-dimensionality and innovation they have set. Every time Dr. Hanna took the mike at the conference she pressed CFS researchers to submit these kinds of studies.

When I asked her and Dr. Pinn about funding programs such as Centers of Excellence or Research Centers that could jumpstart CFS research they invariably responded by stating that the best research opportunities for CFS researchers lay in attempting to get CFS patients involved in basic science studies. When I asked Dr. Pinn whether studying CFS at the NIH was viewed as a kind of researcher suicide she demurred but again stated the opportunity now was to get CFS research studies shoehorned under other research projects. *Ironically it appears that Dr. Theoharides took just that approach when he got a project on a subject (anti-depressants) - of little interest in CFS - and with a focus – a hyperactive HPA axis – opposite to that found in CFS – approved as a CFS grant in the Neuroimmune RFA!* Dr. Pinn's assertion that 'CFS' does not have to be in the title of a study that nevertheless includes CFS patients, while undoubtedly useful, still underscores the negative environment CFS research finds itself.

I asked Kimberly McCleary if the over reporting of CFS research funding at the NIH involved a situation similar to that which occurred at the CDC some years ago. The GAO investigation of that incident resulted in the CDC's commitment to payback funds it stated it had spent on CFS research but had not and a period of independent oversight that has just ended. She replied that the two situations were different; the CDC incident involved lying to Congress about funds specifically appropriated for CFS research. The NIH, on the other hand, is under no legal obligation to fund a specific amount of money on CFS.

The NIH itself is in a time of great transition as it is reorganized under the Roadmap Initiative. The Office in which the CFS research program is located, the Office for Research into Women's Health (ORWH), is a small Office located whose budget (@ $40 million dollars) pales in contrast to the billion dollar plus budgets of some of the institutes. Dr Pinn, the leader of the ORWH, explained that an NIH reorganization bill that was unexpectedly passed in the last hours of the last Congress gave the NIH six-eight months to determine how the Offices will be altered. She listed a range of options that could occur from outright elimination

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of the ORWH to establishment of a new oversight committee that controlled her budget. Until this issue is resolved there will be no new programs for CFS.

There is some opportunity here, however. The Roadmap Initiative proposes that the NIH focus more on multidisciplinary initiatives – a focus the ORWH has been employing with CFS for the past five years. The Trans-NIH group that is now the focus of CFS research efforts at the NIH is a model that the NIH could employ in the future.

Thus there is the possibility that the CFS research program could, given its present direction, take advantage of the huge changes taking place in this immense institution. On the other hand one wonders if it also could be swallowed up or further sidelined without much afterthought. Although Dr. Pinn and Dr. Hanna both were knowledgeable about CFS and appeared committed to producing a successful CFS research program at the NIH the CFS research program there has clearly not enjoyed the support of the upper level NIH officials.

On a more positive note the CFS SEP - the review committee that has been perceived to be a thorn in CFS researchers sides by some advocates – will undergo changes as Dr. Hoffeld, a lightning rod for criticism over the past five years, will be retiring in the near future.

The CDC: Two major events will effect future CFS research at the CDC; the 'payback funds' resulting from the 2000 GAO Investigation are being exhausted, and the CDC is also being reorganized. I spoke to several CDC researchers at the conference. One said enthusiasm within the CFS research team was high but that the whistleblower incident and the GAO investigation in the late 1990's was a huge embarrassment to the agency and that resentment towards both Dr. Reeves and the CFS research program still lingers.

Dr. Reeve's program has been extremely innovative in its efforts to meld genomics, proteomics, laboratory measures and clinical data. The CFS research program has become a kind of showcase for this next step in medical research technology and this, in itself, may help insulate it. On the other hand not all are in agreement with this new approach. Without new funding the CDC program will certainly decline; one researcher spoke of possible cuts of 60%. The future of the CFS research program at the CDC like that of the NIH is in flux.

Both the NIH and CDC appear to be in similar circumstances; while the individuals directly involved in CFS research in both institutions appear to be committed to the success of their programs but it is not at all clear that that commitment is shared by those around them. Indeed, Dr. Agwunobi, the Asst. Secretary of Health, was refreshingly direct when he told the CFSAC that *"You still have to convince the institutions of the importance of this fight"*. Convincing the powers that be in the Department of Health and Human Services that CFS research is important may be the greatest task facing the CFS movement in the U.S. The success or failure of that enterprise will most likely affect every CFS patient. How to achieve this task is the question to which we now turn.

Tom Sheridan, Legislative Advocate for the CFIDS Association of America (CAA): Legislatively Speaking

Tom Sheridan, the legislative advocate for the CFIDS Association of America (CAA), gave an hour long talk on the state of CFS advocacy in Washington. Unfortunately I was lost on the road during his talk. I was, however, able to get an overview of his talk from another CFS patient and talked to Tom afterwards.

Making a Difference: CFS patients may not be able to directly sway the views of NIH or CDC officials but they can dramatically alter how they will act. Tom talked about a CFS patient who got to know a low ranking California legislator in the early nineties who, when he became part of the Appropriations Committee, substantially increased

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funding into CFS. We can look back and see a dramatic spike in funding that was essentially the result of one CFS patient's effort to make a difference. Another moment of serendipity occurred in the early 1990's when CFS advocates were able to get language recognizing CFS into the NIH Reauthorization Act that gave CFS research a foothold in the NIH for the next 15 years.

Given this it was heartening to hear Tom Sheridan say that he believed that scientific and political support for CFS was building up to the critical mass at which real progress may be made. Several factors suggest he is correct; the CAA has been able to build up increasing Congressional support, the good publicity created by the recent CDC media event accompanying the Pharmacogenomic studies and by the ongoing CAA media campaign has resulted in a mostly positive media environment. The administration changeover at the last election creates new possibilities as new individual take over important committees. We have seen how one individual may make a difference in this area. It is important that CFS patients make their lawmakers familiar with CFS issues. This is where we can get the most bang for our buck; where it is possible for one input to multiply a thousand fold.

In fact a recent success story dramatically illustrates how effective advocacy can be. The Whittemore's in Nevada have been able to parley their considerable legislative influence into convincing the state of Nevada to sponsor the first state funded CFS Research Center. This Center will combine research, education efforts with graduate students and physicians and treatment. I was able to talk to Anne briefly at the conference and she indicated her strong commitment, in particular, to build a treatment center for CFS patients. Kimberly McCleary hope that a successful Reno Center will help build a case for a Center of Excellence program at the NIH.

The Whittemore's daughter came down with CFS some years ago and languished until she entered into an Ampligen treatment program. We're very lucky to have in the Whittemore's a couple that is willing to commit both considerable financial resources and time and energy into realizing this project. Anne indicated that a website for the Center will be opening soon. Phoenix Rising will following the progress of this exciting project closely.

I was able to grab Tom and Kimberly Cleary and ask them some questions. Since the termination of the Cooperative CFS Research Centers in 2001 CFS advocates have been trying to get the NIH to open Centers of Excellence that would combine CFS treatment and research. Doing so was an important part of the recommendations that the CFSAC, the federal advisory group for the NIH, submitted to the Director of Health and Human Services. P.A.N.D.O.R.A has been advocating for a Center in Florida lead by Nancy Klimas.

When I asked Tom about the fight to create a Center he explained that the way to get the Centers established was to generate enough heat on the right officials. These Centers, which cost somewhere about a $1,000,000 a year are not expensive relative to other medical research projects. If legislators generate enough heat on NIH officials they could make them happen simply to get them off their desk. We don't have that kind of heat yet. This is one reason why it is important that CFS patients become aware of who their representatives in Congress are and what they are responsible for, and make them aware of our needs.

The possibility that CFS advocacy may be nearing some sort of critical mass doesn't mean CFS is in for good times; indeed failure is a real danger. If the progress generated during these periods does not pan out a movement can collapse in on itself. Tom spoke of these times as a 'make or break' period. Therefore we turn to the next set of talks – those designed to support CFS patients in making a difference with their advocacy.

Support Our Advocacy Organizations: Although a least a million people in the U.S. have CFS the world of CFS advocacy is not a large one.

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The largest CFIDS Association in the U.S., and the only one that is an effective advocate at the federal level, the CAA, has only about 8,000 members, a mere fraction of those effected. Despite its prominence within the CFS community and the many activities it is involved in, the CAA is not a large organization; Kimberly McCleary told me there have been times the CAA has been forced to choose between focusing on the CDC and the NIH. Its staff numbers twelve several of whom are engaged in administrative duties.

The CAA has a grassroots advocacy program patients can join and every year it produces a Lobby Day in Washington, D. C. (click here). The federal advisory committee for CFS, the CFSAC, meets regularly during the year. It is important that CFS patients participate in these meetings in order to demonstrate their support for CFS research. Patient participation has fallen near zero lately however. The CFSAC website has a great deal of information on the federal issues in CFS.

The CAA is the big guy on the block and has at times been a lightning rod for criticism from CFS patients disappointed at the rate of progress in their illness. About 10 years ago, for instance, I had problems with the makeup of the Chronicle and quit – something I now realize was remarkably short-sighted. This is the only CFS organization able to influence the government at the federal level – we need them to be as vital and engaged an organization as possible. I have just rejoined and will join our other major national CFS organization, the IACFS, shortly.

It is important to empower our local CFS support groups as well or even, if one is not available to create one. A group of strong local groups working on regional and national issues can have a strong impact on the future of CFS. In our interview with Marly Silverman she laid out an overview of the process she went through in creating P.A.N.D.O.R.A.. P.A.N.D.O.R.A has not been on the scene for long but it is already engaged in a variety of important issues. The limitations CFS places on one need not prevent someone from engaging in effective advocacy. Marly explained that groups of CFS patients doing what they can, even if in individually small amounts, can combine to make a large impact.

Media Panel:
How to Convey your Advocacy Message to the Media

Moderator: *Marly C. Silverman*
Panel: *Martin Kramer; Ron St. John; Marla Schwartz; and Diane Mohoreanu / Martin Kramer – Media Training 201*

Another way to build CFS support is through the media. Tip O'Neil once said that all politics is local and the much the same is true for the media. National television is the ultimate media event – in one swoop a single interview on a morning news program will reach tens of millions of viewers but such coverage is very rare. All stories start somewhere, though, and this makes local sources such as community newspapers very important. Everyday employees at the media outlets comb through hundreds of community newspapers looking for stories.

Diane Mohoreanu recommended that CFS patients identify reporters who write health related stories and pitch them with stories. If you do get in touch with a reporter it's very helpful to become a source for them and give reporters websites, phone numbers etc. that can help them with their story. If you can get in as a source you have a chance of really making a difference. Familiarity in the media breeds familiarity; reporters like to get a good source and stick with them and this can result in a CFS patient becoming a kind of guide for an entire region. Marly Silverman appears to have achieved this in the Miami/Fort Lauderdale region where she's now been interviewed on the radio and TV. This, of course, takes time. When I asked her how she got to this point she noted it took several years before her efforts really began to bear fruit.

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If you are interviewed there are some things to remember; it's important to speak in personal terms. When news outlets do a piece on CFS they will often want to talk to patients, researchers, physicians, etc. The CFS patient's job in this case is to provide some personal emotional resonance not to give an overview of the state of CFS research or advocacy. If you're lucky enough to get a television interview look the interviewer in the eye and communicate what it's personally like to have CFS. Don't use big words or jargon. Do not comment beyond your expertise – instead refer reporters to people with the appropriate expertise. Never go 'off the record' with a reporter – there is no such thing. Do not answer yes or no questions – these can be traps designed to skew a discussion in a certain direction. Do not step over hostile or inaccurate comments – if something inaccurate shows up in a question then take care of that before answering the question.

One participant in the session said she had been asked by a television host to dumb down her answers (she refused) and asked what she should have done. Our presenter said she should have dumbed her answers down – opportunities on network television are few and far between.

How Not to Build Media Support stated that CFS patients in emotional turmoil or who are severely effected by their illness may not portray CFS in a good light. I talked about this extensively later with a reporter who has CFS. She noted that CFS patients, unfortunately, still sometimes have to fight the perception that not only are they malingerers but that they are 'hysterical' or unbalanced. Because of this they have the extra burden of appearing calm and rational even while they may be are seething inside at the lack of governmental or medical support for their illness.

She related an incident that occurred when a CBS reporter contacted a national CFS organization regarding a CFS story that was, ironically, designed to portray CFS in a positive light. The CFS representative took offense at something the reporter said and ending up posting the reporters private cell phone number on the organizations website. Some of the ensuing phone calls actually physically threatened the reporter. She said this is the kind of bizarre story that makes the rounds at conferences and can damage CFS's credibility for years.

Jacob Teitelbaum, MD:
Understanding and living with CFS/FM. Effective treatment of CFS and Fibromyalgia – including new research on D-Ribose

Unfortunately I did not attend Dr. Teitelbaum's talk on using CORvalen's D-ribose supplement in CFS but I did talk to a Corvalen representative at the conference. D-ribose, which is derived from glucose, is an important structural component of many of the components (DNA, RNA, ATP, FADH, coenzyme-A, and NADH) the mitochondria in our cells need to keep them well supplied with energy. CORvalen's D-ribose has been shown to increase diastolic functioning, physical functioning overall, exercise tolerance and quality of life in congestive heart failure patients. It has also been used to restore energy levels after intense exercise.

Each patient in Dr. Teitelbaum's study took one scoop (5 g) of CORvalen three times a day with food or liquids. The CORvalen representative recommended that CFS patients take the normal dose for a month or so and then cut back to two scoops a day if they wished. It often takes several weeks for CFS patients to determine if its working. He reported that Dr. Cheney began using CORvalen in the middle of 2006.

Why does CORvalen assist diastolic functioning? Because, as Dr. Cheney pointed out at the conference, it takes more energy to relax the heart than to contract it. The CORvalen representative indicated that this applies to the other muscles as well and that the stiffened contracted muscles found after exercise in many CFS and FM patients could be due to energy depletion.

He said that CORvalen, like other CFS treatments, will not cure CFS but it could very well be benefi-

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cial. He was giving out samples and I took one and experienced a substantial energy boost. (I respond quickly and well to most supplements). You can read more about CORvalen in the last issue of Phoenix Rising and visit the CORvalen website at http://www.corvalen.com/index.php.

The Ask the Experts Section

Moderator: *Nancy Klimas, MD*
Panel: *IACFS Board of Directors: David S. Bell, MD; Lucinda Bateman, MD; Kenny De Meirleir, MD, PhD; Patricia Fennell, MSW, CSW-R; Fred Friedberg, PhD; and Charles W. Lapp, MD*

In this session CFS patients got the opportunity to ask CFS experts questions.

What are the chances for full recovery? Does it matter how long you've been ill?

Dr. Lappe stated that its best to get to patients early but that he's had 5, 10, 15 and even patients who've had CFS for 22 years become well – there's always hope for recovery.

What supplements/treatments do you find most effective?

Dr. Lappe started this talk off and others added to it. He noted that none of these are a cure for CFS. What they do is improve your health. He recommended:

- B-12 (3000 mcgs/twice a week) -
- DHEA (quantity unknown) - but said 40-60% of CFS patients showed improvement
- NADH (quantity unknown) - NADH is a current favorite
- COQ10 (100 mgs./day) – about 35% of CFS patients respond
- Magnesium w/malate – good for CFS and FM
- Lysine – orally
- Acetylcarnitine (1000-1500 mgs. 2x's/day)

Dr. Bateman added:

- Vitamin D
- Omega 3 fatty acids

Dr. De Meirleir added:

- Lipoceutical glutathione

Dr Evengaard added:

- Probiotics

How effective is human growth hormone?

Dr. Lappe stated that he always checks the sex hormones and has had some success with estrogen if it's low but not so much with testosterone. He said that two studies have shown modest improvement with HGH but that it was very expensive and because it can contribute to cancer the FDA very tightly regulates who can and cannot use it. Essentially he seemed to feel that it was hard to get, it was very expensive ($1500) and that while it may work it wasn't really worth the effort. He felt that secretagogues that are said to stimulate growth hormone were too weak to be effective.

How important is inactivity a factor in maintaining or contributing to CFS in those who cannot get around?

Dr. Friedman said that there are no hard statistics for this but he felt that only maybe 1 in 4 patients were really inactivity enough for inactivity to be a maintaining factor.

Dr. Lappe said he used the adage 'If you rest you rust'. He said he thought CFS patients were like cement trucks, that as long as truck keeps going the cement can flow but once it stops they really start to hurt. *This does not mean that Lappe advocates continually exercising. Part of the reason that catching CFS early is helpful, I believe, is the physician's ability to initiate appropriate rest periods. I've spoken to a Lappe patient; Lappe does advocate pacing and being attentive to one's body and allowing for rest but he also believes that too much rest can be harmful.*

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Dr. Fennell brought all the pieces together when she stated that particularly during the onset period or during periods of crisis there is a very definite ceiling that CFS patients traverse at their peril. She said that during other periods there is a definite floor as well and that CFS patients should be as active as their floor and ceiling allow. *Dr. Fennell's book deals extensively with the different stages of CFS – she was one of the most dynamic speakers in the conference.*

Cognitive Behavior Therapy (CBT) is a hot button topic in CFS. What role, if any, does CBT play in CFS treatment?

Dr, Friedberg stated that ten ago he said he would have said none, now he feels it does – not as a cure, but as an aid. He noted that CBT is not used just CFS, it is used in heart disease and diabetes and should be useful in virtually any chronic disease.

Dr. Fennell again referred to the different stages that CFS patients go through and felt that CBT is probably useful in some and not in others.

How important is thyroid disorder in this disease? This kicked off a big discussion.

Dr. Lappe said that the idea that because CFS have low basal temperatures they have 'Wilson's Syndrome' was not only inaccurate but dangerous. The low temperatures in CFS are not due to thyroid problems but to hypothalamic problems.

Dr. De Meirleir stated that an RNase L fragment appears to block the activity of the thyroid receptor and this could lead CFS patients to be hypothyroid without have low thyroid levels. He laid out several indices that could be checked to determine if this was so.

Dr. Klimas noted that prescribing thyroid in CFS was quite controversial. Dr. Bateman weighed in by stating that unless there were signs of overt thyroid deficiency that she did not prescribe thyroid. Dr. De Meirleir ended the discussion with the idea of pulsing the thyroid medication if it was used to avoid possible injury.

Some researchers believe that CFS is one of a spectrum of diseases that include fibromyalgia, Gulf War Syndrome, irritable bowel syndrome, multiple chemical syndrome and others. Do you believe this to be true?

Dr. Bateman finds a great deal of similarities between these patients and finds they intergrade with each other greatly. It sounded like clinically they appeared to be different subsets of one general disorder.

* * *

Part II: Dr. Bell and Sleep / Dr. De Meirleir, the Gut and RNase L / What's New in CFS? – A Talk With the Experts / The Sand Castle Awards / Dr. Cheney's Keynote Address

David Bell, MD:
Sleep Disorders are they the Cause or the side effect of CFS?

An engaging talker with a sly sense of humor Dr. Bell showed an impressive grasp of the sleep issues in CFS. He listed nine clinical sleep abnormalities that can be found in CFS and FM. Importantly Dr. Bell noted that studies have shown that 18% of 'CFS patients' don't have CFS: they have a sleep disorder that can, if identified, be treated successfully. He pointed out that sleep studies have shown that sleep architecture in CFS – the way patients move from one stage of sleep to another – is not dramatically different from that of healthy people. However, Dr. Bell is not a big fan of sleep studies. He noted one patient who didn't sleep at all during his stay – a fact noted at the end of the sleep lab report – but nevertheless tested out 'normal'! *We will see evidence of parasympathetic nervous system activation during sleep in the Professional Conference – is this the missing element? Dr. Natelson is also studying cytokine production during sleep.*

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Dr. Bell stated that sleep problems, at least so far as we understand them, are not the cause of CFS. He indicated that virtually everyone with CFS has sleep problems that can be treated fairly well but that doing so does not resolve their CFS. The most common sleep problem is the 'tired but wired' state in which the patient is exhausted but still can't get to sleep. He believes this problem is a by-product of the bodies attempt to increase blood flows to the brain through production of the stimulant adrenaline (epinephrine). Dr. Bell believes that this adrenaline production – which is appropriate when the CFS patient is upright – fails to turn off they lie down, and this prevents them from relaxing. He stated that benzodiazepines such Xanax, valium, etc. can helpful if used properly. *(Benzodiazapine: A class of compounds with antianxiety, hypnotic, anticonvulsant, and skeletal muscle relaxant properties – Stedman's Medical Dictionary)*. He noted that while the over-the -counter medication Benadryl cannot be used continuously it can be used once in a while to go to sleep.

Some CFS patients have the opposite problem, hypersomnia, or excessive sleep. Dr. Bell stated that stimulants such as Ritalin, if used cautiously, can be quite helpful. *A poster in the professional conference will suggest the modafinil can work as well.* Proper sleep behavior or 'sleep hygiene' can be very helpful. This involves going to bed and waking up at certain times, not lying in bed before bedtime, and not lying in bed if you can't get to sleep.

Questions

Q: One patient asked about waking up early in the morning and not being able to get back to sleep.

Dr. Bell suggested that some people don't need as much sleep as they think and that the person consider whether they are one of those people.

Q: One patient said that after going into a hot tub she woke up well rested for the first time in years and asked why.

Dr. Bell noted that a hot shower dilates the blood vessels in the legs and this draws blood down from the brain causing drowsiness and thus can be helpful with sleep for some CFS patients. He believes the alcohol intolerance in CFS is due to the same process.

This discussion got Dr. Bell into a short discourse on low blood volume, a subject he has great interest in. Eighty percent of the patients in Dr. Bell's practice are about a quart low on blood – a rather significant finding given that losing 1 ½ quarts of blood in an auto accident can leave you near death. He doesn't know why blood volume is low, would love to find out but emphatically stated it is not due to altered red blood cell shape. Just as with sleep he has medications he can use to increase blood volume *but it does not help with CFS*. He did note the intriguing case of patients improving on IV saline but does not recommend it. *We will see a poster on IV saline treatment and a fascinating presentation on a low blood volume study in the professional conference.*

Kenny De Meirleir, MD, PhD:
Integrative and complementary medicine in CFS

Dr. De Meirleir gave an overview of his RNase L/ PKR theory of cellular dysregulation in CFS. I was able to talk with Dr. De Meirleir several times – he is a delight to talk with, with an impish sense of humor. At one point he joked that he was getting bored with CFS, that he'd figured it out and was looking for another disease to study. His theory is quite complex but is well worth studying as it is almost uncanny how many aspects of CFS it has come to incorporate over time.

Dr. De Meirleir's major problem is getting funding. He said he could whip out several clinical studies a year, but doing basic research was expensive. He felt he could make major progress in this disease very quickly if he had the funding available to him. He has recently moved to the U.S. in an attempt to drum up more funding. I believe he will be associated with Reno Research Center. For the time being, legal restrictions prevent him from practicing in the U.S.

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In this talk he extended the RNase L model to two areas that have not really been highlighted before; the ability of nitric oxide upregulation to cause muscle weakness by binding to the ryanodine receptors on muscles, and the ability of PKR upregulation to decrease CRH hormone production and, in turn, cause the low cortisol levels we see in CFS.

Dr. De Meirleir has found that CFS patients have higher than normal reactivities to heavy metals particularly nickel. When their lymphocytes are exposed to these substances they proliferate like mad, a reaction that suggests that these substances could be at in part the source of the immune activation in some CFS patients. High heavy metal loads can be treated using IV drips of EDTA, DMSA, HMP and antioxidants (?). He said that because long term DMSA causes kidney damage he prefers using chelators such as glutathione and herbs.

Dr. De Meirleir is focusing heavily on the gut now. He believes there is an underlying weakness in gastrointestinal functioning that predisposes CFS patients to their disease. He has found high levels of antibodies (IgA, IgM) to harmful bacteria in the blood of CFS patients. This indicates that these bacteria have penetrated the lining of the gut and made their way into the blood. The antibodies indicate that B-cells in the immune system have been fighting them off.

Later on in the conference he will note that 70% of the immune surfaces in the body are found in the gut. He believes these harmful bacteria initiate an immune response that can explain many problems in CFS. Initially bacterial proteins called lipopolysaccharides (LPS) activate the toll-like receptors on cells. These receptors then trigger the PKR enzyme to produce prostaglandin (PGE2) and activate the inducible nitric oxide enzyme to produce nitric oxide. The PGE2 prostaglandin causes inflammation, peripheral vasoconstriction (low blood supply to the tissues) and increased blood viscosity. Increased nitric oxide levels cause impaired memory, low NK cell activity, low neutrophil levels, herpes virus reactivation, slowed gastric emptying and low blood pressure. *Note that the probiotics Dr. De Meirleir uses are designed to introduce 'good' bacteria into the gut to replace the harmful.*

I asked him how the process of RNase L dysfunction gets started. He believes that high amounts of cell suicide (apoptosis) allow cellular debris to essentially overwhelm the body's clean-up mechanisims. (Several studies have, in fact, found increased rates of apoptosis in CFS patients and we will see more evidence of its importance in CFS in the professional conference.)

Over evolutionary time a great deal of retroviral DNA has become inserted in our DNA and Dr. De Meirleir believes that apoptotic activity releases these fragments. These are very small nucleotide chains that prompt the 2-5OAS enzyme to produce a peculiar type of 2-5A which binds to the RNase L enzyme but leaves it vulnerable to attack. If this occurs when inflammatory enzymes such as elastase are present they will break RNase L into fragments some of which are 6-10x's more active than normal.

RNase L's job is to cut up RNA and Dr. De Meirleir believes one RNase L fragment cuts up enough human RNA to keep immune cells from functioning properly. One fragment that appears able to affect the ion channels that transport substances in and out of the cells could cause muscular problems, pain sensitization, and immune dysfunction, and also impair heavy metal elimination and glutathione homeostasis. When he put one RNase L fragment into healthy cells he found that they died at lower levels of mercury exposure.

Some proteins produced during this process target cellular thyroid receptors for destruction which could cause the metabolic problems and weight gain seen in some CFS patients. Activation of the PKR system from infections, heavy metals or other processes could cause inflammation, Th2 dominance, nitric oxide upregulation (70% of CFS patients) and increased apoptosis.

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Treatment: Dr. De Meirleir notes there are a lot of subgroups in CFS. His general treatment regime focuses on restoring immune competence, the Th1/Th2 ratio, hormonal balance and intestinal flora, and in treating metal allergy. He often uses a short course of antibiotics (1 week) followed by three months of probiotics. He also uses digestive enzymes, omega-3, vitamin C and B12 and others (lipoceutical glutathione). On average, this results in a 74% decrease in levels of the pro-inflammatory enzyme elastase. Almost 60% of CFS patients experience improvement on the regime.

Q: In general how confident are you that you can help a CFS patient?

Dr. De Meirleir stated that if they're under 30, about 80% have acceptable results. If they're over 50, then results are usually poorer. It depends on how much damage has occurred. He said CFS physicians were still missing important factors in this disease.

What's New in CFS & FM Science, Treatment and Demographics

Introduction: *Nancy Klimas, MD*
Moderator: *Eleanor Hanna*
Panel: *Dharam V. Ablashi, DVM, MS, Dip. Bact.; Kenny De Meirleir, MD, PhD; Birgitta Evengård, MD, PhD; Leonard A. Jason, PhD; Hirohiko Kuratsune, MD, DMedSci.; and Gudrun Lange, PhD*

Dr. Klimas had high praise for Dr. Hanna of the Office for Research Into Women's Health (ORWH) in the NIH, calling her a hard worker endowed with passion for her work, and a real hero for the CFS movement. Dr. Hanna led this discussion. Throughout it she pitched the need for innovative, multi-disciplinary research proposals from CFS researchers to the NIH.

Dr. Kuratsune laid out the very intriguing state of CFS research in Japan. Chronic fatigue research in Japan is booming. The Japanese recognize that chronic fatigue in their population is a real threat not only medically but economically and the Japanese government has initiated a large research program to uncover the causes of chronic fatigue and to uncover treatments. The Japanese government has gone so far as to require that anyone who works over a certain number of hours a month be checked by an 'industrial physician' for signs of chronic fatigue. They estimate that a third of Japanese workers suffer from some form of chronic fatigue and that the problem costs the economy over $10 billion dollars a year.

Kuratsune's research team has marched down a lot of false trails but believes they have found a biomarker for CFS using spectroscopic analysis of serum samples. Dr. Kuratsune was unable to respond to Rich Van Konynenburg question regarding which proteins the analysis revealed because of patent issues, but he seemed quite excited about the finding. He is presently trying to develop an international collaboration to develop the test for world-wide use.

Dr. Gudrun Lange stated that fMRI studies show that CFS patients can generally function fairly well but, to do so, have to use different parts of their brains from those healthy people use. In general patients' brains appear to be functioning in ways similar to those of people who are much older. Its unclear right now if there is a dysfunction in just one part of the brain or if it's systemic; CFS patients show signs of both kinds of dysfunction.

Dr. Kenny De Meirleir believes that most problems in CFS originate in the gut and then branch out from there. Approximately 70% of the immune system surface in the body is found in the gut – a system that covers about the size of a football field. Eighty percent of CFS patients exhibit maldigestion of certain substances. Regular findings of antibodies to intestinal bacteria in the blood indicate that disturbed barrier functioning in the gut has allowed intestinal bacteria to make their way into the blood. CFS patients also exhibit increased uptake of heavy metals with almost 60% of them having an allergy to nickel, an immune system inducer.

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Dr. De Meirleir believes predisposing factors are present in CFS but that the triggering factor is often an infectious agent.

Dr. Hanna asked about the efficacy of SSRI's given the large number of serotonin receptors in the gut. Dr. De Meirleir replied that some CFS patients improve on them, some don't, and some get worse.

Dr. Leonard Jason noted how important the IACFS was becoming as an organization. He felt it had been revitalized in recent years and will provide a strong impetus for research. The IACFS developed a Pediatric Definition that indicates that kids with CFS have somewhat different symptoms than do adults. He noted that since 4-5% if the population has six or more months of fatigue, it is critical that researchers be able to develop homogenous groups to sample. He also noted that the escalation of the war in Iraq will deprive medical researchers of much needed funds.

Dr. Daram Ablashi is trying via the HHV-6 Foundation to assess the prevalence of HHV-6A in multiple sclerosis and CFS. They have not been able thus far to find antibodies that differentiate HHV-6A and B. The Foundation has looked at a lot of antiviral compounds but most have not worked.

Question Period

Q: Rich Von Konynenburg asked if glutathione had been effective in treating HHV-6. (The HHV-6 Foundation has been testing numerous substances against HHV-6 in test tubes. Early tests suggested that lipoceutical glutathione might be quite effective)

Dr. Ablashi – stated that while lipoceutical glutathione worked on some tests, it did not appear to affect HHV-6 in cells.

Q: What is the current thinking on Epstein-Barr Virus?

Dr. Klimas – EBV reactivation is possible in CFS. Dr. Glaser believes that EBV may be giving the cell DNA that is gumming up the works.

Q: CFS research generates about 300 papers a year vs. about 15,000 on breast cancer. What's going on here? (This question generated applause.)

Dr. Hanna stated that there is a great deal known about breast cancer and that it's been studied extensively for years. CFS will not get large amounts of funding until there is a critical mass of basic science to build on that will help CFS researchers put the pieces together.

Dr. Klimas noted how frustrating this problem was. She said CFS vitally needed to have more scientists interested in studying it.

(The breast cancer analogy was an interesting. Dr. Pinn has stated that breast cancer research funding was very low when she became head of the ORWH in the early 1990s. One wonders if one of CFS's sister diseases, fibromyalgia, is reaching that critical mass as we're seeing a lot of fibromyalgia studies now. *A poster in the conference will speak to this.* If this is true it demonstrates that the tide can turn even for controversial diseases.)

Q: A representative of the Great Plains Laboratory asked Dr. De Meirleir to comment on the fact that they are seeing some similar markers in autism and CFS, FM and multiple sclerosis.

Dr. De Meirleir stated that mothers with CFS have 3-4 times perhaps even 10 times more chance of having autistic children. He's collecting data on this now.

Dr. Hanna closed the session by imploring CFS researchers to be creative in looking for funding right now. She noted that there's a lot of money going into autism research right now and creative CFS researchers could tap into it. When I talked with her later she said it's very possible to have a 'CFS study' that doesn't mention CFS in the title but has a CFS patient control group. She appeared somewhat frustrated that some CFS researchers

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felt they had to have CFS in the title of their paper.

Next we had the dinner and during it the Sand Castle Awards and the Keynote Address.

The P.A.N.D.O.R.A. Sand Castle Awards

- **Life Time Achievement:** Marc Iverson
- **Outstanding Male Advocate of the Year:** John Herd
- **Outstanding Female Advocate of the Year:** Pat Fero
- **Pioneer Spirit Awards:** Paul Cheney; Nancy Klimas; David Bell; Dan Peterson
- **Author of the Year:** Dorothy Wall for *Encounters with the Invisible*
- **Founder's Award:** Rebecca Artman

Dorothy Wall was unable to attend the conference but did provide an address via video.

Keynote Address

Dr. Paul Cheney:
The State of the Art of CFS

Dr. Cheney's address was both exasperating and exciting. After a long conference day and a full meal, patients were hardly ready to take in a lot of technical information but they sure got it. Around my table I saw eyes rolling and people getting up and heading for the door. I had trouble keeping my eyes open as well but every now and then, as he always does, Dr. Cheney would drop in something absolutely riveting. Because I was unable to keep up with Dr. Cheney's rapid fire presentation parts of it will be missing. My comments are in italics.

CFS Patients Are Functionally Hypoxic. Dr. Cheney started off in characteristically dramatic fashion showing a slide of Mt. Everest (29,028 ft.) with ⅓ of the oxygen at sea level and announcing that the problems CFS patients face are very similar to those that climbers at the top of Mt. Everest face. *(Hypoxia: Decrease below normal levels of oxygen in inspired gases, arterial blood, or tissue – Stedman's Medical Dictionary)*

Next he jumped to picture of a fetus noting that a fetus gestates at an effective altitude of 29,000 ft. because it does not have the physiology to handle oxygen. Although oxygen plays a central role in the aerobic energy production process it is not a benign substance. Oxygen is delivered into the mitochondria of cells by red blood cells where it functions as an electron carrier in the electron transport chain. As oxygen becomes charged it turns into a free radical called superoxide which can, if it is not quickly degraded, be turned into two free radicals: peroxynitrite or the hydroxyl radical. Superoxide degradation is so critical that it constitutes the most rapid enzymatic reaction that takes place in the body. Energy production is synonymous with free radical production.

Dr. Cheney believes an injury to the antioxidant system that degrades superoxide is the central facet of CFS and that the 'body' down-regulates ATP production in order to spare it from free radical injury. *Although the outward manifestations of Dr. Cheney's theory have changed dramatically, this aspect has not – it has been a central part of his theory for many years. His explorations with whey protein were an attempt to boost the antioxidant properties of the cell.*

Early in their development fetuses grow under hypoxic conditions but later on grow under normal oxygen levels. The foramen ovale allows oxygen rich maternal blood to bypass the lungs as it travels from the right to the left side of the fetuses heart. The foramen ovale is closed at birth by increased blood pressure on the left side of the heart.

Energy Production and the Heart. Dr. Cheney noted that most of the energy consumed by the heart occurs not when it pumps out the blood during the systolic phase but during the relaxation or diastolic phase in which it (the left ventricle) fills up with blood. This means that if someone has an energy deficit – as he believes CFS patients do – they're not going to have a problem with pumping the blood out but with drawing blood into the heart. The filling phase has two parts; first the mi-

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tral valve opens to allow blood in – this allows some filling but the heart needs more. In the second phase, a contraction forces more blood into the ventricle.

A Personal Tragedy Results in New Insights. Dr. Cheney then shared how his own experience with heart failure contributed to his new look at CFS. As he began to recover from his heart transplant Dr. Cheney felt he was recapitulating many of the symptoms that his CFS patients had suffered from. It was then that someone handed him the just-published Peckerman paper which suggested CFS patients that cardiac problems in CFS were accentuated while they were lying down – a sign of diastolic dysfunction. *Even though their cardiac output was higher when the CFS patients were lying down the difference between their output and that of the healthy controls was actually greater then. The weak heart is actually under more stress when lying down because it has to deal with more blood than when one is standing. Heart failure patients end up standing upright 24 hours a day in order to spare their heart.* Approximately 50% of the CFS patients in Dr. Peckerman's study had low cardiac output. Dr. Cheney noted that more of his patients did (@80%) probably because he had a more disabled patient population.

Dr. Cheney calls the heart problems in CFS "CFS Associated Cardiomyopathy" or "CAD". *In an earlier talk Dr. Cheney accentuated that CFS patients were in "heart failure".* Here he noted that 25% of heart failure patients die within a year but that none of his CFS patients had ever reached that point. *There is a difference between diastolic dysfunction and diastolic heart failure. In diastolic dysfunction the heart is behaving improperly but it has not reached the point at which the heart muscle has entered a precipitous decline. One researcher has postulated that diastolic heart failure is reached when the patient is exhibiting symptoms of blood backing up into the lungs (pulmonary congestion). Since this is not usually observed in CFS patients, it seems that diastolic dysfunction is a more appropriate term for the process occurring there. As I remember this is the term Dr. Cheney usually used.*

One of the questions regarding Dr. Cheney's theory of heart failure in CFS has been that CFS patients rarely exhibit the key sign of heart failure, namely "shortness of breath". Dr. Cheney explained this conundrum by saying that diastolic heart failure patients more commonly evidence orthostatic intolerance – a condition often found in CFS – than shortness of breath. *Dr. Cheney's slide of typical heart failure signs/symptoms (fatigue, exercise intolerance and others) did not include several other symptoms also commonly found with heart failure, including morning edema in the ankles, distinctive heart and lung sounds and heart enlargement. All the websites from major medical organizations still associate diastolic heart failure with shortness of breath upon exertion. One site furnished findings from a study that indicated that shortness of breath was more commonly found in diastolic than in systolic heart failure. Perhaps Dr. Cheney has information that they do not.*

Dr. Cheney then introduced an intriguing slide showing that diastolic heart failure rates among women had risen dramatically since about the mid 1980s – or about the time CFS showed up on the scene. He said that researchers had been unable to account for this rise. *He didn't explain why he showed this slide but it suggested he thought that there was a commonality between the two.*

Dr. Cheney then went through a variety of different cardiac findings in CFS and concluded that most CFS patients display a pattern of blood flow through the heart called 'pseudonormalization.' which is indicative of an intermediate case of diastolic dysfunction. He noted that almost all CFS patients had at least one abnormal reading in four different tests of blood flow. He then introduced an interesting table that looked at population-wide averages of diastolic dysfunction in older Americans.

Opinions differ on what constitutes diastolic dysfunction (DD). Several of the tests of diastolic dysfunction, including some but not all used by Dr. Cheney, have not been found to correlate well with fitness or with more stringent measures of cardiac functioning and this has lead some to question their importance. This is presumably why Dr. Cheney introduced what he called a conservative measure of

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diastolic dysfunction created by the Mayo Clinic and then compared how many CFS patients versus older patients in the general population met the criteria for diastolic dysfunction. *Diastolic dysfunction has been believed to be primarily an older person's disease. Intriguingly it is also primarily a women's disease.* This was, I thought, one of the more convincing arguments for its association with CFS. Unfortunately my notes are not clear as to percentages but while a subset of CFS patients did not meet the Mayo criteria for DD, most of his patients met the criteria for either mild or intermediate DD.

As was noted earlier most CFS patients have a pseudonormalized pattern of blood flow. This would indicate that the left ventricle has stiffened sufficiently to prevent it from filling properly during the second (a) phase of the diastolic pulse. My reading of medical papers indicates that this phase is usually accompanied by hypertrophy of the heart and shortened breath during exertion – two problems Dr. Cheney did not say were present in his patients. Patients with this condition should also demonstrate abnormalities during the Valsalva maneuver – again something studies have not found in CFS. The diastolic dysfunction in CFS appears to be different than normally found?

Functional hypoxia – A Key Aspect of CFS. Dr. Cheney then popped open eyes that had begun to glaze over by showing, this time using a hyperbaric chamber, that if you put young men in an environment with really low oxygen levels their hearts begin to look very much like those of CFS patients (going to back to the reference to the Himalayas). He went through this pretty quickly but the confluence in test results between the two was striking. This suggested that heart problems in CFS may be due to a low oxygen environment.

Patent Foramen. Dr. Cheney reported that his CFS patients exhibit very high rates (90%) of an abnormality called a 'patent foramen'. Remember the valve (patent ovale) that is closed in a fetus once it is born? The patent foramen (ovale) (foramen = hole) is what that valve is called if it opens in adults (= becomes patent).

Every time the patent foramen opens it allows some CO2/O2 to escape into an artery. Some of these gases may find their way into the brain and Dr. Cheney indicated that patent foramens may be implicated in stroke and migraine. But what is causing this problem in CFS? Dr. Cheney showed that simply giving CFS patients oxygen through the nose caused the patent foramen to close off in a significant subset of his patients. He concluded that the patent foramen and the other cardiac problems in CFS are due to an 'oxygen dependent diastolic dysfunction' and that this is a hallmark of CFS.

Patent foramen (ovale). *The patent foramen ovales may be more prevalent in CFS but is it in itself a significant medical problem? This is another grey area in medicine. Approximately 25% of the population has one and physicians differ as to their significance. Patent foramens differ in severity; some open only when one is lifting something or coughing, others are open more frequently. Because they can be induced some believe physicians are finding more of them simply because they are looking harder for them. Recent studies suggest they are not implicated in stroke but this is still a grey area. There is e is disagreement about how aggressively they should be treated or, indeed, if they should be treated at all. Patent foramen ovales are not associated with any symptoms. See the professional conference summary for Dr. Cheney's theory on why they are so common in CFS.*

Treating a CFIDS Associated Cardiomyopathy (CAD). We now come full circle to Dr. Cheney's thesis that a functional hypoxia is central in CFS. *This is not your normal garden variety of hypoxia – CFS patients don't appear to have even mild systemic hypoxia.* Dr. Cheney again stated that he believed the problem lay in the inability of the antioxidant enzyme system (glutathione peroxidase/catalase) to degrade the free radicals produced during mitochondrial activity. He noted that some viruses can inhibit these enzymes and that the glutathione peroxidase enzyme that produces the master detoxifier glutathione may be particularly vulnerable to mitochondrial problems because it requires a lot of energy. Now Dr. Cheney came to the treatment.

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Here the address almost came to a halt as Dr. Cheney was informed he had used up his time! The patient outcry, of course, was rather intense as they saw their reward for sitting through a highly technical lecture after a really full day about to be dashed, and Dr. Cheney was allowed to finish.

The detoxifying enzymes (catalase, glutathione peroxidase) are produced by the liver and Dr. Cheney's strategy is to boost their levels by boosting liver production. He is attempting to do this by using, if my notes are correct, adolescent porcine liver extract ???, hawthorn and low amounts of human growth hormone to jumpstart the process. He said that at 90 days he saw about 30% improvement in one common diastolic abnormality (IVRT).

This was a fascinating lecture. It is still unclear how important diastolic dysfunction is to the pathophysiology of CFS, i.e. whether it is a primary or secondary feature, but Dr. Cheney is presenting evidence that it is present and should be investigated further. What was most interesting to me as a layman were the connections between Dr. Cheney's findings and others presented at the conference. These connections will be explored further in the upcoming Professional Conference overview.

* * *

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Philosophy

To do is to be.
– Socrates

To be is to do.
– Jean-Paul Sartre

Do-be-do-be-do.
– Frank Sinatra, "Strangers In The Night"

Just what else does CFS stand for?

CFS: **California Floaters Society** (society for river craft – canoe, kayak etc – enthusiasts, US)
CFS: **Canadian Federation of Students**
CFS: **Canadian Forces Station** (military installation)
CFS: **Canadian Forest Service**
CFS: **Center for Faulkner Studies** (Southeast Missouri State University, US)
CFS: **Center for Family Studies** (US)
CFS: **Center for Fluorescence Spectroscopy** (US)
CFS: **Center for Food Safety** (US)
CFS: **Center for Frontier Sciences** (at Temple University, US)
CFS: **Certificate in Forensic Studies** (Australia & US)
CFS: **Česká Fyzikální Společnost** (Union of Czech Mathematicians and Physicists, Czech Republic)
CFS: **Christian Family Schools** (homeschooling, US)
CFS: **Church Farm School** (US)
CFS: **Child and Family Service** (Hawaii)
CFS: **Climate Forecast System** (US)
CFS: **Clinical Financial Services** (US)
CFS: **Collegiate Funding Services** (US student loan institution)
CFS: **Colonial First State** (financial institution. Australia)
CFS: **Columbia Funeral Service** (US)
CFS: **Computer Forensic Services** (law firm specialising in computer analysis, US)
CFS: **Consumer and Family Sciences** (College at Purdue University, US)
CFS: **Container Freight Station** (Mumbai Customs, India)
CFS: **Continuous Funding System** (Karachi Stock Exchange)
CFS: **Co-operative Financial Services** (UK financial institution)
CFS: **Corvallis Folklore Society** (US)
CFS: **Country Fire Service** (South Australia)
CFS: **Creative Financial Staffing** (employment agency, US)
CFS: **Cubic feet per second** (cfs)
CFS: **Customer First Stores** (combination pharmacy and supermarket, Japan)

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Welsh study points to need for CFS education for general practitioners

A Welsh study published in BMC Family Practice sheds light on the beliefs and CFS knowledge of the region's general practitioners (GPs). Interestingly, the results seem to mirror what many CFS patients worldwide express as frustration about a lack of information and validation on the part of doctors.

The aim of the Cardiff University study was to investigate the opinions of CFS sufferers and compare them to the current thinking of GPs from the same geographical region.

More than 100 survey booklets were sent to GP offices in the Gwent Health Authority region of Wales. Another 197 survey booklets were sent to CFS sufferers.

The GPs surveyed were asked two fundamental questions:

(1) did they believe that there was a single entity called chronic fatigue syndrome; and if so,

(2) had they ever diagnosed patients with this illness? GPs who answered yes were then asked to supply details of diagnostic criteria and treatment strategies. They were also asked if their offices carried any CFS information for patients.

Patients were asked questions about diagnosis, treatment and physician attitudes.

Of the 45 GPs who responded, just 56 percent believed that CFS is a recognised condition. Of those who believe the illness exists, none reported using the CDC or Oxford criteria for CFS definition. Surprising, since both case definitions are readily available. In addition, nearly 40 percent of the GPs weren't aware that a CFS specialist was available within their region.

Both patients and GPs indicated that it took an average of six visits to diagnose CFS. Interestingly, an overall range of 2 to 20 appointments to diagnose the condition was identical for both groups.

Armed with this information, Welsh health authorities hope to launch a CFS education program for health care professionals and patients.

Medical Editor's note:
This Welsh study's results mirror other similar studies, including one done in Australia several years ago. How can CFS sufferers get the help they need with this level of ignorance?

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Colin's choice

When the husband came home from work, he was greeted by his wife with the demand that she be taken out that night.

"Where would you like to go?" he asked.

"I don't know… somewhere expensive," she replied.

So he took her to a petrol station.

– author unknown

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Research on CFS and working memory

Casera X, Mataix-Cols D, Giampietro V, Rimes K, Brammer M, Zelaya F, Chalder T, Godfrey E. Probing the working memory system in chronic fatigue syndrome: a functional magnetic resonance imaging study using the n-back task. Psychosomatic Medicine 2006; 68:[e-published ahead of print]

A collaborative study by researchers in Spain and the U.K. found that CFS patients do not engage the working memory of the brain in the same way as healthy control subjects do. The results were published in the peer-reviewed journal Psychosomatic Medicine.

Working memory refers to the capacity to store information in short-term registers while simultaneously manipulating it to perform a task. This is a crucial cognitive function for human thought processes such as reasoning and comprehension because it enables us to process task-relevant information.

Using fMRI imaging on the brain, 17 patients with CFS and 12 healthy control subjects were scanned while performing a specific set of increasingly challenging memory tests. Study participants were presented with a series of capital letters projected onto a screen, one at a time. As this occurred participants were required to press a button whenever the letter presented was the same as one presented a specified number of images previously – first at 1 image previously, then at 2 and finally at 3 images previously (1-back, 2-back and 3-back). This is called an n-back test.

Both groups performed comparably well and activated the working memory network during all task levels. However, during the "1-back" test session, the fMRI showed that patients with CFS experienced greater activation in the medial prefrontal regions of the brain. Furthermore, on the "2- and 3 -back" sessions, patients, but not control subjects, significantly activated a large cluster in the right inferior/medial temporal cortex. In fact, trend analyses of task load demonstrated statistically significant differences in brain activation between the two groups as the demands of the task increased.

These results suggest that patients with CFS show both quantitative and qualitative differences in activation of the working memory network compared with healthy control subjects. The researchers leading this study speculate that patients with CFS may recruit alternate regions of the brain to compensate for problems in the working memory network.

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From the President (continued)

(Continued from page 5)

I wish you a good 2007 on behalf of all of us at the Society. May your inner life be rich and your outer life marked by better health and by increased support and understanding from those you interact with. And I hope that you'll join your energies with ours to make this a year when things get better for everyone with ME/CFS and MCS in South Australia.

Peter Cahalan

Study: How is memory and concentration affected in CFS?

A study is being undertaken into cognitive functioning in chronic fatigue syndrome by a University of Adelaide Masters student, Susan Cockshell, and her supervisor, Assoc. Prof. Jane Mathias in the School of Psychology. The aim is to better understand how cognitive functioning in people with CFS is related to effort, CFS symptoms, daily activities and psychological status. To investigate the commonly reported problems of memory and concentration, Susan is using a selection of cognitive tests and questionnaires that help to capture and quantify these problems. In the future, this research may help in identifying problems in this area in people with CFS so that assistance and strategies can be developed and changes in functioning recorded.

Unfortunately, we do not have a measure of a person's performance before they developed CFS. Therefore, each individual is 'matched' to a healthy person who is the same gender, age and education level. Since July 2006, 50 people with CFS and 17 healthy people have generously donated their time to be a part of this study. To complete the study Susan needs 60 people in each group (a total of 120 people), to answer some questionnaires and spend a few hours exploring their memory, concentration and other cognitive areas. If you have CFS, are seeing one of the following doctors (for consistency of diagnosis): Dr Richard Burnet; Dr Peter Del Fante; Dr Ian Buttfield, and are interested in this study, please contact Susan using the details provided below. Alternatively, if you or someone you know is healthy and may be able to contribute to this important study by acting as a participant in the healthy comparison group, please encourage them to contact Susan to discuss this possibility.

The study should be completed by mid-year and a summary of the results will be provided in this newsletter later in the year. For further information, or to indicate your interest, please contact Susan Cockshell by telephone on 08 8365 5935 (home) or 041 337 0366 (mobile) or email: susan.cockshell@student.adelaide.edu.au.

And on the subject of memory...

- -

Patient: "Doctor, I can't remember anything! I forgot what happened yesterday. I forgot what my car looks like. I can't even remember my own name."

Doctor: "When did this happen?"

Patient: "When did what happen?"

- -

Memory is what tells a man his wedding anniversary was yesterday.

- --

- -

Husband to wife, "The doctor gave me some pills yesterday to improve my memory."

"So?" exclaimed the wife.

"So I forgot to take them," replied the husband.

- -

Thirty days hath September,
All the rest I can't remember.

- -

Carnitine Study

Study Title: *Comparison of Plasma Carnitine Levels in Patients with Chronic Fatigue Syndrome and Healthy Controls*

Researcher: ***Stephanie Reuter*** *(PhD Candidate)*
Phone: 8302 1872
Email: stephanie.reuter@unisa.edu.au
Institution: *Sansom Institute*
University of South Australia
Frome Road
Adelaide, SA, 5000

Stephanie is conducting a clinical research study to investigate the blood levels of a naturally occurring compound called Carnitine in Chronic Fatigue Syndrome patients and healthy subjects. Carnitine is found in all mammals and is involved in energy production. Previous research has suggested that the levels of carnitine in the blood of patients with Chronic Fatigue Syndrome are different to those in healthy people.

Each volunteer will have a blood sample collected on a single occasion. This blood sample will then be used to determine the amount of carnitine and its related compounds in plasma (a component of blood). The amount of carnitines will be compared to results obtained from healthy subjects. Basic demographic details and details about each individuals Chronic Fatigue Syndrome will also be recorded.

Redlabs U.S.A.

By ***Peter Mitchell****.*

Those who have been researching ME/CFS will probably be aware of the existence of RED Laboratories. The lab has put in place procedures developed by Prof Kenny De Meirleir and his colleagues.

Formed in Belgium, RED Laboratories is a company which has developed and patented tests and recommendations for treatment of ME/CFS. This is big news in the ME/CFS community.

Since late 2006, they are in the USA as well, having set up Redlabs U.S.A. in Nevada. Their new website (http://www.redlabsusa.com) provides lots of information not only for doctors, but also for patients and their supporters.

Some pages were still under construction as we prepared this edition, but there is still lots there of interest.

Members who attended Prof De Meirleir's talk or the follow-up sessions in Adelaide in 2005 will recognise some of the material in the PowerPoint presentation on the website's Physician's Resources page.

New therapy for chronic fatigue syndrome to be tested at Stanford University School of Medicine

STANFORD, Calif. – A preliminary study suggests there may be hope in the offing for some sufferers of chronic fatigue syndrome with a new therapy being tested by researchers at the Stanford University School of Medicine.

José Montoya, MD, associate professor of medicine (infectious diseases), and postdoctoral scholar Andreas Kogelnik, MD, PhD, have used the drug valganciclovir – an antiviral often used in treating diseases caused by human herpes viruses – to treat a small number of CFS patients.

The researchers said they treated 25 patients during the last three years, 21 of whom responded with significant improvement that was sustained even after going off the medication at the end of the treatment regimen, which usually lasts six months. The first patient has now been off the drug for almost three years and has had no relapses. A paper describing the first dozen patients Montoya and Kogelnik treated with the drug was published in the December issue of *Journal of Clinical Virology*.

"This study is small and preliminary, but potentially very important," said Anthony Komaroff, MD, professor of medicine at Harvard Medical School, who was not involved in the study. "If a randomized trial confirmed the value of this therapy for patients like the ones studied here, it would be an important landmark in the treatment of this illness."

Montoya has received a $1.3 million grant from Roche Pharmaceutical, which manufactures the drug under the brand name Valcyte, to conduct a randomized, placebo-controlled, double-blind study set to begin this quarter at Stanford. The study will assess the effectiveness of the drug in treating a subset of CFS patients.

Montoya is speaking about his efforts at the biannual meeting of the International Association for Chronic Fatigue Syndrome in Fort Lauderdale on Jan. 11 and 12.

Chronic fatigue syndrome has baffled doctors and researchers for decades, because aside from debilitating fatigue, it lacks consistent symptoms. Although many genetic, infectious, psychiatric and environmental factors have been proposed as possible causes, none has been nailed down. It was often derided as "yuppie flu," since it seemed to occur frequently in young professionals, though the Centers for Disease Control and Prevention says it's most common in the middle-aged. But to those suffering from it, CFS is all too real and its effects are devastating, reducing once-vigorous individuals to the ranks of the bedridden, with an all-encompassing, painful and sleep-depriving fatigue.

More than 1 million Americans suffer from the disorder, according to the CDC. The disease often begins with what appears to be routine flulike symptoms, but then fails to subside completely – resulting in chronic, waxing and waning debilitation for years.

Valganciclovir is normally used against diseases caused by viruses in the herpes family, including cytomegalovirus, Epstein-Barr virus and human herpes virus-6. These diseases usually affect patients whose immune systems are severely weakened, such as transplant and cancer patients. Montoya, who had used the drug in treating such patients for years, decided to try using it on a CFS patient who came to him in early 2004 with extremely high levels of antibodies for three of the herpes family viruses in her blood. At the time, she had been suffering from CFS for five years.

When a virus infects someone, the levels of antibodies cranked out by the immune system in response typically increase until the virus is over-

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come, then slowly diminish over time. But Montoya's patient had persistently high antibodies for the three viruses. In addition, the lymph nodes in her neck were significantly enlarged, some up to eight times their normal size, suggesting her immune system was fighting some kind of infection, even though a comprehensive evaluation had failed to point to any infectious cause.

Concerned about the unusual elevations in antibody levels as well as the swelling of her lymph nodes, Montoya decided to prescribe valganciclovir. "I thought by giving an antiviral that was effective againstherpes viruses for a relatively long period of time, perhaps we could impact somehow the inflammation that she had in her lymph nodes," said Montoya.

Within four weeks, the patient's lymph nodes began shrinking. Six weeks later she phoned Montoya from her home in South America, describing how she was now exercising, bicycling and going back to work at the company she ran before her illness. "We were really shocked by this," recalled Montoya.

Of the two dozen patients Montoya and Kogelnik have since treated, the 20 that responded all had developed CFS after an initial flulike illness, while the non-responders had suffered no initial flu.

Some of the patients take the drug for more than six months, such as Michael Manson, whose battle with CFS has lasted more than 18 years. The former triathlete was stricken with a viral infection a year after his marriage. After trying unsuccessfully to overcome what he thought were lingering effects of the flu, he had no choice but to drastically curtail all his activities and eventually stop working.

During his longest period of extreme fatigue, 13½ weeks, Manson said, "My wife literally thought I was passing away. I could hear the emotion in her voice as she tried to wake me, but I couldn't wake up to console her. That was just maddening."

Now in his seventh month of treatment, Manson is able to go backpacking with his children with no ill after-effects. Prior to starting the treatment, Manson's three children, ages 9 to 14, had never seen him healthy.

Montoya and Kogelnik emphasized that even if their new clinical trial validates the use of valganciclovir in treating some CFS patients, the drug may not be effective in all cases. In fact, the trial will assess the effectiveness of the medication among a specific subset of CFS patients; namely, those who have viral-induced dysfunction of the central nervous system.

"This could be a solution for a subset of patients, but that subset could be quite large," said Kristin Loomis, executive director of the HHV-6 Foundation, which has helped fund a significant portion of the preparatory work for the clinical trial. "These viruses have been suspected in CFS for decades, but researchers couldn't prove it because they are so difficult to detect in the blood. If Montoya's results are confirmed, he will have made a real breakthrough."

"What is desperately needed is the completion of the randomized, double-blind, placebo-controlled clinical trial that we are about to embark on," Montoya said.

People interested in participating in the clinical trial must live in the San Francisco Bay Area. More information about the clinical trial is available online at http://www.vicd.info/clinicaltrial.html.

Stanford University Medical Center integrates research, medical education and patient care at its three institutions: Stanford University School of Medicine; Stanford Hospital & Clinics; and Lucile Packard Children's Hospital. For more information, please visit the Office of Communication & Public Affairs site at http://mednews.stanford.edu.

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Information about ME/CFS

What is ME/CFS?

Myalgic Encephalopathy/Chronic Fatigue Syndrome (ME/CFS) is characterised by **severe, disabling fatigue and post-exertional malaise**. Fatigue is just one symptom – there are a multitude of others. ME/CFS is a not uncommon medical disorder that causes significant ill health and disability in sufferers.

Myalgic Encephalopathy/Chronic Fatigue Syndrome (ME/CFS) is also known by other names such as Post Viral Fatigue Syndrome, Chronic Fatigue and Immune Dysfunction Syndrome (CFIDS) and Myalgic Encephalomyelitis.

It is now officially recognised by the World Health Organization International Classification of Diseases and by recent international and Australian guidelines on ME/CFS.

Prevalence

ME/CFS affects all social and ethnic groups. There is a predominance of females (2 to 1) and a bimodal distribution with peaks between 15-20 year olds and 33-45 year olds. The prevalence of ME/CFS varies between 0.2% and 0.5% of the total population. In South Australia this translates to between 3,000 and 7,000 cases at any one time.

Main characteristics of ME/CFS

Disabling fatigue for at least 6 months, along with cardinal symptoms such as:

- muscle aches and pain;
- unrefreshing sleep or altered sleep patterns;
- neuro-cognitive dysfunction (e.g. poor concentration and memory);
- gastro-intestinal symptoms (e.g. irritable bowel);
- orthostatic intolerance (e.g. low blood pressure);
- and unusual headaches.

A hallmark of the condition is that symptoms are usually ***worsened*** with minimal physical and mental exertion.

Diagnosing ME/CFS

Note that there are many *other conditions* which may need exclusion by your doctor before a diagnosis of ME/CFS may be made. These include, Hypothyroidism, Hyperthyroidism, Diabetes Mellitus, Addison's disease and Multiple Sclerosis, just to name a few.

ME/CFS may also *co-exist* with or mimic symptoms associated with: fibromyalgia; multiple chemical sensitivity; Irritable Bowel Syndrome; depression; anxiety disorders; and somatoform disorders.

This can make the diagnosis of ME/CFS and any coexisting conditions difficult.

Definition

There are many definitions of ME/CFS. The Fukuda Criteria (1994) is still considered the international benchmark for use in ME/CFS research, and is often used as a de facto clinical definition. However, many see the criteria as being vague and over inclusive. Furthermore, they downplay (i.e. make optional) post-exertional malaise and other cardinal ME/CFS symptoms.

The term Chronic Fatigue Syndrome may convey the perception that sufferers are simply overtired. However, fatigue is just one of a multitude of symptoms.

The Canadian Expert Consensus Panel published the first diagnostic ME/CFS criteria for clinical use in 2003. In contrast to the Fukuda Criteria, this new definition made it compulsory that to be diagnosed with ME/CFS, a patient must become symptomatically ill after minimal exertion. It also clarified other neurological, neurocognitive, neuroendocrine, autonomic, and immune manifestations of the condition.

A modified tick chart of the Canadian Clinical Criteria is included in the document "ME/CFS Guidelines: Myalgic Encephalopathy (ME)/ Chronic Fatigue Syndrome (CFS): Management Guidelines for General Practitioners – A guideline for the diagnosis and management of ME/CFS in the community or primary care setting", available on our website and distributed to all GPs in SA.

How is ME/CFS treated?

All treatment should be patient-centred and involve supportive counselling, lifestyle management and the setting of realistic goals. There is no known cure for ME/CFS. Management is geared at improving functionality and symptom control through an effective therapeutic alliance between the patient and their GP.

Therapy for ME/CFS is intended primarily to relieve specific symptoms. It must be carefully tailored to meet the needs of each patient. Sleep disorders, pain, gastrointestinal difficulties, allergies and depression are some of the symptoms which may be relieved through the use of medications and other interventions.

Lifestyle changes including appropriate rest, reduced stress, dietary measures/restrictions and nutritional supplementation may be of benefit. Supportive therapy, such as counselling, can help to identify and develop effective coping strategies.

There is still a great deal of controversy surrounding the issue of whether people with ME/CFS should undertake intentional exercise. Most ME/CFS patient groups recommend that sufferers pace themselves by starting with gentle exercises and slowly increasing levels of exercise without causing a significant relapse of symptoms. It is important to maintain physical fitness if possible, but we recognise that exercise is not always the best possible use of sufferer's limited energy reserves.

Prognosis

The prognosis for ME/CFS patients is variable. Most will generally improve in functionality to some degree over time, usually 3 to 5 years. However, symptoms may fluctuate or relapses may occur from time to time. Early intervention and positive diagnosis often result in a better prognosis. However, a significant proportion of patients will remain quite debilitated for longer periods of time.

Support Groups

Adelaide Support Group

The Adelaide Support Group meets on the fourth Tuesday of each month.

Venue: Uniting Pilgrim Church, 14 Flinders Street, Adelaide (behind Adelaide City Council).
Time: 12:00 pm to 2:00 pm.
Contact: Darryl Turner.
Phone: The office on (08) 8410 8929 to confirm attendance.

Glenelg Support Group

The Glenelg Support Group meets on the third Wednesday of each month.

Venue: Cinema Centre Coffee Lounge, Jetty Road, Glenelg.
Time: 1:00 pm.
Contact: Marion Hansen.
Phone: Marion on (08) 8234 2342.

Northern Metropolitan Support Group

Contact: Merindah Whitby.
Phone: Merindah on (08) 8287 3195.

Northern Yorke Peninsula CFS Support Group

Venue: Community Health Centre Wallaroo.
Phone: David on 8862 1665.

Southern Fleurieu Support Group

Second Thursday alternate months: February, April, June, August, October, December.
Phone: Melanie Stratil (Dietician) 8552 0600 for venue details.

Murray Bridge Group

The Murray Bridge group is not meeting at present.
Please ring to register your interest.
Phone: Fran McFaull (Dietician) 8535 6800.

Youth Support: SAYME

South Australian Youth with ME/CFS

The idea behind having a Youth group is to get young people with Chronica Fatigue Syndrome together at the same place at the same time to relax, chill out, and to have a bit of fun within the limits of their condition and to develop a network of friends with Chronic Fatigue Syndrome that understand the issues we face. Together we can help each other through the tough times.

The Youth group is open to young people up until the age of 30. Please contact Emma Wing in the office on Wednesdays on **8410 8929** for a program of events or if you would like to receive our quarterly magazine. We would love to meet you.

Support Contacts

SA Support Groups

Adelaide City	Office	8410 8929
Glenelg	Marion	8234 2342
Murray Bridge	Fran	8535 6800
Northern Yorke Peninsula	David Shepherd	8862 1665
Southern Fleurieu	Melanie	8552 0600

Misc. Support Contacts

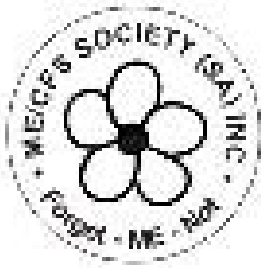
North Eastern	Julie	8264 0607
North Eastern	Pat	8264 9328
SAYME	Liz	8278 2093
SAYME Parents	Marg	8276 5353

Country Support Contacts

Auburn	Kay Hoskin	8849 2143
Barossa Valley	Dennis	8563 2976
Mt. Gambier	Di Lock	8725 8398 or 0438 358 398 (mobile)
Murray Bridge	Fran	8535 6800
Port Lincoln	Jade and Pauline	8683 1090
Port Pirie	Marj	8633 0867
Riverland	Kathy Southeren	8586 3513
Victor Harbor	Melanie	8552 0600
Whyalla	Peter	8644 1897
Yorke Peninsula (central)	Caroline	88374335
Yunta	Gloria	8650 5938

Please note that meeting times are subject to change.

If you are attending a meeting for the first time please call the contact or the Information and Support Line for confirmation of meeting days and times: 8410 8930 or 1800 136 626.



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