Talking Pump

September 2003 Official Journal of the ME/CFS 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.

Medical Advisor

Dr P.Del Fante – GP, BSc DipCompSc MBBS (Hons) MSc (Public Health Medicine), Medical Director of the Western Division of General Practitioners.

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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):

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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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Talking Point

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Talking Point Subscriptions:

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

President: Peter Cahalan
Vice-President: vacant
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Peter Evans
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Adelaide, SA 5001.

Note: It is our policy to ignore anonymous correspondence.

The Society has an office: Room 510, 5th floor, Epworth Building, 33 Pirie St, Adelaide.
At the time of printing the office hours are:
Tuesday and Thursday 10am to 3pm (subject to volunteer availability).
Our email address is: sacfs@sacfs.asn.au

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

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CHARITY DIRECT
A SIGN OF ETHICAL FUNDRAISING

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Contents

Thanks to *Emerge* for articles that appear in this issue of *Talking Point*.

CFS/ME forum: "Impact on the community"

A CFS/ME forum entitled "Impact on the community" was held on Friday November 14, 2003 at the Legislative Assembly Chamber, Parliament House, Melbourne, Victoria.

Part 1: Introduction by Simon Molesworth QC (Chair)

Simon Molesworth AM QC welcomed everyone in attendance on this important occasion. In particular he thanked Tony Robinson MP, Member for Mitcham, without whose support and assistance the day would not have been possible. Tony was particularly thanked for proactively suggesting a number of steps that could be taken to raise the awareness of CFS/ME.

One of Tony's important roles was to ensure that our Society had an opportunity to meet with the Minister for Health in Victoria. The Minister hosted an excellent function earlier in the year, the highlight of which was the handing over of a cheque to confirm the ongoing funding of the core operations of CFS/ME Victoria by the State of Victoria. That in itself was an important step forward for CFS/ME Societies in this country because more often than not they are underfunded and not supported by their communities or by their Governments. In this country at the moment only three of the seven CFS/ME Societies actually receive external funding from any Government. Of the three only two – New South Wales and Victoria – receive what one would call "real funding."

Simon Molesworth QC

This lack of Government funding reflects an aspect which plagues this illness – described in the past as "***the crisis of credibility.***" Not only do sufferers of CFS/ME have to battle on a daily basis their own physical illness – but also the ***barrier of being accepted as having a serious physical illness***. It is a consequence of such barriers in the workplace, the schoolroom, the university, the home, with the community, or wherever, that sufferers have to battle with others. In this respect they should be taken seriously.

It is also partly a consequence of the fact that researchers are still very much in debate with each other as to what the causes are and certainly what the remedies are. Further, it is a consequence of the name – a name that incorporates the word "fatigue" tends to suggest something ephemeral – something passing – not very serious. But we know that this is a very, very serious illness – international definitions remind us that there are at least ten symptoms that, if suffered, will render an individual into a state of the most serious ill health. Many don't recover, many have the illness for decades many are totally and utterly dependent on carers.

Any effort to give this illness, and those who are fighting for it on a daily basis, an opportunity to gain greater exposure is to be greatly welcomed. The Forum today gives us this opportunity whereby we can gain wide public exposure to the issues, to remind the community, Governments, decision makers, researchers and Australians generally that we have a challenge of the utmost seriousness – a challenge that we can only overcome by working together.

CFS/ME Victoria is determined to stand by patients and carers and find ways to remedy their problems. These problems are not just health problems but ones of social support, economics, and credibility. The Society endeavours to find a multiplicity of ways to stand by you, the patient and the carer to ensure your future is a brighter one and that there is a real chance you can overcome the illness or if not to overcome it, then to alleviate the worst excesses of the challenges that you have to face.

This Forum is part of such programmes embarked

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upon every day on your behalf by the Society and others like it around the country. As mentioned before, most do not have any level of support from Governments and hence don't get the credibility which accompanies such Government support. It is not a fashionable illness.

As a consequence we find it far more difficult to attract donations from the private and philanthropic trusts than, I would say, any other charity in the community. I've worn a variety of hats in the public sector and charitable organisations and even though their causes are important there has never been an area that has been more challenging and difficult to overcome than the CFS/ME area. I can walk in to a philanthropic organisation wearing another hat and walk away with a five and a half-million dollar cheque. I go wearing my CFS/ME hat and walk out with a warm handshake and sympathetic smile and a "no, not this year." That differentiation is our challenge.

As I look around today, this is not a crowded room and that is a reflection of the illness itself – it is difficult to travel to the centre of Melbourne. However, you can be assured that whatever transpires in the chamber today will have a life and an impact on decision-makers and that is the most positive outcome of today. ***Today will make a difference***.

Today's programme covers the full field of relevant areas which should be covered at a Forum such as this – research, medical perspective, psychiatrist, lawyers and those battling within the family context:

- **Christine Hunter** – Founder of the Alison Hunter Memorial Foundation – perhaps one of the most outstanding organisations in this country. The AHMF has provided world leadership in networking between researchers, leaders and people focused on CFS/ME. If it were not for Christine's concept of founding this organisation, then we would not have seen the bringing together in Sydney, on three occasions, to three conferences, all those who hitherto were not talking to each other.

- Queensland's **Alastair Lynch** – one of Australia's most well-known footballers – a hero in sport in Australia. A consequence of the awareness of his being a sufferer has caused much debate in this country as to what the nature of our illness is. He will tell his story.

At the end of today's proceedings it is suggested we pass a resolution to demonstrate our determination to take beyond this chamber to the decision-makers, bureaucrats, ministers and Governments outlining what needs to be done. Although the resolution will be in general terms, we will not find the precise answers in the course of the day's proceedings. The fact is that it has been part of a Forum in Parliament House. Together with the way it is conducted we will send a message that this is a serious issue and that we are intent on finding answers…

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CFS/ME forum: "Impact on the community"

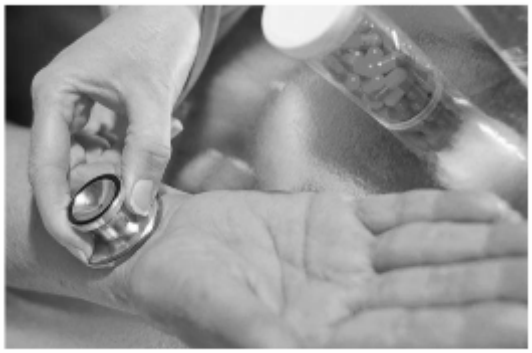
Part 2: Report on the presentations

By Nola Miles

Dr Don Lewis – A GP's perspective

Dr Lewis based his presentation on his experience, referencing the histories of over 400 patients with CFS/ME. He wanted to present facets of the ***REALITY*** of CFS/ME as it is really encountered and how significant this is in a field wider than just the individual. For this presentation he randomly selected histories from approximately half his patient files – details related to investigations, conclusions reached and physical examination records.

He started by saying the key word surrounding CFS/ME is ***DISBELIEF***. Disbelief surrounds all aspects of this illness and turns interpretation of the various features of the illness into ways which are derisive and insulting to an individual. When CFS/ME is associated with disbelief, the symptoms could be interpreted as tiredness and depression.



What Dr Lewis has found is that when a diagnosis is made on history, physical examination and meeting various criteria a conclusion can be reached. Pre-onset history is important – usually an enormous life full of activity, meaning and self worth – and at onset this is totally changed. Always look at the "before" before dealing with the "after."

In his clinic he has discovered that over time there is a definite hierarchy of symptoms which are most troublesome. They are sleep, physical exhaustion, cognitive limitations, musculo-skeletal/neurological features, mood disturbance and finally gastro intestinal upsets. This was the same whether male or female, unwell for less than one year or more than twenty and, interestingly, mood disturbance remains second bottom. When asked what troubled the patient the most, i.e. what would they like "fixed" first, two-thirds named physical fatigue as the principal issue, a half thinking difficulties, one fifth pain, and only one said depression was the problem.

There are other specific features relating to the illness – post-exertional features, neurological/cognitive features, euro-endocrine features and dysfunction of the nervous system that controls much of the body's response.

Although many books say the patients present as "normal," of the patients Dr Lewis has examined 80% have a fever, with the average temp 37.5 (therefore some are over 38), 70% have glands that can be felt, 50% have tender liver, 80% have features of allergies, 90% have heightened sensitivity to touch and 90% have the need to take a deep breath. There are other things such as orthostatic intolerance as well.

Other things he has found are

- ANA auto immune – 1 in 3 is abnormal (general population is 1 in 20)
- 10% have antibodies to their thyroid gland and if untreated will lead to an under active thyroid condition
- 75% increased insulin response to glucose – response to high glycemic food
- 14% had a normal insulin response but three-quarters of these were still symptomatic. It would appear that some become symptomatic with High GI Food so a low GI diet could be important.

He concluded by saying

- **This disability is significant and physical**
- **The help these people need is considerable**
- **And yet the help patients and carers are receiving is negligible**
- **Recognition as a disability is vital** (to assist with such things as the disability pension, not having to do job search when unable, home help, taxi assistance and disabled parking).

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Jim Chambers – Impact on the family

Jim Chambers' son, Jeremy, has a severe case of CFS/ME. Time to do research outside family needs is limited. As each corner is turned a new hurdle is discovered.

It has been a difficult journey. Jim has found that, although there are so many health organisations, there is little or no support. In the $60 billion health industry you go from health authority to health authority and get plenty of sympathy – but there is an attitude of "Can't help you, go somewhere else."

His key messages for the health service:

- 160,000 sufferers is the best estimate as there is no research
- There appears to be a lack of leadership by all of the health authorities in tackling this problem
- $200,000 spent on the Guidelines may have had good intent but it produced something that is not supported by the stakeholders
- CFS/ME is like taking all cancers and calling them "Big Tumour"
- It is there for life – like diabetes it needs to be managed
- Most sufferers recover to resume their life in some form but it is a reduced level of performance
- Some are bedridden for twenty years – the justice system equates twenty years to a "Life Sentence"
- PBS don't recognise CFS/ME and medications that assist CFS/ME are not available under PBS.

It dismays him that we are not getting the right information out there – kids are falling over because they are given the wrong advice.

Jim categorised the illness into three key stages:

1. **Initial bewilderment – searching for the simple solutions and coming to grips with reality.**
   Jeremy was leading a fit and active undergraduate life in 1997 with a brilliant writing career ahead of him – caught glandular fever resulting in CFS/ME and hasn't been well since.
   Sadly he sought the best advice in Melbourne and he was advised to follow a graded exercise program, which he did, and he attributes this to putting him in bed for four years.
   Why is it that out of all the kids that contract a viral illness only a small percentage go on to get CFS/ME and why will one or two of those not recover in twenty years?

2. **Managing your life during the illness.**
   You may have one child with CFS/ME but you probably have other children in the family as well. How do you ensure the other children don't sacrifice their teenage years for a sibling who is chronically ill? One of the biggest issues in this sufferer's household is what his younger sister can use as deodorants etc that don't send him "into outer space." Jim has been unable to undertake maintenance or refurbishment tasks on his family home due to Jeremy's chemical sensitivities.
   Other Effects
   There is a significant financial burden, a time burden, chaotic schedule – day shift, night shift and evening shift, constantly apologising for cancelled or late appointments and impact on your own health.
   It changes the whole lifestyle and focus of the family.

3. **Rehabilitation.**
   This appears to be two steps forward and 1.9 steps back. Having been out of "society" for so long, sufferers want to try and do everything immediately. Jeremy took twelve months to "get off the floor" and sit in bed. After four years he could be taken in a wheelchair for X-rays and was in a wheelchair for another year before he could walk the few metres from the car to the doctor's office. Jeremy joined in a family celebration for the first time in five years. His sister was 13 when he was struck down and she was 18 for this family event.
   When well enough to look for work, even if you

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have completed university, the question is asked "what have you been doing for the past "xx" years – many go on to part time, sometimes menial physical work which exacerbates their symptoms.

Dr Nicole Phillips – A Psychiatrist's Perspective

Dr Phillips also divides this illness into three stages – pre-diagnosis, what happens at diagnosis and what happens to people throughout the diagnosis.

Firstly there is a sense of confusion with many trips to doctors trying to get an idea of what is wrong. This is when the invalidation process starts. As the suggestions of psychological illness start, sufferers go away with feelings of abandonment. In Dr Phillip's case she was advised in her consultation – "I'm sorry there is nothing I can do" – this is the last thing you want to hear and it is not true.

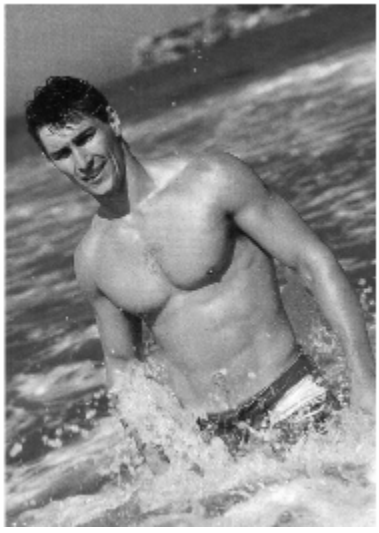
As the illness goes on there are ten key points (in no particular order):

- Denial, – I don't want to have a chronic illness.
- Feelings of anger – why me?
- Vulnerability – as with any chronic illness, there are quacks and others who will prey on this vulnerability.
- Uncertainty and fear – loss of control, what's happening to your world? Relapses come and go.
- Guilt and shame – can't fulfil normal responsibilities – stigma, difficult to treat, no known cure.
- Grief and loss – huge issues – loss of self, self esteem, social life, previous relationships, healthy friends and finances. When loss is not dealt with appropriately it can lead to clinical Depression.
- Abandonment and isolation, by health professionals, friends and family.
- Invalidation – there is a tendency to blame the patient rather than the illness.
- Hope and hopelessness – every time you start to feel better, you feel great, you have a relapse – hopelessness.
- Acceptance – to live with real optimism – provide yourself with some emotional space to start your recovery

Dr Phillips has found 80% of CFS/ME patients have concurrent Depression. There is an interaction between CFS/ME and Depression. Is there something about CFS/ME, or the invalidation, perhaps the same biology involved? Dr Phillips refutes the debate that CFS/ME is masked Depression. They are different entities.

Impact of psychiatry

Dr Phillips felt the impact in her first year of psychiatry. She experienced victimisation, harassment by professors and colleagues. At conferences she heard colleagues talk about the new hysteria, masked Depression. Concerning terms are creeping into research – such as neurasthenia, somatisation and neuropsychiatric disorder.



Alastair Lynch

Dr Phillips concluded by saying what we need is really good quality research and support organisations like the one in Victoria.

On CBT Dr Phillips believes that, while some wrongly tout it as a "cure," it is an accepted management technique to restructure the way you view the world around you. This impacts positively on the immune system, which in turn can impact positively on your health. These are skills that ***EVERYBODY*** should have not just those who are ill.

Alastair Lynch – Personal Impact

Alastair returned home from a weekend football trip not feeling very well but thought this was only to be expected. However, by Wednesday of that week he was very ill. He woke up with stomach pains, cramping, bad headache and could not get himself out of bed. He went from doctor to doctor and was checked out for blood disorders and malaria. After three weeks and no improvement they found CMV virus in his system. On his really bad days he was bedridden – he was sleeping up to 18 hours a day and waking unrefreshed. His whole day was waking up and having breakfast with his girlfriend and going back to bed again and then waking again when she came home after work.

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On his best days he felt "hung over" but felt pressured into getting back to training. He would push through and would then vomit. This would set him back a couple of weeks but there was no talk of anything other than having a virus and that he would be over it shortly.

When he was struggling to train for the first match his manager finally insisted they find out "what was wrong." He was farmed out to specialists who eliminated everything and at every visit he hoped he had whatever it was they were looking for. Finally a doctor said to him, "You have Post Viral Fatigue Syndrome or what you might hear called Chronic Fatigue Syndrome. It is important to rest, don't play for the rest of the season." (six months).

Alastair appreciates that he was fortunate to have great support from his partner/carer and from his employer – the football club – even though it must have caused great frustration at all levels from the Board down. He had medical staff available every day with a vested interest in getting him well to play football. He tried many and varied treatments. "You look for confidence and direction from everyone – you do get taken for a ride – sometimes you had no idea what they were talking about but they wanted $50 at the end of it."

Alastair has heard so many stories of people bedridden for years. There is a young swimmer at the end of his street who spent three years in bed and the girl who was flown up to Brisbane by air ambulance and is now not well enough to get home.

There is still a long way to go.

There is light at the end of the tunnel – Alastair has found what worked for him was to give his body everything it needed – eg vitamin supplements, to rest, learn how to manage it and know when the stop sign is coming up.

"I still suffer from the dregs of what I used to have. I still have to manage sleep, I still have problems but the gaps are much longer. I never appreciated my health until the day it left me."

John Berrill – Workcover and Superannuation

John Berrill thinks that there may be a connection between how share prices are performing for insurance companies and how those insurance companies treat people. Insurance Companies have now put CFS/ME exclusions and limitations on policies such as income protection, total and permanent disability and some life insurance. Some companies have "standard cover" and "enhanced cover," where the standard cover excludes CFS/ME and related conditions or has a two year limit on claims, with the enhanced cover, possibly including CFS/ME, attracting an extra premium – and this is for people who don't already have CFS/ME when they apply. If you have a pre-existing condition most won't touch you or, if they can even see indications of something that might end up as CFS/ME, they will exclude you as well. .

The theme of these insurance companies is to limit liability and CFS/ME is an unacceptable risk. In the underwriting manuals, CFS/ME is bundled together with mental illness and then linked to Fibromyalgia.

The bizarre twist to this is that a couple of years ago John would have said that the days where the courts don't accept CFS/ME are gone but the trend is reversing – claims are now being treated with more suspicion.

The methodology used is that they come with preconceived ideas of the illness. The starting point is that it is NOT permanent. They also do not properly look at the circumstances, i.e. how long off work, transferable skills or how de-skilled a person has become since being out of the workforce.

There are dispute resolution schemes for superannuation and insurance – the Superannuation Complaints Tribunal, Finance Industry Complaints Service, etc. These sit below the level of the court and

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are an alternative to taking your case to court. They make written decisions with reasons and a lot more disputes are using these schemes. There is a worrying trend in the Superannuation Complaints Tribunal regarding total and permanent disability claims. The bar is set pretty high but it is not impossibly high.

John quoted from a recent tribunal decision: "The complainant suffers from CFS an illness which demonstrates a variable course over time and for which a diagnosis and prognosis is problematic." So that was the starting point. This person had been out of the workforce for ten years and was totally deskilled and had been diagnosed for 12-13 years. All medical evidence showed on the balance of probabilities that she would not be able to go back to work. The Superannuation Complaints Tribunal sent her off to two independent doctors one of whom reported that he didn't accept this woman had anything wrong with her. The other one said "Yes I think she's got CFS for want of a better phraseology for her collection of symptoms but I don't think it's permanent. I think she'll get back to the workforce." The tribunal clearly started with suspicions of CFS/ME, which it would not share in relation to other conditions.

There are avenues available to assist you with complaints – the Disability Discrimination Act and the Equal Opportunity Act. Both cover against people with disabilities relating to insurance and superannuation. In Victoria we have the Victorian Civil Appeals Tribunal and the Victorian Equal Opportunity Act which can be used if you find an insurance company who won't give you cover. Under Federal Law there is also the Insurance Contracts Act.

If leaving a job, always check for the continuation options on any insurance you may have.

Christine Hunter – Impact on Children

Christine Hunter started by quoting from the Sydney Morning Herald article of May 2002. Professor James Isbister, the head of Haematology at Royal North Shore Hospital, referred to Christine's daughter, the late Alison, as "a brilliant girl, intellectually very vibrant." "To be honest I felt helpless towards the end." Isbister says, "On many occasions I was extremely embarrassed about the way she was treated by the system. A lot of the terrible things Alison went through were through doctors projecting their own fears and inadequacies. How anyone could not think she had a major illness was beyond me. Alison was like someone going through a concentration camp suffering terrible physical distress compounded by insults and inhumanity."

Isbister laments the edifice of medicine that cannot acknowledge things it does not understand.

That was the first validation of her illness but unfortunately came seven years after her death.

Alison went through lot of periods of good remission where it was thought she was fully recovered but every time she was taken down again by further infection. Alison clearly had no effective response to infections.

Severe ME does not discriminate.

Christine went on to explain what Laura Hillenbrand, the acclaimed author and advocate for CFS/ME, would have had to cope with had she been a child. Most likely she would have ended up in hospital, treated by doctors who had no idea what they were dealing with and would have treated her badly and, when her family intervened, the matter would have fallen into Dispute and Child Protection Services would be called in. She would have been labelled with Munchausen Syndrome by Proxy, Pervasive Refusal Syndrome or even Abnormal Illness Behaviour. Some children have as many as nine psychiatric diagnoses wandering throughout their notes. Many families have said on seeing the notes that they don't recognise what is written in them. If one doctor writes something it is read by the next one and so on. Each then goes to the child with a preconceived idea and builds on that.

The Countess of Mar in the House of Lords has spoken very strongly about this issue of the way children are treated with this disease – of their

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disproportionate suffering. Nigel Speight, part of the reference group for the CMO's report in the UK, bluntly called it "Child abuse by health professionals."

Chris then went on to describe sitting in a four day court case in Australia about a child who was locked away in a ward for five months and put on a "management plan" called a "normalisation plan," the concept being to introduce the child to the expectations consistent with the unit and her age group. The program would create behavioural challenges to her beliefs. It was noted that she was to have no special foods/diet, despite having great difficulty ingesting food, and had to have a tube put down as many severely ill do. She had to sit on a chair all day – no bed rest – despite being confined to a wheelchair.

This is why we must not trivialise this illness – it is most certainly not one illness just as with Consumption. When medical science caught up this included severe Asthma, Cystic Fibrosis, Tuberculosis, etc., each responding differently to management.

What has the Government done?

$200,000 was given to the Royal Australasian College of Physicians for the Clinical Practice guidelines – those Guidelines were to be evidence based. Straight away this is backward looking – what research has been done – not what is on the cusp of development here in a disease that is poorly understood.

Chris stated she had been misled in the early 1990s after writing to the Government to find out what they had done. The Federal Minister for Health advised Parliament that two amounts – $213,000 and $259,000 – for research were given in 1994 (these were for Chronic Fatigue – not Chronic Fatigue Syndrome) and $500,000 was allocated over five years for research into psychiatric characteristics in post infective fatigue and CFS . All three studies were given to Ian Hickie (recent CEO of Beyond Blue and now with Mind Brain Institute attached to Sydney University). The next study was allocated $360,000 to find out what psychological determinates could be that were keeping them sick. All this is whilst other physiological research which could prove effective is not funded at all and has had to be disbanded.

Good research is vital – what is needed is a meeting of high level health researchers from NHMRC to work out a good definition so we can study those populations. We need some way to link university studies to clinical findings. The UK has recently given 8.5 million (pounds sterling) to CFS/ME and $12 million has been allocated in the US. We get a lot of talk, sympathy and interest but behind their hands they express scepticism and use meaningless statistical data.

Acknowledgements

In closing the Forum, Simon Molesworth said, "This brings me to the time of all such Forums to say thank you. To put together such a Forum takes a lot of effort – a few but not many will realise just how much pressure there is to keep a Society such as this going and to fulfil the myriad of tasks asked of it. Our thanks go to:

Nola Miles and her team at CFS/ME Victoria – I know they work in an extremely dedicated and tireless fashion – not just for our members, but for all 13,000 to 15,000 CFS/ME sufferers and their carers in Victoria. Thank you Nola and your team for what you have done for this Forum.

Tony Robinson – your offer to suggest this venue and your determination to proceed with this idea has brought us here today. It is a very special contribution by an MP – you will go down in the records as a person who stood by us in a way that is rarely done in this country.

To each of the speakers – Don Lewis, Jim Chambers, Nicole Phillips, Alastair Lynch, John Berrill and Chris Hunter – we thank all of you. All contributed to the debate in a very real and positive fashion.

I close the Forum and thank you all for being part of it.

This Forum was presented by CFS/ME Victoria in conjunction with the ME/CFS Association of Australia Ltd and Tony Robinson MP.

With grateful acknowledgement of the sponsorship from the MW/CFS/FM Association of Queensland.

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CFS/ME forum: "Impact on the community"

Part 3: Resolutions

Legislative Assembly Chamber, Parliament House
Melbourne, Victoria

Friday November 14, 2003

The following Resolutions were carried by a unanimous vote at the Forum:

1. That the Federal, State and Territory Governments in Australia be requested, as a matter of urgency, to consider and address the following issues which were highlighted during the presentations and discussions at the Forum held today in Parliament House, Melbourne.

   • The inadequate recognition across Australia of the full spectrum of CFS/ME especially with respect to its most serious manifestations

   • The unacceptable consequences of widespread ignorance of the illness in the community giving rise to credibility issues which adds to and exacerbates the burden of those with CFS/ME

   • The urgent need for better guidance to assist the medical profession in diagnosis and determining appropriate treatment of CFS/ME

   • The consequences for CFS/ME patients and their carers of inadequate care and essential support services

   • The urgent requirement to address the need to improve the quality of life of persons with CFS/ME who are isolated or greatly restricted by their illness.

2. That in order to facilitate the processes by which the Federal, State and Territory Governments of Australia consider and address the issues highlighted at the Forum and set out in the first resolution, the Ministers of Health in each of the Governments in Australia be asked to place CFS/ME on the agenda of the next meeting of the Council of Australian Government's Health Ministers' Council for full discussion.

3. That in order to assist the Federal, State and Territory Governments of Australia to have an ongoing capacity to receive excellent professional and experienced advice on CFS/ME, the Federal Government be requested to fund and facilitate the establishment of a permanent national CFS/ME Forum comprising a panel of appointed experts whom together would be knowledgeable and/or experienced in all aspects of CFS/ME. The permanent national CFS/ME Forum would have as its prime objectives: (a) the giving of advice to Australian Health Ministers and their Departments whenever requested to do so; and (b) the provision of advice to the Ministers and their Departments in circumstances where, on its motion, the Forum considers advice on particular aspects of CFS/ME to be both timely and necessary.

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What price glory?

Laura Hillenbrand, author of "Seabiscuit," discusses her Chronic Fatigue Syndrome and how the book affected her life.

Interview by Anne A. Simpkinson.

This interview first appeared on Beliefnet on May 21, 2001. Laura Hillenbrand, now 36, remains disabled by Chronic Fatigue Syndrome. "Seabiscuit" is currently the country's number-one bestselling paperback.

How did you first come to write about horses and horse racing?

For me, being a writer was never a choice. I was born one. All through my childhood I wrote short stories and stuffed them in drawers. I wrote on everything. I didn't do my homework so I could write.

In terms of writing about horses, I fell backwards into that. I was intent on getting a Ph.D., becoming a professor, and writing on history but I got sick 14 years ago when I was 19. Getting sick derailed that plan completely.

I spent the first year of my illness pretty much bedbound and when I began to improve a little bit in 1988, I needed some way to justify my life. I had an idea watching the Kentucky Derby in 1988, something I could write about that hadn't been discussed much. So I wrote an essay and mailed it to *Turf & Sport Digest*.

The magazine no longer exists but it had a huge circulation when the sport was at its height, back in the thirties and forties. It was on its last legs when I submitted the piece – they never did pay me – but they published me and said, "Do you want to keep writing?" I said sure because I was enjoying it. It was making me feel so much better about myself. I wasn't just a person lying in bed, now I was a writer.

You got sick in college with Chronic Fatigue Syndrome (CFS). Can you explain what CFS is and how your illness started?

It started in a very typical way – very suddenly. Prior to that, I was a straight A student, perfectly healthy. I was a very serious athlete. One evening I was driving back from spring break. I think I ate something that was bad earlier that day and I developed food poisoning.

For about two weeks, I was very sick. With CFS, it's typical to have a triggering problem. It could be food poisoning, a bad flu, pneumonia. I woke up two weeks after getting the food poisoning and I simply couldn't sit up in bed.

The biggest problem has been exhaustion. I've spent about 6 of the last 14 years completely bedridden. At times, I have been unable to bathe myself. I have gotten so bad I couldn't really feed myself and a couple of times I needed someone to spoon feed me. I have had trouble rolling over in bed.

Almost everybody gets night sweats and chills. I've had a fever for 14 years. Some people have very severe joint pain and muscle pain.

You've said that the first year you were sick was very tough, mainly because you couldn't get a diagnosis. Talk about that first year.

It was extremely frightening. I lost 22 pounds in the first month and I didn't have that weight to lose. I lost all my vitality. My hair started falling out. I got sores all over my mouth and my throat. I was running fevers all the time. I would go to doctors and they didn't know what it was, and their inclination was to assume that it was psychological or that it was an effort to get out of doing school work. It was really enraging and upsetting because when doctors don't support you, you lose the support of family and friends, just about everyone.

Because they begin to doubt you?

Right. I had unequivocal symptoms. You could put a thermometer in my mouth and see I was running a fever. Yet they were trying to find reasons for making this [illness] somehow my fault. I was told I was bulimic. I was not bulimic; I never threw up. My throat was beet red; I had huge lymph nodes. I was told I was depressed. I was told I had an attitude problem and needed to get my act together. One doctor wrote down that I was simply trying to get out of school, which was quite amazing. I had a 4.0 average at college. I was not

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having problems in school.

What finally turned the situation around?
I went to Baltimore to Johns Hopkins and saw the head of infectious diseases. He said, "Do not listen to these people. You have a very serious illness. It's called chronic fatigue syndrome." He couldn't do anything for me but to finally get a diagnosis, to finally have someone be compassionate and take me seriously was an enormous event.

So this physician was able to diagnose the problem, but couldn't do anything for you?
Not really. The reason so many doctors had shrugged me off was that this illness was only then being recognized. In their defense, there wasn't anything in the diagnostic manual. But because they didn't want to believe that they didn't know everything, they wanted to find a reason why it was my fault.

The following year the Centers for Disease Control recognized CFS and NIH began researching it in earnest. Today, there's enough research on CFS to be able to give it a definitive diagnosis.

Laura Hillenbrand

Are there prescriptive protocols for people with CFS?
There are some things they tell you to do. A lot of it is very simple. You can't stress yourself. You can't push too far because if you do, your whole body will collapse and you can wind up for six months or eight months back in bed again.

You learn that right away because you make mistakes. I made a really big one. I was starting to get better when, in 1991, I tried to take a car trip to Saratoga Springs, New York, with my boyfriend. It was a really stupid, enormous mistake: I collapsed in a little town in New Jersey and went into shock.

I got much sicker than I'd ever been before. I spent the next two or three years completed bed-bound. The vertigo started with great ferocity and it was hell on earth. I've never come back from that and that was ten years ago.

Writing the book took physical vitality out of you. But do you feel that the book fed you emotionally, psychologically, spiritually?
I identified in a very deep way with the individuals I was writing about because the theme that runs through this story is of extraordinary hardship and the will to overcome it. That is the fundamental struggle of my life, trying to get over this extremely devastating physical condition. There are times when I think, "I can't stand this any more." But you find a way to do it.

That's the story of the individuals I wrote about: They were successful in overcoming what they had to deal with. Stepping out of my body and into their lives – they were vigorous men, who lived wild eventful lives that swung in gigantic parabolas – was an escape for me. I lived for four years in the 1930s with these individuals and the only time that I wasn't thinking about dealing with physical suffering is when I was working on this book. I've never been more alive as when I worked on this book.

At the end of chapter five you wrote: "The racehorse, by virtue of his awesome physical gift, freed the jockey from himself." And: "For the jockey, the saddle was a place of unparalleled exhilaration and of transcendence." I was wondering whether the relationship of the jockey to the horse might have been similar to you and the process of writing.
That's exactly it because, for the jockey, there are tremendous risks involved in getting on a racehorse. They punish their bodies to get themselves down to weight and then they have to go out and take the kind of risks that almost nobody has the courage to take. It's a ridiculously dangerous job.

But they get this prize at the end of it. They get to enjoy something that none of us enjoy who stay on the ground which is the exhilaration of being on the most remarkable creature God ever created, of being able to take part in that speed and power. That's very similar to

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the risk I was taking and the joy I got from writing it.

How did you choose to tell the Seabiscuit story?
I've known about the horse since I was a little kid. I read a book called "Come On, Seabiscuit," which somebody bought me for twenty cents at some book fair or something. I read the covers right off of it. I mean, the thing is falling apart. I still have it, all bound up in rubber bands.

So I knew the horse's story. Then in 1996, I was going through some old racing documents and came across some facts about the owner, the trainer, and the jockey that I had never known. I thought, "That looks really interesting." I kept looking and the story just kept getting better and better and I knew I had a book. You wait your whole career for a story like this.

It was many stories. Each of the main characters had their own story. The horse had a story and –
And other people. I got to interview more than 100 very elderly people who had actually lived this story. They gave it so much color.

I guess none of the principals were still alive.
They weren't, no. The last one, Marcella Howard [wife of Seabiscuit's owner], died in 1987. Red [Pollard] died in 1981. George [Woolf] [a jockey who rode Seabiscuit when Pollard was recuperating from an accident] had been dead a very long time. But a lot of people who were very closely associated with them were around. Alfred Vanderbilt, who arranged [Seabiscuit's] match race with War Admiral, was a huge help. George Woolf's best friend; Red's sister and children; a lot of Seabiscuit's exercise riders, grooms, stable agents. I was very fortunate. I'm right at the end of living memory with this one.

What would be your advice for people who have been diagnosed with CFS?
It's such an individual journey. But what I would say is, no matter what happens with this illness, I think it is possible to carve out a dignified and productive life. This illness takes everything away from you, and you have to find completely different ways to define what your life will mean to you. But I think it's possible to make a good life. I have been happy in the time that I've been sick. It requires a real redefinition of everything, but I think it is possible to do.

You sound at peace with your situation.
I wouldn't say I'm at peace; some days I really struggle with it. I have times of despair. When my vertigo came back and I lost the ability to write, it was a very difficult thing to adjust to. But I have learned to have very low expectations. I am not somebody who thinks I am entitled to good health or to a good peaceful happy life.

We are fortunate when we have them, but when we don't have them it's not that someone's taking them away from us. It just happens. [This attitude] has made it easier for me to deal with [my illness] than someone else who thinks, "Why me?" I've never thought that. CFS is definitely a very difficult thing to deal with. I go through times of real despair, but I pull myself out of it and keep going. I have no choice.

Are you living independently?
I am not really. I have a boyfriend who's wonderful, who's been with me since before this illness. We've been together more than 14 years. He does a lot of the things I can't do like get the groceries. He does the laundry. I do the cooking. I do some of the cleaning – and I earn the money. He is the most wonderful person in the world and I'm very fortunate in that.

If you're still struggling with CFS, will you continue to write?
I want to. It's really wrapped up in who I am. But finishing off the book, I was just working myself half to death. I've been doing a lot of interviews, and I have now lost the ability to read and write altogether. I've really paid the ultimate price. The vertigo is just so bad now. It actually causes nystagmus, an involuntarily rolling of the eyes.

Can you focus when that happens?
Not really. I feel very, very dizzy. I'm at the point where reading and writing are over for me, at least for a while. I have to recover in order to resume my career and I don't know if I've done myself in for good. But it was important to me and I knew I was taking a gamble. This is the price. But I'm so happy to have brought this story to the country.

Talking Point – 2004 Issue 1

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

Feeling her pain

By January Payne

She doesn't look disabled. Some doctors believe her condition isn't real. But for the author Fibromyalgia makes every day a struggle.

The doctor pressed his thumbs into my skin, first on the back of my neck, then my arms, my back and my legs. It was my first visit with him, but he managed to find painful spots I didn't know existed. He looked serious and focused on his hands. How long had I been in pain, he asked. Where did it hurt the most? Was I tired all the time?

This was my diagnostic exam for Fibromyalgia, a controversial often debilitating condition of chronic muscle pain and fatigue first recognised by the American College of Rheumatology in 1990. The group's diagnostic criteria for the ailment include a history of widespread pain lasting longer than three months and pain in at least eleven of eighteen "tender points." Doctors press each point for about four seconds while asking if the pressure causes pain. I "passed" the exam. I had Fibromyalgia. I was 17 years old.

I had spent the previous year and a half feeling exhausted and hurting all over after a November 1996 car accident. I had bounced from specialist to physiotherapist and back to my family doctor several times, only to be told that all of my blood tests and X-rays were normal. My pain had no identifiable medical cause.

But there it is, on mornings when I can't turn my head sideways because of a shooting pain across the back of my neck, or on days when it's hard to walk because of the throbbing in my right knee, or the many times the dragging fatigue kicks in after even mild physical exertion. Some days the weight of my head on my neck is terribly painful.

There are two types of Fibromyalgia: post-traumatic and primary. Mine is the post-traumatic type, usually caused by a serious injury or severe illness. The primary type is assumed to be inherited and lifelong. And I learned, as do many of the estimated 3 million to 6 million Fibromyalgia patients nation-wide (US), that getting a diagnosis is the key to getting successful treatment. There is no cure.

Fibromyalgia is a syndrome identified only by a set of symptoms. There is no blood test to identify it, no body scan that can "see" it, no way to identify it beyond the patient's reported pain and medical history. "To treat it successfully," said my rheumatologist, Russell Rothenberg, a George Washington University Medical School professor and clinician, "The pain, fatigue and other symptoms must be treated at the same time." For me, that means a three-time-daily painkiller and a muscle relaxer to help me sleep at night and light aerobic exercise three times a week.

But some doctors wonder if the condition really exists

"I don't feel it's a unique condition," said George Ehrlich, a University of Pennsylvania Medical School professor. "Most people experience chronic pain at some point in their lives," he said, "And many require treatment, but that does not warrant a special diagnostic category. I obviously appreciate that the people who complain have the pain that they complain of .... but it's part of the spectrum of chronic pain. It's unfair to make it a separate condition when it really isn't."

Such opinions are not unique. Fibromyalgia patients who can't work full-time often struggle to qualify for Social Security disability benefits. Some cannot get insurers to cover treatment. Ehrlich critical of doctors and lawyers who make their living fighting for disability benefits for Fibromyalgia patients. "It's become a big industry for trial lawyers," he said.

"Fibromyalgia – the word means 'pain in the muscles, ligaments and tendons' – primarily strikes women aged 20 to 60," Rothenberg said, "with most in the 40 to 60 range." Experts aren't sure why the disease affects these women, but some think that children, men and younger women tend to ignore their symptoms, leading to a delay in diagnosis.

A condition some experts believe may be linked to Fibromyalgia is Chronic Fatigue Syndrome (CFS) which has no diagnostic exam and is also viewed sceptically.

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Its paramount symptoms are prolonged tiredness and fatigue, though CFS sufferers sometimes complain of muscle weakness and pain. Many of the same medications are used to treat both CFS and Fibromyalgia. But researchers can't agree on whether the two conditions actually comprise one disorder.

A veteran at 23

Now at age 23, I've been living with Fibromyalgia for nearly seven years. I was diagnosed at a younger age than many, but I am not alone. Robin Ray, 27, of Arlington, and I share what experts say is a common Fibromyalgia personality trait – the tendency to be overachievers.

"I've always been a Type A personality," Ray said, adding that her desire to achieve often leads to overwork, which can trigger Fibromyalgia flare-ups. While attending college she was exhausted and sore much of the time, but she found the cause of her discomfort only when she was diagnosed with Fibromyalgia at the age of 21.

When she graduated, Ray was too worn out to pursue a master's degree in music performance, a step she'd always assumed she'd take after getting a bachelor's degree. "I was just too tired and too depressed. I just couldn't do it," Ray said. Up to twenty percent of Fibromyalgia sufferers experience depression, according to Daniel Clauw, a University of Michigan rheumatologist.

While I was never depressed, I became frustrated before my diagnosis with the limits that being sore and tired put on my life. I had been poked, prodded, X-rayed and scanned – all to find out why what appeared to be simple whiplash and knee injuries became excruciating pain that spread from my head to my toes.

The orthopaedist I initially saw thought I would heal completely within a few months of my accident. He put me into physiotherapy and dismissed my complaints when I told him I wasn't getting better.

Each physiotherapy session began with moist heat applied to my back for thirty minutes. Next came increasingly intense and painful exercise on weight machines. A few times the doctors prescribed aquatherapy classes, where the senior citizens who made up the rest of the group would often tell me I was too young to be in the pool with them. The water therapy helped, but its effects wore off as soon as my six-week sessions were over.

My physiotherapists would usually end my stints early, telling my doctor they didn't know why I wasn't getting better. My knotted back muscles grew more sore as I was pushed through round after round of intense exercise. Even their attempts to massage my tight muscles proved fruitless and painful.

My orthopaedist told me I was young and needed to get over it. He didn't understand it wasn't that simple. Lacking proper treatment, I continued to miss school nearly every day because sitting upright for my classes was too painful. At first tutors came to my house to help me keep up, but my school didn't have tutors for all subjects, so I quickly fell behind, turning my honour roll grade into incompletes.

My friends kept in touch at first, stopping by the house and calling on the phone to catch me up on the latest gossip. But as my attention turned towards healing my body, I lost touch with my friends and instead focused on researching Fibromyalgia. I combed the Internet for health articles daily, looking for anything that might help me. There wasn't much.

Learning the ropes

New research could address the doubts of those looking for a more objective way to diagnose Fibromyalgia. A study done last year by the Georgetown University Medical Center and the National Institutes of Health provides the first strong evidence that Fibromyalgia pain is real. "This is objective evidence that when Fibromyalgia patients say they're sore, they actually are," said Clauw, who led the study which was published in the Journal of Arthritis and Rheumatism.

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Researchers monitored brain activity of sixteen people with Fibromyalgia and sixteen health volunteers while applying pressure to the participants' thumbs. "If a Fibromyalgia patient gets five pounds of pressure to their thumb, that five pounds of pressure is rated (by the patient) as being moderately painful and we can see (corresponding) brain activity," Clauw said. Healthy volunteers had no brain-activity response to the same amount of pressure and reported that it caused them no pain.

But this study has not silenced Fibromyalgia critics. Rheumatologist Nortin M Hadler, a professor at the University of North Carolina School of Medicine in Chapel Hill, downplayed the study's significance. "Someday we're going to be able to do functional imaging of the brains of elite athletes and show that they're different from you and me," Hadler said. "That doesn't mean they're diseased."

Back to Life

Still, I am optimistic that Clauw's research will lead to a better understanding of Fibromyalgia. My diagnosis gave me an incentive to start planning my future. I finished high school through a community college GED programme and started college there so I could live at home and manage my condition better.

But during my freshman year I experienced the kind of flare-ups Ray endured as an under-graduate. Mine usually came after days of not sleeping properly, coupled with late night studying. The key to staying healthy has been planning my schedule so that I can avoid sacrificing sleep.

But it's on those days of painful flare-ups that the reality of this illness strikes me the hardest, when I suddenly realise I can't take a trip to the mall with my friends or party at weekends. I am often told that I'm mature for my age, which I think comes as a by-product of Fibromyalgia. It requires maturity to recognise your own limitations.

The outlook is more promising now than in the past. Clauw said new medications are being developed that increase the levels of the brain chemicals serotonin and norepinephrine and decrease the levels of a pain-inducing chemical called substance P. Researchers expect the medications to be available within the next two years.

For now, doctors recommend a balanced treatment plan: getting enough rest, exercising regularly, avoiding over-exertion and taking prescribed medicines. Mine has allowed me to complete college. I graduated with a bachelor's degree in journalism from the University of Maryland, College Park in December 2003. And I'm doing something I once thought I'd never be able to handle: a 40-hour week as a reporter for a news service run by the university. I have my bad days and will have more in the future – though good days tend to outweigh the bad.

I understand how some might be sceptical about how serious Fibromyalgia is. On those days when we feel well enough, Fibromyalgia patients get up, get dressed and put on makeup, which gives us the appearance of being healthy.

People can't see the pain or fatigue we feel, a fact demonstrated by the questions they ask when I park in a space reserved for the handicapped: "Are you really handicapped? You sure don't look like it."

My reaction tells me I've come a long way since that first tender point exam. In those days I took offence when anyone implied my pain was minor, or worse, not real.

Now I look at these comments as compliments. After all, looking good and healthy is a positive thing – especially when your days are often spent feeling just the opposite.

This article first appeared in the Washington Post on November 10, 2003 and is reprinted here with the permission of the author.

To Magazine Editors: *January Payne holds the copyright for this article. Permission to reprint can be sought from January by e-mailing her on january_payne@msn.com.*

Fibromyalgia: “Moving Towards Wellness 2004” course

Arthritis SA runs regular courses to train people to self-manage their disabilities. The ME/CFS Society (SA) Inc audited the program in 2003 and received very good feedback from a group of members who volunteered to do the program and reported back. The following is the 2004 schedule of courses.

You attend 2.5 hours one day a week for six weeks.

Unless otherwise noted, please ring Jenny Bennett on 8423 0902 for details on all courses:

ARTHRITIS FOUNDATION
Unit 1, 202-208 Glen Osmond Road, Fullarton.
Day Courses
Wednesday February 11 to Wednesday March 17 – 1:00 to 3:30pm
Thursday May 20 to Thursday June 24 – 1:00 to 3:30pm
Tuesday August 10 to Tuesday September 14 – 1:00 to 3:30pm
Wednesday October 27 to Wednesday December 1 – 1:00 to 3:30pm
Evening Courses
Tuesday February 24 to Tuesday March 29 – 7:00 to 9:30pm
Tuesday October 26 to Tuesday November 30 – 7:00 to 9:30pm

ELIZABETH – RESTHAVEN NORTHERN THERAPY SERVICES
Gillingham Road, Elizabeth.
Ring Jenny (see above) or Rosalind on 8252 6811 at Resthaven.
Wednesday May 26 to Wednesday June 30 – 10:00am to 12:30pm

MUTUAL COMMUNITY
Level 2, 99 Gawler Place, Adelaide.
Thursday April 29 to Thursday June 3 – 10:00am to 12:30pm

MODBURY – ADELAIDE NORTH-EASTERN DIVISION OF GP’s
Education Centre, Modbury Public Hospital, Smart Road.
Tuesday February 17 to Tuesday March 23 – 1:00 to 3:30pm

CAMPBELLTOWN
North Eastern Community Hospital, North East Road, Campbelltown.
Monday June 7 to Monday July 19 (not on Monday public holiday) – 1:00 to 3:30pm

ASTHMA SA
300 South Road, Hilton.
Ring Jenny (see above) or Vicky at Asthma SA on 8238 9300.
Thursday February 12 to March 18 – 10:00am to 12:30pm

WOODVILLE – ADELAIDE WESTERN DIVISION OF GP’s
Unit 5, Woodville Centre, 98 Woodville Road, Woodville.
Friday April 30 to Friday June 4 – 10:00am to 12:30pm

GOOLWA
Alexandrina Centre for Positive Ageing, Goolwa.
Ring Jenny (see above) or Heather on 8555 2134.
Friday April 16 to Friday May 21 – 1:00 to 3:30pm

OTHER VENUES WHERE COURSES WILL BE OFFERED
Noarlunga Health Services – ring Sally Rowe on 8384 9233.
Onkaparinga / Mitcham Council Area – ring Cathy Powell on 8358 6086.
Campbelltown, Barossa Valley, and others – ring Jenny Bennett on 8423 0902.

COURSE FEES

Member Participant:	$31.00
Non-member Participant:	$38.50
Member Pensioner:	$22.00
Non-member Pensioner:	$27.50
Accompanying person:	$5.00

Mutual Community members ring Jenny Bennett on 8423 0902. You may be eligible to have your costs covered.

For more information visit www.arthritissa.org.au.

Problems with Fibromyalgia?

The FM Association can help.

Fibromyalgia SA c/o The Arthritis Foundation of SA Inc.,
Unit 1/202-208 Glen Osmond Road, Fullarton SA 5063.
Phone (08) 8379 5711,
Freecall 1800 011 041.

Arthritis FOUNDATION SA INC.

PUBLIC HEALTH ALERT

NEGLIGENCE AND HUMAN RIGHTS ABUSE AT THE OFFICE OF CHEMICAL SAFETY

The government claims the public is being protected from harmful exposure to toxic chemicals and that international standards in chemical regulation are working adequately.

The truth is that low levels of common chemicals in pesticides, paint, cleaners, new building materials, perfumes, plastics, glues and many other products are causing multiple chemical sensitivity and other poorly recognised health problems.

The failure of governments and bureaucrats to address these in chemical regulation has resulted in a public health crisis with large numbers of people disabled with MCS and ignored.

The Commonwealth's Office of Chemical Safety advises the government to take no action on MCS, has failed to protect the public health interest and is engaged in serious human rights abuses against people with MCS.

STOP THE CHEMICAL NEGLIGENCE
STOP THE ABUSE

DEMAND REFORMS IN CHEMICAL REGULATION IN THE PUBLIC HEALTH INTEREST

Chemical Sensitivity Information

For people with:

- Food intolerances
- ME/CFS
- Chemical sensitivites
- Hyperactivity – ADD

Ph: (08) 8381 9286

SOUTH AUSTRALIAN TASK FORCE ON MULTIPLE CHEMICAL SENSITIVITY
Responding To The Public Health Crisis Of Chemical Injury
PO Box 3308, Port Adelaide, 5015 • Phone: (08) 8240 5084 • E-mail: satfmcs@optusnet.com.au

PUBLIC HEALTH RALLY

RECOGNISING

MULTIPLE CHEMICAL SENSITIVITY

WEDNESDAY MARCH 17
12 NOON
OFFICE OF CHEMICAL SAFETY
55 CURRIE STREET ADELAIDE

Multiple Chemical Sensitivity (MCS) is a serious and growing public health problem that affects people of all ages, races and economic backgrounds. People with MCS are made sick by exposure to chemicals found in common products such as pesticides, perfumes, tobacco smoke, new carpets, air "fresheners," new paint and building materials, and many cleaning and laundry products.

Symptoms of MCS vary from mild to life-threatening and include headache, asthma, nausea, diarrhoea, fatigue, muscle and joint pain, dizziness, irregular heart beat, and seizures. MCS symptoms in children include attention deficit, hyperactivity and other learning and behavioural problems. People with severe MCS are often diagnosed with Chronic Fatigue Syndrome.

Many people have developed MCS after a pesticide or solvent exposure

Public health studies in the USA show that around 5% of the US population have been medically diagnosed with MCS. Many of these people have been permanently disabled.

MCS has no cure but it can be prevented. Avoiding toxic chemicals is essential for a healthier environment.

Prevent MCS – Demand Clean Air

Multiple Chemical Sensitivity: Ideas needed

Efforts by the SA Task Force on Multiple Chemical Sensitivity (MCS) and support by the Democrats has led to the Social Development Committee inquiring into and reporting on Multiple Chemical Sensitivity. The Social Development Committee is a standing Parliamentary Committee of six elected representatives who regularly investigate issues of public concern.

The Committee will investigate the issue with particular reference to:

1. which chemicals are most responsible for MCS symptoms and how exposure can be minimised;
2. the effect of chemical exposure on human fertility;
3. status in other countries of MCS as a diagnosed medical condition;
4. best practice guidelines for handling chemicals to reduce chemical exposure;
5. current chemical usage by government departments and changes that could be made to reduce chemical exposure; and
6. ways that South Australians with MCS might better access support from government agencies.

The Social Development Committee is accepting submissions now on MCS and will consider these after February 2004. The CFS Society is planning to provide a submission from a CFS perspective, particularly as it relates to points 5 and 6 above.

If you have any ideas, examples, case studies or human interest stories on MCS, please contact Lorenzo Pizza by February 28, 2004 on 8161 7721, 0405 122 988, or e-mail themoz3@hotmail.com.

Please feel free to give personal stories of the difficulties which you've faced in confronting chemical exposures.

CFS shifting to clinical studies

From the CFIDS Chronicle Writer 2003 Vol 16 Issue 1

The US Centres for Disease Control and Prevention (CDC) runs the worlds largest CFIDS research program. Last year the CDC spent nearly $US9 million on programs to study the illness and educate health care providers about diagnosis and treatment. Yet the CDC remains highly controversial in the CFIDS community. From 1995-98, officials diverted $US12.9 million earmarked for CFIDS research to other programs. The funds are being paid back to the CFIDS program over the course of several years.

In this interview, Dr William Reeves, head of the CFIDS program at CDC, talks about current research underway at CDC – and discusses the future of the CFIDS program in light of current terrorist threats facing the nation.

What are the CDC's main goals for CFIDS research?

Answer – We have several objectives. The first is to estimate the magnitude of the public health problem that CFS (another term for CFIDS) poses in the United States. We accomplish this by surveillance. Information from surveillance is important for health care providers and is critical to determine allocation of health resources.

Our second objective is to try to determine if CFS represents a single disease or is a common response to more than one insult. The analogy I like to use is arthritis. By definition, arthritis is hot, tender swollen joints. This can be caused by autoimmune diseases, like rheumatoid arthritis or lupus, by repetitive stress or other injuries; or by infection. They all present the same way as far as the patient is concerned, but their causes, treatment and prevention are completely different. I don't believe it is clear whether CFS is a "thing," or if it is more like arthritis, a common final response to quite different causes.

Our third objective is to determine the pathophysiology of the disease; in other words, how does CFS affect normal body processes? The fourth is to identify causal agents, risk factors and diagnostic markers for CFS, and the fifth is education. We are doing some of that now with the CFIDS Association.

Our entire program reflects CDC's mission to prevent and control disease. But until we figure out risk factors, diagnostic markers, and what causes CFS, we really can't develop effective prevention and control.

Until recently, the CFS program has emphasised surveillance. However, I think it is pretty clear from our studies and from other population-based studies (such as those of Dr Leonard Jason), that we have a pretty good idea of the magnitude of the problem. It is somewhere between half a million and a million adult Americans with the disease. Although CFS affects adolescents, it is much less common than among adults.

You have cancelled a nationwide study on the prevalence of CFIDS. Why?

Answer – The main reason the study was put on hold was September 11. We had started a pilot study about three months before and we ended about three months after. We encountered some problems following the tragedy. People weren't so willing to answer personal questions – and we had some real worries that 9/11 might have changed the occurrence of CFS. We are doing some analysis to see whether that has happened. We did screen more than 7,000 people in eight areas around the country, which should yield some interesting data.

Cost and staff resources were also a big consideration. It didn't look from the pilot study as if our estimates of occurrence would change substantially. So it didn't appear to justify the $3 million or $4 million to complete it. We felt the funds and scientific effort would be better applied to other priorities. As an aside, the CFIDS Association collaborated in co-ordinating the pilot survey and was responsible for the clinical evaluation component.

So your emphasis is starting to change?

Answer – We are moving much more into pathophysi-

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ology and clinical studies now. We have some incredible opportunities to study groups of people with CFS in ways no research group has been able to do before.

Much of this has been possible because of our surveillance program in Wichita, Kansas. Wichita is like a poster city for mainstream America. We screened 20 percent of the entire city's population for CFS and followed 4,000 subjects annually over four years.

We have identified a representative sample of people with CFS, of people with not-quite CFS, and with CFS with various co-morbidities, like major depressive disorders. They represent the general population – we are not limited to patients with CFS who are seeing health care providers. If you only look at those folks, you do not get an accurate picture of the scope of everyone suffering from CFS.

We now have the opportunity to study these people clinically. And that is what we are doing. We have invited all subjects we identified in Wichita who have ever had CFS; those who would have had CFS except that they have exclusionary depressive disorders; people with severe chronic fatigue who didn't quite meet the case definition for CFS; and a group selected from the general population, who are matched by age, race, sex and body mass index. It is about 400 people, including approximately seventy with CFS. They are representative of the Wichita population.

We are inviting them for a two-day hospital stay, during which they will have a complete battery of neuroendocrine and immune function studies. Response has been excellent so far and most are volunteering to participate. Since most people with CFS report sleep problems our subjects also have formal sleep studies. These include two overnight sessions and multiple sleep-latency tests. Evaluating sleep at night, one can tell about a lot about sleep problems. But you also have to look at people during the day too. That is called sleep latency. You look at how quickly you can nap during the day, how easily you can stay awake in a darkened room – things that are influenced by different sleep disorders.

Most people with CFS also report problems with concentration and memory. People in the Wichita clinical study are also undergoing formal mental function (cognitive) studies, using a group of tests called the CANTAB. In order to separate interactions between CFS and depression, we are assessing subjects' psychiatric status.

It is increasingly clear that neuroendocrine and immune function reflect physiologic adaptation to accumulated events over one's life. So, we are doing a rather complete measurement of the subjects' lifetime stress history and their reactions to stress.

Finally, all of those with CFS and the controls will have tilt-table testing done. The study is about as comprehensive as we could possibly make it.

What other clinical studies are underway?

Answer **–** The big ones are modelling studies. In modelling studies, you enrol subjects who have been exposed to something that you know will cause symptoms of CFS and measure how the body reacts. We are doing two studies with Emory University and another one in Australia (see next heading).

All of our studies include cutting-edge laboratory tests using gene expression and proteomics. Gene expression measures activity of messenger RNA. We are able to describe the activity of 10,000 to 30,000 genes at a pop – which ones are "on," which ones are switched "off," which ones are turned up a little and which ones are turned down. Differences in gene expression profiles can help to distinguish between people who have CFS and those who don't.

In contrast, proteomics measures all the proteins that exist in a sample of someone's blood. Genes code for the creation of proteins, so proteins can only be there if

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

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the genes call for them. But there is not a one-to-one relationship. Proteins have their own cycles and regulate each other, to some extent independently of gene expression.

Why are these tests important?

Answer – There are several benefits. First, if we can identify a pattern of gene expression that distinguishes people with CFS from controls, we will have a diagnostic test for CFS.

In addition to diagnosis, gene expression analysis provides a window into the pathophysiology of CFS. What protein or cell pathways are these over- or under-expressed genes part of? How might these relate to CFS? While it doesn't really matter what the particular gene or protein is for a diagnostic test, it makes a big difference when you are looking at what may be causing CFS or searching for targets amenable to therapy.

The two sets of data together can be powerful. We have done some preliminary work that shows we can separate people with CFS from non-fatigued controls.

What new studies are in the pipeline?

Answer – We are already thinking about the next clinical study. We have done everything we can imagine in the Wichita clinical study – but we have not done any of it in great detail.

For instance, for the neuroendocrine measures, we are only collecting blood once. This will be less disruptive to cognitive and sleep studies. Detailed measurements of neuroendocrine function would be taken over one or two days and the subject would be sampled constantly in conjunction with application of various stimuli, perhaps done in conjunction with brain imaging.

The comprehensive set of measurements we are collecting in Wichita will tell us what we might need to examine in more detail. It is a starting point. We will do a much more detailed study based on what we find.

Q. Are you cutting back on anything?

Answer – Surveillance as I said before. And we have suspended our efforts to identify infectious agents as causes of CFS. It is clear from studies that we and other people have done that none of the infectious agents we know of are the direct cause of most cases of CFS. We have recently completed a comprehensive set of studies to identify novel or previously unknown infections agents in CFS – there are ways to do that – and no infectious agent is significantly associated with CFS. Clearly, some people develop CFS following an acute infectious illness such as mononucleosis (Epstein -Barr virus) but this is not the case for most people with the CFS. We believe it will be more productive to focus on clinical studies and searching for markers. This may lead us back toward in infectious agent, at which point we will look again.

The full text of Functional Status of Persons with Chronic Fatigue Syndrome in the Wichita, Kansas Population in: *Health Qual Life Outcomes 2003 Oct 3; 1 (1):48* Solomon L, Nisenbaum R, Reyes M, Papanicoloau DA, Reeves, WC.

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VISITOR/PEN PAL WANTED

I am house bound with CFS and FMS, and welcome anyone who can visit, email or phone me.
I live in the Gawler area.

Pamela Du-Valle
Phone: (08) 8522 3778
Email: tahu007@iprimus.com.au
Web: http://home.primus.com.au/tahu007/Tahu's~1/HOME_PAGEx.html

A Single Rose Can Be My Garden
A Single Friend, My World

Influenza vaccination – is it appropriate in Chronic Fatigue Syndrome?

Journal, Am J Respir Med. 2002; 1(1): 3-9 Sleigh KM, Marra FH, Stiver HG
Affiliation: Division of Infectious Diseases, Department of Medicine, Vancouver, British Columbia, Canada

Chronic fatigue syndrome (CFS) is a recognised illness of unknown cause and pathophysiologic mechanisms. Immunising patients against influenza would seem to be a prudent strategy since infection has been associated with symptom exacerbation. However, patients with CFS have demonstrated variable abnormalities in the immune system, the clinical significance of which is unclear. Anecdotal information has suggested that, due to the etiologic uncertainty surrounding CFS, many patients reject immunization, fearful of untoward effects. This article attempts to clarify the situation by reviewing immunologic findings in CFS and influenza vaccines in current use.

Results from a recent survey of perceptions of patients with CFS regarding immunisation revealed that 31% felt immunisation was neither safe nor beneficial. This opinion was universal in those patients who never received influenza vaccine. Among patients who had received vaccine and experienced an adverse effect, 26% felt the vaccine was safe and 28% felt it was beneficial. Among those who had received vaccine without an adverse effect, 45% believe the vaccine was safe, and 55% felt it was effective. CFS patients as a group expressed concern that influenza vaccine would alter an already dysfunctional immune system, or worsen CFS symptoms.

Significantly more patients with CFS who had never received influenza vaccine voiced this opinion than did patients who had received immunisation for influenza in the past. Contrary to the opinions expressed by the sample, clinical trials in CFS have yet to find that any type of immunisation has produced a deleterious effect on symptoms or functioning. Moreover, patients with CFS in a randomised placebo-controlled, double blind trial of influenza immunisation produced an antibody titre in the protective range to inactivated trivalent influenza vaccine, although the geometric mean titre was slightly blunted compared with healthy vaccinees.

Although patients with CFS in placebo and active groups reported four times the number of post-injection adverse effects of healthy vaccines, data re-analysis revealed that this finding was related to the overlap of common, post-influenza immunisation symptoms and CFS constitutional symptoms.

CFS is a poorly understood illness and some patients may believe in causal theories that lead to the rejection of disease prevention strategies such as immunisation. However, influenza immunisation appears to provide protective antibody levels without worsening CFS symptoms or causing excessive adverse effects.

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CFIDS research goes micro

The centrepiece of the CDC's research program for CFIDS is a series of modelling studies looking at how the illness develops in people who suffer "insults" to their body systems – factors such as viruses, drug treatments, other stresses accumulated over the life-span that may result in CFS and similar illnesses.

These studies are all taking advantage of new technologies that can probe deeper, further and more accurately into the development of CFIDS. Researchers say they are very hopeful that the new tools may unlock mysteries that have so far eluded them.

"We are very jazzed about these studies," says Dr William Reeves, Chief of the CDC's CFIDS research program. "To me, they're the most exciting thing going in this field."

The first study is based in Australia. Researchers there are looking at the development of CFS in people who are infected by viruses that cause several different diseases, including Ross River Virus, Q Fever and Epstein-Barr Virus.

It is well known that a percentage of people who contract these viruses will go on to develop CFS symptoms. By identifying these people early in the development of their illnesses, researchers will be able to track the changes to the patients as they occur and predict who will develop CFS.

The Australian study is using a testing tool called the gene expression microarray. Researchers take samples of genetic material called messenger RNA in the blood of patients, then create a "biochip" that shows the status of tens of thousands of genes. The biochip can tell which genes are "expressing" – that is, which ones are switched on to create proteins and which ones are not.

Researchers are looking for patterns. If people with CFIDS have similar gene expression patterns, the microarray test could be used to help diagnose people with the disease. This would be the first sure-fire diagnostic test for CFIDS.

Early results are promising, according to Dr Suzanne Vernon, a microbiologist and head of the CDC's gene expression program for CFS. Can the microarray tell the difference between people with CFS and others? "The answer is; yes it can," Vernon told *Smithsonian* magazine. Vernon says she believes the microarray will someday become a routine diagnostic tool for CFS.

Other studies also use microarray technology. In one taking place at Emory University in Atlanta, researchers are tracking the development of CFIDS in patients infected with hepatitis C virus who receive treatment with interferon alpha – a drug known to produce symptoms consistent with CFIDS. This study also is using new-wave brain imaging technologies such as functional magnetic resonance imaging (fMRI) scans. Unlike regular MRIs, which provide a snapshot image of the brain, fMRIs look at the changes that occur in the brain over a period of time. This gives researchers a better look at how brain activity differs in people with CFIDS.

Emory is also working with the CDC on a study of how the release of interleukin 6 (IL-6), a protein produced by blood cells and implicated in the development of CFIDS. This study will incorporate the microarray technology – as will the follow-up clinical studies now underway in Wichita, Kansas. The IL-6 study is also funded in part by the CFIDS Association of America.

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Only a third of people with chronic fatigue have Chronic Fatigue Syndrome

Darbishire L, Ridsdale L, Seed PT. Distinguishing patients with chronic fatigue syndrome; a diagnostic study in UK primary care. Br J Gen Pract 2003;53:441-50

In this cross-sectional British study, patients aged 16 to 75 years with fatigue lasting more than six months were evaluated with the Centers for Disease Control's 1994 case definition for chronic fatigue syndrome (CFS).

The criteria require patients to have severe chronic fatigue of six months or longer, with other known medical conditions excluded by clinical diagnosis, and concurrently to have four or more of the following symptoms; substantial impairment in short term memory or concentration; sore throat; tender lymph nodes; muscle pain; multi-joint pain without swelling or redness; headaches of a new type, pattern, or severity; unrefreshing sleep; and postexertional malaise lasting more than 24 hours.

The patients in the study completed questionnaires assessing depression, anxiety, function and perception of the aetiology of their fatigue. They had normal laboratory results, including thyroid, blood count and erythrocyte sedimentation rate, in the preceding six months. The authors excluded patients with psychotic illness, organic brain syndrome, or substance dependency; those with concurrent physical problems that the doctor felt could have caused fatigue symptoms; and those obtaining mental health care.

Of 178 eligible patients, 141 consented to participate in the study. Only 44 (31%) of the patients had CFS. Patients with CFS average about one consultation a month compared with one consultation about every two months for the patients with chronic fatigue. Additionally, patients with CFS were more likely to be unemployed (27% v 12.4%; P = 0.03), to be in a self-help group (20% v 0%), and to have concomitant depression (48% v 18%). Half of all patients, regardless of CFS status, attributed their fatigue to psychological causes.

Bottom line: Among patients with chronic fatigue, only a third meet the criteria of the Centers for Disease Control for chronic fatigue syndrome.

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NUTSHELLS

Through all of this I have learned one important lesson: not to overlook my abilities, even if other people constantly do so because of my illness.
(Farrah Tate, *Emerge* Summer 2000)

Cytokine causes rapid increase in CFS symptoms

Scientists at the National Institutes of Health (NIH) have found that administration of interleukin-6 (IL-6), a pro-inflammatory cytokine (see glossary), causes a more rapid onset of flu-like symptoms in CFS patients, compared with healthy controls.

The 19 CFS patients immediately experienced an increase in aches, fatigue and fever, while the 10 controls did not experience symptoms for six hours. This suggests that people with CFS have an increased sensitivity to IL-6; however the researchers were unable to identify a reason that this would be the case.

Contrary to the researchers' hypothesis, the CFS group did not score worse on tests of cognitive function than the controls. This paper was published in the August 2002 issue of *Psychological Medicine*.

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Nutritional supplement has no effect on symptoms

Researchers in the Netherlands report in the October 2002 issue of *Quarterly Journal of Medicine* that an antioxidant nutritional supplement with vitamins, minerals and co-enzymes did not improve CFS symptoms.

The double-blind placebo–controlled treatment study evaluated fatigue severity CFS case definition symptoms and function following 10 weeks of treatment with the polynutrient formula. The researchers found no differences on any measure among the 27 people who were given the treatment and the 26 who received the placebo. All patients met the 1994 CFS case definition criteria and had high levels of fatigue severity and disability.

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Mycoplasma found in European CFS patients

A new study has found that Mycoplasmal species infections were detected in 68.6 percent of 261 CFS patients in a Belgium CFS clinic, compared to only 5.5 percent of 36 healthy controls. Mycoplasmas, which are tiny parasites have also been found in higher rates in American CFS patients. The authors suggest that the high rates of Mycoplasma in CFS provides further evidence for a role of the agent in the pathophysiology of CFS as a cause, co-factor, exacerbator or result of the illness. This study was published in the November 15 issue of *FEMS Immunology ad Medical Microbiology*.

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CFS Glossary – terms you need to know

Autonomic nervous system (ANS): The segment of the central nervous system that controls involuntary body functions, such as the strength and frequency of heartbeats, breathing, digestion, sweating and secretion from certain glands. Dysfunction in the ANS appears to be common in people with CFS. Recent research shows that 40 percent of CFS sufferers suffer from orthostatic intolerance – an ANS-related condition that causes dizziness and other symptoms upon standing.

Cytokines: Proteins that are produced by white blood cells and help control the body's immune system response. The body creates more than 100 different types of cytokines, each controlling a specific reaction. The balance of cytokines in CFS sufferers is often disturbed. For instance, many people have elevated levels of a cytokine called interleukin-1-alpha (IL-1 alpha), which promotes inflammation. The exact role of cytokines in CFS remains unclear; whether the cytokine levels somehow cause CFS, or whether they are a reaction to another problem, is unknown.

Peer-reviewed: Papers that have been approved for publication by experts in the particular field of research. Peer-reviewed journals are considered the gold standard of research publications, since the articles in them have passed muster for accuracy, completeness, selection of study subjects and other criteria. Most of the world's prestigious medical journals, including The Lancet, the Journal of the American Medical Association and Science are peer-reviewed publications.

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Low brain essential fatty acids found in CFS

Oliver Wright, Health Correspondent, Health News, UK
December 22, 2003

Doctors believe that they may have found the first scientific evidence for chronic fatigue syndrome, which affects more than 150,000 people in Britain.

A team of researchers at Hammersmith Hospital, London, scanned the brains of sufferers of CFS, which is also known as myalgic encephalomyelitis (ME) or "yuppie flu," and found enlarged gaps in fatty acids that were non present in non-sufferers. They have been backed by similar findings in Scotland and Japan.

They found that when sufferers were later treated with fish oil supplements the gaps in the brain closed and they started to feel better.

Researchers found that sufferers were low in a group of essential fatty acids, known as EPAs, high levels of which are found particularly in fish. Bassant Puri, a neuro-psychiatrist at Hammersmith, said: "It was these natural gaps that we found to be enlarged in people with CFS. We have found what appears to be a cause for CFS but we don't know why people get it."

Action for ME, which represents sufferers of the illness in the UK, said that the research was welcome but it believed that there may be several causes. Chris Clark, the charity's chief executive said: "All the evidence so far suggests that there is no single cause."

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Regular checkups

Please remember to have regular medical checkups with your doctor.

ME/CFS does not confer immunity to other illnesses. New symptoms may not be due to ME/CFS and should be discussed with your doctor.

Support Groups: Metro

Adelaide Support Group
Venue: ME/CFS Society Office, Room 510, 5th Floor, Epworth Building, 33 Pirie Street, Adelaide.
Time: 12:00 pm to 2:00 pm.
Contact: Bill Daniels or Darryl Turner.
Phone: Ring the office on (08) 8410 8929 to confirm attendance.
Dates: *2004*
January 27; February 24; March 23; April 27; May 25; June 22; July 27; August 24; September 28; October 26; November 23; December 28.

Glenelg Support Group
Venue: Cinema Centre Coffee Lounge, Jetty Road, Glenelg.
Time: 1:00 pm.
Contact: Marion Hansen.
Phone: Ring Marion on (08) 8234 2342.
Dates: *2004*
January 21; February 18; March 17; April 21; May 19; June 16; July 21; August 18; September 15; October 20; November 17; December 15.

Support Groups: Country

Auburn Support Group
First Thursday of each month.
Venue: Dennis Tea Rooms, Main North Road, Auburn.
Time: 1 pm.
Phone: Kay on 8849 2143.

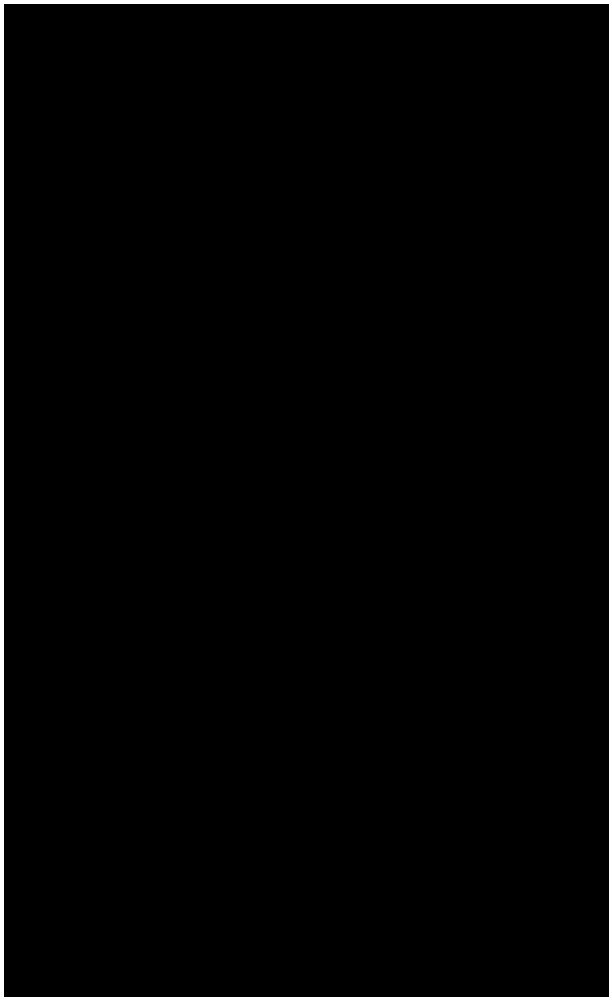
Northern Yorke Peninsula CFS Support Group
Venue: Community Health Centre Wallaroo.
Phone: Jane on 8826 2097.

Southern Fleurieu Support Group
Second Thursday alternate months: April, June, August, 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.

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

Support Contacts



Youth Support: SAYME

South Australian Youth with ME/CFS

General enquiries:
- Skye on 8339 1614; or
- Liz on 8278 2093.

SAYME has two support groups. **The Rice Cracker and Spring Water Extravaganzas** (RCSWE) are aimed at school-aged sufferers as a fun way of meeting new people in a friendly environment. Parents are invited too. These meetings are held in members' houses on the last Friday of each month. These meetings are actually two meetings in one – one for youth, one for parents. Two separate rooms are provided at each venue – one for each of these groups to chat away independently of the other. Contact: Sarah on 8296 9051.

The **20s-30s meeting** is for CFS sufferers over school age. These meetings are less structured than the RCSWEs and involve various activities such as meeting for a meal, drink, movie or gentle walk. Group contacts: Kristen on 8297 1274; Emma on 8381 1417.

Information about ME/CFS

What is ME/CFS?

ME (myalgic encephalomyelitis) / CFS (chronic fatigue syndrome) is a serious and complex illness that affects many different body systems. The cause has not yet been identified.

It is characterised by incapacitating fatigue (experienced as profound exhaustion and extremely poor stamina), neurological problems and numerous other symptoms. ME/CFS can be severely debilitating and can last for many years.

ME/CFS is often misdiagnosed because it is frequently unrecognised and can resemble other disorders including chronic viral infections, multiple sclerosis (MS), fibromyalgia (FM), Lyme disease, post-polio syndrome and auto-immune diseases such as lupus. [In the USA it is known as CFIDS or Chronic Fatigue and Immune Dysfunction Syndrome.]

How is ME/CFS diagnosed?

Despite more than a decade of research, there is still no definitive diagnostic test for ME/CFS.

According to the CFS case definition published in the December 15, 1994, issue of the *Annals of Internal Medicine*, diagnosing ME/CFS requires a thorough medical history, physical and mental status examinations and laboratory tests to identify underlying or contributing conditions that require treatment.

Clinically evaluated, unexplained chronic fatigue can be classified as chronic fatigue syndrome if the patient meets both the following criteria:

1. Clinically evaluated, unexplained persistent or relapsing chronic fatigue that is of new or definite onset (i.e., not lifelong), is not the result of ongoing exertion, is not substantially alleviated by rest, and results in substantial reduction in previous levels of occupational, educational, social or personal activities.

2. The concurrent occurrence of four or more of the following symptoms: substantial impairment in short-term memory or concentration; sore throat; tender lymph nodes; muscle pain; multi-joint pain without joint swelling or redness; headaches of a new type, pattern or severity; un-refreshing sleep; and post-exertional malaise lasting more than 24 hours. These symptoms must have persisted or recurred during six or more consecutive months of illness and must not have pre-dated the fatigue.

How is ME/CFS treated?

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 can be relieved through pharmacological and other interventions.

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

There is a great deal of controversy surrounding the issue of whether people with ME/CFS should undertake exercise. Most ME/CFS patient groups recommend that sufferers exercise as much as they are able – to pace themselves. 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.

Do persons with ME/CFS get better?

The course of this illness varies greatly. Some people recover, some cycle between periods of relatively good health and illness, and some gradually worsen over time. Others neither get worse nor better, while some improve gradually but never fully recover.

Prevalence

ME/CFS strikes people of all age, ethnic and socio-economic groups. ME/CFS is three times more common in women as men; a rate similar to that of many auto-immune diseases such as MS and lupus.

In Australia, very few studies have been undertaken to determine the prevalence of ME/CFS in the community; estimates range from 0.2 to 2.5% or even higher depending on definition. These studies use different criteria for defining ME/CFS and consequently arrive at widely differing results.

A reasonable estimate for the prevalence of ME/CFS is 0.2-0.7% of the population. From these figures we expect that 3,000-10,500 people in South Australia have ME/CFS.

RACP, Chronic Fatigue Syndrome Clinical Practise Guidelines 2002,. Published in the Medical Journal of Australia May 6, 2002, page S28. See online: www.mja.com.au/public/guides/cfs/cfs2.html.

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.
MESA News, ME Association of South Africa, PO Box 1802, Umhlanga Rocks 4320, South Africa.

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