

# Talking *Point*

2003 Issue 1 Official Journal of the M.E./C.F.S. Society (SA) Inc.

*Your  
Society*



Proudly Supported By:



Office Ph: (08) 8410 8929 Fax: (08) 8410 8931

Support & Information Line City Callers: 8410 8930 Country Callers: 1800 136 626

[www.sacfs.asn.au](http://www.sacfs.asn.au)

### 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

Page 2

### 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.

### Membership

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

#### New Members:

Single membership.....	\$32
Single Concession .....	\$22
Professional.....	\$40
Family .....	\$38
Family Concession .....	\$28
Overseas – as above plus.....	\$10

(Family membership is designed for families with more than one sufferer, or more than one person who will directly benefit from the membership at the same place of residence. Family Concession applies when the main breadwinners are concession card holders.)

### Disclaimer

The ME/CFS Society (SA) Inc. aims to keep members informed about research projects, diets, medications, therapies etc. All communication both verbal and written is merely to disseminate information and not to make recommendations or directives. Unless otherwise stated, the views expressed in Talking Point are not necessarily the official views of the Society or its Management Committee and do not imply endorsement of any products or services (including those appearing in paid advertisements) or treatments — always consult your medical practitioners before commencing any new treatments.

### Deadline for Next Issue June 1st 2003

### Talking Point Subscriptions:

Professionals:.....	\$30
PWME/CFS:.....	\$22
Overseas (Asia-Pacific):.....	\$32
Overseas (Rest of World): .....	\$38

### Management Committee 2001/2002

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

President: Paul Leverenz  
Vice-President: Peter Cahalan  
Secretary: Peter Worsley  
Treasurer: Geoff Wilson  
Management Committee Members:  
Margaret Wing, Peter Evans, Kirsty Cordingley, Glenn Domeika, Adrian Hill & Rebecca Cordingley.

### Contact Details

Any correspondence should be directed to:  
ME/CFS Society (SA) Inc. PO Box 383,  
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:

Monday, Tuesday & Thursday 10 am — 3 pm. (Subject to Volunteer Availability)

Our email address is: [sacfs@sacfs.asn.au](mailto:sacfs@sacfs.asn.au)

### Talking Point

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

### Donations



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

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

### Notice to Vendors

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

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

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

### EDITORIAL



Best wishes to Farah Tate who has moved on from co-editing this journal with me.

This last month has seen one of the most significant documents released relating to CFS: The Canadian Consensus Clinical Guidelines for CFS. A bit of a mouthful YES, but nonetheless a seminal work.

An international team of researchers / clinicians worked with the Canadian government and the Canadian consumer group, the National ME/FM Action Network, to produce a comprehensive set of guidelines for health professionals and government to tackle CFS. Such collaborations between consumers, government and health professionals represent the best-practice. And in this case the result was achieved amicably—though with a lot of hard work. This contrasts with the difficulties consumers have had working with health professionals and governments in this country and in the UK.

I would also like to draw your attending to the three major events the Society is conducting in May: a seminar, a film night and a badge day (see pp 26-28 for details.)

I hope to see as many of you as possible at these events.

Paul Leverenz  
Editor

# Contents

## SECTION 1: GENERAL

- 4. Management Committee Report
- 6. News: Ciguatera and ME/CFS
- 8. News: Canada Leads the World with a Medical Milestone
- 10. An age-old issue by Val Rubie
- 11. I Found My Light by Kelly Gooch

## SECTION 2: MEDICAL MATTERS

- 13. Q&A: Procrit Trial Focuses on Red Blood Cells *by Mark Giuliucci*
- 14. Research Q&A: CFIDS and the Autonomic Nervous System *by Mark Giuliucci*
- 16. Sleep Dysfunction in CFS *by Richard Podell*
- 18. Grief and Depression *by Dr Nicole Phillips*
- 19. Summary of Canadian CFS Case Definition
- 20. New Theory Links Neurotoxins with Chronic Fatigue Syndrome, Lyme, MCS and Other Mystery Illnesses *by Patti Schmidt*

## SECTION 3: SOCIETY MATTERS

- 26. Awareness Week 2003 May 10th Seminar
- 27. Film Night: May 16th 2003
- 28. I Remember Me by Kym Snyder
- 29. Badge Day, 30th May 2003
- 30. Contacts

### Advertising

To advertise your products or services in Talking Point, please call the Society office on (08) 8410 8929. Small ads submitted by our members are free subject to the following conditions. Talking Point reserves the right to reject any advertisement it considers unsuitable for publication or decline to publish for any reason at its absolute discretion. Advertisements lodged with Talking Point must comply with the Advertising Codes of the Media Council of Australia and with the interpretations of the Advertising Standards Council.

# Management Committee Report

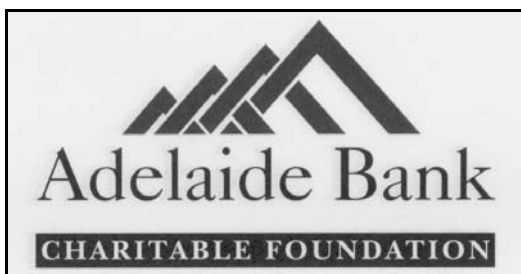
Page 4



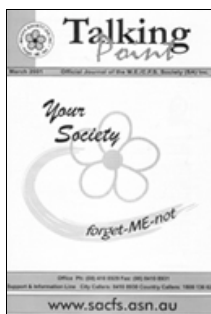
## From the President

Hello and welcome to new members for whom this is their first edition of Talking Point. I have made a conscious effort to get this edition out on time and plan to keep on track.

We received a great boost in December when the Adelaide Bank Charitable Foundation donated \$5300 to assist with Talking Point for this year – hence the logo on the front cover. We thank them very much for their assistance. Without this we would be looking at a concerning loss for this financial year. More about that later.



## More on Talking Point for 2003



The Management Committee has decided to limit Talking Point to 32 pages for 2003. This is because of necessity to reduce our costs, and to minimize my considerable workload. I believe we can still retain the quality with this adjustment.

I remind you all that the 'Society Matters' section of Talking Point contains valuable information about

upcoming Society news and events. If you can't get time (or you are not well enough) to read all of Talking Point, then please make sure you flick through that section first of all—we count on you reading it.

## May 2003 Awareness Events

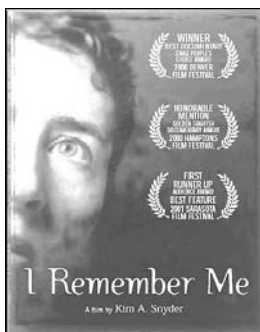
I am very excited to let you know about our Awareness Week (May 10<sup>th</sup> – 16<sup>th</sup>) events. You may be aware that May 12<sup>th</sup> is International ME/CFS/FM Awareness Day. Wear a blue ribbon on this day to draw attention to these conditions.

## Seminar May 10th (see page 26)

On May 10<sup>th</sup> we have a seminar from 12:30 – 5 pm with David Torpy, Endocrinologist RAH, as our keynote speaker. Dr David Gillis, Immunologist, will speak on the differences between FM and CFS, and Dr Peter Del Fante will give a summary of the research being conducted here in Adelaide into these conditions. In addition Jenny Bennett from the Arthritis Foundation will speak briefly on self-management.

The seminar is being conducted in conjunction with Fibromyalgia SA and will provide a lot of information. Representatives from other related organizations will have trade stalls, and be there to let you know about other services in the community that you might benefit from. Each person who attends the Day-seminar will receive a goodie-bag containing useful items and information.

## Film Night May 16th (see pages 27,28)



On the evening of Friday May 16<sup>th</sup> we are holding a film night – to raise awareness about CFS and hopefully raise a bit of money for the Society. Please bring your friends along to this event – it will be a great night with great food and drinks.

## Taking a Risk

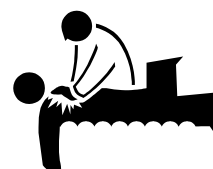
In organizing these events we are taking a big risk. We have tried to keep the costs down, and to offer a significant



## 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.



## MANAGEMENT COMMITTEE REPORT

member discounts. I hope that you can understand that unless we can find major sponsors we do have to charge for such events. And well organized and professional events cost. (At last years' awareness event, which cost approx. \$4000, we charged a nominal entry fee but was only able to do this because we had been given \$3000 from a sponsor.)

So we are taking a gamble by running two events that have costs involved. I hope that with the notice given, you can budget ahead of time.

(As per usual our Seminar will be taped and those tapes made available to our country support groups.)

### Badge Day May 30th (see page 28)

On May 30<sup>th</sup> we rattle our tins once again in the city of Adelaide.



### Government Support

Government support has continued to eluded us, but it is high on our list of priorities. The Management Committee is committed to expanding the Society's services, and to the necessary task of convincing the State Government that it needs to support us financially.

### Finances

We are looking at a \$5, 000 - \$8, 000 loss for this financial year (this assumes too a successful badge day appeal on May 30<sup>th</sup>.) We have the financial reserves to cover this sort of loss for a couple of years, but obviously it is not the ideal situation. All the more reason why we need the government funding above.

### Talking Point Electronically

A number of people have taken up the option of receiving Talking Point electronically. By doing so you save us at least \$6 p.a.

\* \* \* \* \*

Hope to see you during Awareness Week!

Paul Leverenz



## NUTRICIA

# Nutritional support for chronic fatigue syndrome with Efamarine

Patients who had been suffering from chronic fatigue syndrome for 1-3 years were found to have reduced levels of omega 3 and 6 fatty acids in their red blood cells.

After 3 months of supplementation with eight capsules daily of Efamarine, 85% had improved. There was a further improvement of most symptoms, with no adverse effects reported.<sup>1</sup>

Efamarine is a rich source of preconverted omega 3 and 6 fatty acids.

Efamol, with 22 years of research, is a trusted and respected brand available from pharmacies and health food stores including Go Vita and Healthy Life.

For optimum results we recommend continual use.

### FOR FURTHER INFORMATION

Phone freecall 1800 064 953.

1. Behan et al, Effects of high doses of EFA's on PVFS, Acta Neurolscana, 1990:82:209-21

CHC 31792-02/02



EA13-09/2002

# Ciguatera and ME/CFS: Neurotoxin Discovered in Chronic Fatigue Syndrome

*The National CFIDS Foundation recently issued exciting news about research into ciguatera, which is a form of poisoning you can get from eating tropical fish. In the study, Dr. Yoshitsugi Hokama used a newly developed blood test to look for ciguatera toxin in people with CFS, cancer, and liver disease, and compare them to people who have actually been diagnosed with ciguatera poisoning as well as healthy people. The toxin was found in the blood of all 26 CFS patients. In fact the patients with CFS had some of the highest levels in the study.*

*The National CFIDS Foundation press release is below. For more information please see:*

<http://www.ncf-net.org/library/neurotoxinPR.html>

## Neurotoxin Discovered in Chronic Fatigue Syndrome

Scientific Breakthrough Announcement Occurs in Okinawa, Japan

A formal announcement of the National CFIDS Foundation's scientific research took place recently at the International Symposium on Toxins and Natural Products in Okinawa, Japan on November 17-19, 2002.

Announcing the scientific breakthrough was invited guest speaker Yoshitsugi Hokama, PhD. Dr. Hokama is a Professor in the Department of Pathology at the John A. Burns School of Medicine at the University of Hawaii at Manoa. He is a leading world expert in the area of fish toxins with hundreds of peer-reviewed

publications to his credit. His current research into Chronic Fatigue Syndrome and a ciguatera toxin connection was funded by the National CFIDS Foundation's research grant program.

Dr. Hokama presented his preliminary findings to scientists in a lecture titled "Acute phase lipids in sera of various diseases: Chronic Fatigue Syndrome, ciguatera, hepatitis, and various cancer with antigenic epitope resembling ciguatoxin as determined with Mab-CTX."

"Since clinical reports and descriptions of Chronic Fatigue Syndrome (CFS) and chronic ciguatera fish poisoning showed great similarities in symptomology, these similarities suggested the exploration of lipids in the sera of patients with these disorders" said Hokama. This involved using a Membrane Immunobead Assay test, developed at the Burns School of Medicine, on prepared serum samples from patients. Most importantly, the test utilized a specific monoclonal antibody for ciguatera toxin (Mab-CTX), a neurotoxin found in certain ocean fish. "The testing results from Chronic Fatigue Syndrome patients (26 samples) and normal individuals (33 samples) showed significant differences" said Hokama.

Quantitative assay results range from 1:5, the lowest toxin level, to 1:160, the highest toxin level." All CFS samples gave titres of at least 1:20, with the majority of titres from 1:40 to 1:160 (24 samples). The cancer, hepatitis, and acute ciguatera poisoning patient samples were found to have titres well below those seen in many of the Chronic Fatigue Syndrome patients.

Chronic ciguatera toxin poisoning has already been suggested as a scientific model for Chronic Fatigue Syndrome. Ciguatoxins are potent, heat stabile, non-protein, lipophilic sodium channel activator toxins and are recognized as some of the most potent biological toxins known. They produce dramatic neurological manifestations, such as peripheral sensory or motor symptoms (including parasthesias, pain, burning, tingling, numbness), central symptoms such as headache, and autonomic dysfunction.

Gail Kansky, President of the National CFIDS Foundation, stated "we believe this to be a true breakthrough: This is a very severe illness that has not received adequate funding or appropriate medical attention. Although there are still many unanswered

questions and much work to be done, research efforts will ultimately turn the tide in the understanding of this disease and allow patients to receive appropriate medical therapies. We are indebted to Dr. Hokama and his colleagues for providing this monumental first step."

The CFIDS Foundation's website is:  
<http://www.ncf-net.org/>

The National CFIDS Foundation  
103 Aletha Road, Needham, MA 02492  
phone: 781-449-3535 fax: 781-449-8606



**drop in for  
a drink  
on me**

# **WATER PURIFIERS**

*for* **HOME and OFFICE**

- Filters for under sink
- Filters for whole house
- Reverse Osmosis Systems
- Water chillers
- Hydrosmart & Ecovortek Water Conditioners

**The Pure Water Shop**

259 Fullarton Road,  
Parkside 5063

**8373 5500**  
[aquaco@senet.com.au](mailto:aquaco@senet.com.au)



Shop 4a Western Roadway,  
Adelaide Central Markets

**8231 3311**  
[www.waterworld.com.au](http://www.waterworld.com.au)

# Canada Leads the World with a Medical Milestone: Clinical Definition for Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS)

Page 8

Talking Point 2003 Issue 1: The Official Journal of the M.E./C.F.S. Society (SA) Inc

A *Clinical Working Case Definition, Diagnostic and Treatment Protocols* have been developed by an expert medical consensus panel of treating physicians, teaching faculty and world leaders in the research of ME/CFS. **Haworth Press, Inc.** has just published the expert consensus document in a special issue of the *Journal of Chronic Fatigue Syndrome* **11 (1), 2003** on **February 1, 2003**. The definition provides a flexible conceptual framework that more adequately reflects the complexity of symptoms of a given patient's pathogenesis and should establish ME/CFS as a distinct medical entity and help distinguish it from overlapping medical conditions in the absence of a definitive laboratory test.

Most countries have been using the American Centers of Disease Control (CDC) definition, which was designed to standardize research. However, there has been a growing demand for diagnostic criteria designed for a clinical setting. In response to a survey by the **National ME/FM Action Network**, doctors across Canada overwhelmingly concurred that a clinical definition, along with diagnostic and treatment guidelines, would be the most helpful items in diagnosing and treating ME/CFS patients. This led to Health Canada selecting an expert consensus panel and establishing their Terms of Reference.

The panel's clinical case definition determines that more of the prominent symptoms are compulsory and symptoms that share a common region of pathogenesis are grouped together for clarity. In addition to severe prolonged fatigue, the definition includes the hallmark symptoms of post-exertional malaise and/or fatigue, sleep dysfunction, pain, two or more of the given neurological/cognitive manifestations, and at least one of the given symptoms from two of the categories of autonomic, neuroendocrine, and immune manifestations. The consensus document also includes a discussion of prominent symptoms, clinical practice diagnostic and treatment guidelines based on the best available research evidence, and an overview of available research on ME/CFS.

"The clinical definition will enable clinicians to make an early diagnosis which may assist in lessening the impact of ME/CFS in some patients," said Dr. Bruce M. Carruthers, lead author of the definition. "It will reduce the expensive problem of patients being sent to many specialists before being diagnosed and will allow patients to receive appropriate treatments in a timely fashion."

ME/CFS is a severe illness that can be debilitating. There is no known cure. It often begins with a viral type infection

such as an acute respiratory or flu-like illness. But instead of recovering, the person's health deteriorates and many other symptoms appear. A number of viruses have been studied but so far there is no conclusive support for any one pathogen causing the illness. Numerous studies have confirmed that there is a biochemical breakdown of one of the body's defense pathways used to fight viruses, which supports the theory that ME/CFS is triggered by an infection. According to a large American study by Dr. Leonard Jason, approximately 422 per 100,000 people (approximately **150,000 Canadians**) suffer from ME/CFS compared to 26 per 100,000 women who have breast cancer.

To view the clinical definition and for information on how to order the consensus document, please go to the website of the **National ME/FM Action Network** at <http://www.mefmaction.net>

## CONTACTS

**Medical: Dr. Bruce Carruthers** (lead author), phone & fax (250) 539-5717, [carruthers@gulfislands.com](mailto:carruthers@gulfislands.com)

**Other information regarding the consensus document: Marjorie van de Sande** (consensus coordinator), phone and fax (403) 547-8799, [mvandes@telus.net](mailto:mvandes@telus.net). Contact numbers for other consensus panel members will be provided upon request.

**Further information regarding ME/CFS: National ME/FM Action Network, Lydia Neilson** (President CEO), phone and fax (613) 829-6667, [ag922@ncf.ca](mailto:ag922@ncf.ca). The **National ME/FM Action Network** is a Canadian incorporated non-profit organization which advances the recognition and understanding of ME/CFS and fibromyalgia through education, advocacy, support, research and by the publishing of a bi-monthly newsletter 'QUEST'.

## AUTHORS INCLUDE:

\* **Dr. Bruce M. Carruthers**, lead author of the consensus document; co-author of the draft of the original version of the ME/CFS clinical definition, diagnostic and treatment protocols document; internal medicine, Galiano, British Columbia

\* **Dr. Anil Kumar Jain**, co-author of the draft of the original version of the ME/CFS consensus document, affiliate of Ottawa Hospital, Ontario

\* **Dr. Kenny L. De Meirleir**, Professor Physiology and Medicine, Vrije Universiteit Brussel, Brussels, Belgium; ME/CFS researcher and clinician; organizer of the World Congress on Chronic Fatigue Syndrome and Related Disorders; a board member of the American Association for Chronic Fatigue

Syndrome; co-editor of *Chronic Fatigue Syndrome: Critical Reviews and Clinical Advances*, and co-editor of *Chronic Fatigue Syndrome: A Biological Approach*

\* **Dr. Daniel L. Peterson**, affiliate of the Sierra Internal Medicine Associates in Incline Village, Nevada; ME/CFS researcher and clinician; a board member of the American Association for Chronic Fatigue Syndrome; and member of the International Chronic Fatigue Syndrome Study Group

\* **Dr. Nancy G. Klimas**, Clinical Professor of Medicine in Microbiology/Immunology/Allergy and Psychology, University of Miami School of Medicine; ME/CFS researcher and clinician; a board member of the American Association for Chronic Fatigue Syndrome; and member of the federal CFS Coordinating Committee

\* **Dr. A. Martin Lerner**, staff physician at William Beaumont Hospital in Royal Oak, Michigan; Clinical professor and former chief of the Division of Infectious Diseases at Wayne State University's School of Medicine; and ME/CFS researcher and clinician

\* **Dr. Alison C. Bested**, haematological pathologist; former head of the Division of Haematology and Immunology at the Toronto East General and Orthopaedic Hospital; affiliate of the Environmental Health Clinic and Sunnybrook & Women's College Health Sciences Centre, Toronto, Ontario; ME/CFS researcher and clinician

\* **Dr. Pierre Flor-Henry**, Clinical Professor of Psychiatry, University of Alberta; Clinical Director of General Psychiatry and Director of the Clinical Diagnostic and Research Centre, both based at Alberta Hospital in Edmonton, Alberta, Canada; ME/CFS brain researcher

\* **Dr. Pradip Joshi**, internal medicine, Clinical Associate Professor of Medicine at Memorial University of Newfoundland in St. John's, Canada

\* **Dr. A. C. Peter Powles**, Professor Emeritus, Faculty of Health Science, McMaster University, Hamilton; Professor, Faculty of Medicine, University of Toronto; Chief of Medicine and Sleep Disorders Consultant, St. Joseph's Health Centre, Toronto; Sleep Disorder Consultant at the Sleep Disorder Clinic at St. Joseph's Healthcare, Hamilton, and Central West Sleep Affiliation, Paris, Ontario

\* **Dr. Jeffrey A. Sherkey**, family medicine, affiliate of the University Health Network, Toronto, Ontario; and diagnosed with chronic fatigue syndrome nearly 10 years ago

\* **Marjorie I. van de Sande**, Consensus Coordinator; and Director of Education for the **National ME/FM Action Network, Canada**

**ABSTRACT.** Recent years have brought growing recognition of the need for clinical criteria for myalgic encephalomyelitis (ME), which is also called chronic fatigue syndrome (CFS). An Expert Subcommittee of Health Canada established the Terms of Reference, and selected an Expert Medical Consensus Panel representing treating physicians, teaching faculty and researchers. A Consensus Workshop was held on March 30 to April 1, 2001 to culminate the review process and establish consensus for a clinical working case definition, diagnostic protocols and treatment protocols. We present a systematic clinical working case definition that encourages a diagnosis based on characteristic patterns of symptom clusters, which reflect specific areas of pathogenesis. Diagnostic and treatment protocols, and a short overview of research are given to facilitate a comprehensive and integrated approach to this illness. Throughout this paper, "myalgic encephalomyelitis" and "chronic fatigue syndrome" are used interchangeably and this illness is referred to as "ME/CFS".

*Journal of Chronic Fatigue Syndrome 11(1), 2003.* [Article copies available for a fee of \$8.00 U.S. plus \$5.00 S & H from The Haworth Document Delivery Service: 1-800-HAWORTH or (607) 722-5857, ext. 391.

E-mail address: <getinfo@haworthpressinc.com>. Website: <<http://www.HaworthPress.com>>. The publication can also be purchased online at <http://www.haworthpressinc.com/store/product.asp?sku=4958>. 2003 by the Haworth Press, Inc. All rights reserved. Reprinted with permission from Haworth Press.]

See page 19 for a summary of the Canadian Case Definition for CFS



## Problems with Fibromyalgia?

**The FM Association can help. Contact Details:**



FM Association C/O Arthritis Foundation of SA Inc., 1/202-208 Glen Osmond Road, Fullarton SA 5063. Phone (08) 8379 5711, Freecall 1800 011 041.

# An age-old issue

*One of the many misconceptions surrounding M.E. is that it only affects younger people. Unlike society however, the illness doesn't discriminate and can hit anyone: male or female, black or white, young or old. In this issue, psychotherapist **Val Rubie** considers the particular problems of M.E. for the older person and is grateful that so many of you wrote in to share your experiences*

Most of us expect to remain active throughout our sixties, seventies and even eighties. We see pension adverts involving cruises and sunsets while vitamin and food supplement catalogues show pensioners paragliding over the Mediterranean.

This is the age which I suspect is very neglected in terms of diagnosis, as illustrated by Beryl Mordan's letter: 'My doctor recognised the symptoms of M.E. in me but thought it was unlikely to be the right diagnosis because of my age. Instead he sent me to a geriatrician, which I found quite humiliating.'

In fact, as recent research by Help the Aged has shown, elderly people are more likely to get a raw deal from the NHS generally and are to some extent discriminated against in the benefit system. The fact that disability benefit, for instance, is lower for over 65s (attendance allowance) than for those under this age who get disability living allowance, is just one example – as if older disabled people have less right to a decent income.

Letters from members reflect the same picture although to be fair a few mention really understanding and accepting GPs for whom age is not a factor when considering a diagnosis of M.E. or CFS.

## 'What do you expect at your age?'

I was very shocked when I met my first retired person with M.E., many years ago. Unthinkingly I'd assumed it to be an illness associated with younger age groups; as if viruses have some predilection for young bodies. I quickly learned how cheated M.E. makes you feel when older.

You may have worked hard for many years, supporting a family, building a career and finding a life which suits you. You also may have looked forward to easing up and doing what you never had time for, only to find that you don't have the energy to enjoy it. Life may become very flat and meaningless.

The most unfair thing of all is that refrain: 'what do you expect at your age – of course you can't do what you used to.... you will just have to be realistic and slow down.'

Moreover you may be told to feel glad that you haven't got a life-threatening illness like some of your peers. It is possible that the harder an older person tries to get any contacts to understand M.E., the more he or she is accused of failing to accept the ageing process. Our society is guilty of turning a deaf ear to the voice of our older generation.

## Making light of a sad situation

A letter we received from Florence in Kent put it well; 'The hospital physician gently and courteously told me that after an active life I was finding it difficult to adapt to the slowing

down caused by old age.' But as she said to her GP: 'I had already experienced the slowing down caused by age and could testify that it is very different from the exhaustion which still hits me every day.' However, this same lady feels there are certain advantages to being an older sufferer as 'no-one expects much of an octogenarian' but I feel this is making rather light of a sad situation. At the onset of her M.E. she was halfway to her fourth Open University credit and clearly wanted to continue.

Perversely perhaps there is even more of a blame culture against people of this generation with M.E. We have been encouraged to believe that a healthy old age is possible if you avoid saturated fat and go to the gym. Ergo those who are not healthy must have been lazy and eaten junk food, so how dare they complain if they are exhausted and in pain. The comment 'it's your own fault for not looking after yourself' hangs unspoken in the air. This totally denies and overlooks the fear associated with symptoms which people with M.E. of any age experience. But how dreadful to wonder, like Florence, if your forgetfulness is just M.E. or the early signs of Alzheimers'.

## Who cares?

Bereavement in some form is usually a significant part of old age. It is also a significant part of M.E. in a subtler way, whatever one's age. We lose people – lovers, friends, colleagues – for a variety of reasons: they don't understand, they disapprove, or they get plain fed up with the restrictions of your illness.

However, true bereavement can be a double whammy for an older person who may lose their principal carer as well as their lifetime companion. Is one's disability likely to be taken seriously by those who have the power to provide alternative care? After becoming widowed, Megan moved into sheltered accommodation where she is fortunately well enough to join in some social activity. But what about those who are severely affected – is it easier for an elderly M.E. person to gain access to care?

Surprisingly, Help the Aged research indicates the opposite: 'the upper limit on expenditure for an older person in residential or nursing care can be up to 50% less than that spent on a younger adult...' in addition the charity found that local authorities were being given financial incentives 'to encourage older people out of their own homes and into residential care'. So much for respecting our elders.

## Celebrating small triumphs

Each age group affected by M.E. comes with its own set of medical justifications and stereotypical explanations. The spectre of a purely psychological diagnosis hovers over all of us – it is just phrased in slightly different ways depending on our age-related and personal circumstances. Each phase of life, even without illness, has its problems and its triumphs. For those affected by chronic illness those same problems may on bad days seem insurmountable. Perhaps on our better days, we can concede that there will be smaller, different triumphs – like getting out for the first time in months or even being able to sit up for a longer period.

Beryl writes: 'it has not been easy for me to restrict my

# I Found My Light

By Kelly Gooch

Step by step I was reaching my goals. At 17 I had been out of school for two years, had my car, enjoyed my job, did my aerobics 3 times a week and was really happy with the way things were going. Then one day I came home from work, went to bed that night and woke up to have my life changed forever. Apparently 17 and 18 are good years, I couldn't tell you I don't remember them.

At age 12 I contracted (I learnt later) the mysterious illness CMV (Cytomegalovirus); this left me battling through my teenage years not willing to accept that I wasn't really as healthy as I led myself to believe. I found myself falling asleep in class, the teachers telling my parents to keep me at home until I was better. For me, the anxious high achiever, this didn't sit right. Eventually I managed to graduate from school with the grades I wanted and hoped that with school I'd leave the stress of ill health behind me. Not so. Just after I turned 17 I contracted Chicken Pox and later it was thought I had some kind of CMV relapse at the same time. I got over this, then two months later that dramatic change occurred.

I wasn't just that I had no energy, I had no comprehension, no drive and unbelievable pain. My Mum had already heard of CFS so I didn't go through that horrible searching stage of trying to find out what was wrong, our family doctor knew me socially and couldn't believe the change in me. Not wanting to sentence me with CFS she ran all the tests and sent me to specialists, however after six months we accepted the inevitable. The Newcastle University tested me and all was confirmed.

My family was wonderful, they learnt massage as it was the only way to ease my pain. They coped as best they could as their daughter and sister went from being a happy, bubbly person to an intolerant, frustrated zombie-like state. I couldn't cope with visitors, I could barely understand a TV show let alone a conversation. When I was well enough I would join my family for a meal at the table instead of their sitting around my bed. Often though, by the end of the meal, I would be face down on the table, worn out by the effort of eating and sitting up. Remaining that way until I was carried to bed or I summoned the energy to be assisted there. Early

on in my illness I learnt how much of an impact my emotions had on my general well being. Here my sister played a major role by always providing a laugh to bring me out of my lowest times. It wasn't til years later that I learnt how influential our thoughts and emotions are, as you'll see when you read on.

I had no energy to find a solution. How grateful I am to my Mum. She researched tirelessly to first understand then beat this syndrome. I love her dearly but boy did she make me try some gross "remedies" from naturopaths and the like! I changed my diet quite a few times, took massive doses of vitamin C (this had to be oral as I am needle phobic, something that has only been enhanced since the CFS), did the Liver Cleansing diet, took the cold bath 'solution', hydrotherapy and many more I can't even remember. Some of these things made a huge difference. It was like each new thing brought me up level in my quest for better health, I would improve for a while then the advancement would level off.

I would have highs and lows for the next 5 years. Then came a huge high. I met the man of my dreams and we planned our big day. Although the stress was high during this time, I don't doubt that the emotional high I was on had a real positive affect on my health. After the wedding, I expected to "crash", however I managed to keep going. I wasn't working – I still had my disability pension, so keeping a home was all I could manage. My husband sat me down one day and clasped his hands in front of me and said, "This is you. My thumb is your CFS, but look it's only one part of you, there are so many things that make you Kel. So let's not just focus on that one thumb, but on all of you." Wow! That really blew me away. Since then I have been reading a lot of personal development books that explain how the brain works ie. If you are always saying your sick your brain doesn't differentiate between reality and what you're saying so it will make sure you're not a liar and keep you sick. There is of course far more to it than simply thinking 'happy thoughts', yet I know doing so has been of great benefit. One book I really enjoyed was entitled 'Being Happy' by Andrew

*(Continued on page 12)*

*(Continued from page 10)*

activities but I am blessed with an understanding family and am looking forward to my first great-grandchild.'

I'll end with some advice that has helped Mr GL. It was given to him by his late wife, an MS sufferer: 'if you pity yourself, no-one will sympathise with you'.

But the final word goes to Florence. She believes that the emphasis must be on younger people whose whole life is still before them but pleads: 'Don't marginalize old people. Our time ahead may be limited but our quality of life

remains important.'

Your letters have made me appreciate yet again how people with M.E. are some of the bravest I have encountered. In spite of all the odds most do survive and with a grace that takes my breath away.

Used with permission

Taken from InterAction Issue 42, magazine of Action for ME [www.afme.org.uk](http://www.afme.org.uk)



(Continued from page 11)  
Matthews. I recommend it.

By this stage I was on a very strong multivitamin which I called my 'proton pills', I wasn't improving I just was managing to cope with life. Now married for about a year I decided to try a take on a job again. Finding work with a business that understood my limitations wasn't easy but I found one. I would work for 3hrs two days a week, which left me sleeping away most afternoons just to cope.

Then some friends told of some high quality supplements they were on just to maintain health in the toxic environment that we live. I was dubious, I tried enough and I was kind of coping with life. Plus I read the testimonials of fantastic results from the products, yet my scepticism remained. After much deliberation we decided to give it a go. To be perfectly honest, it really was a leap of faith for me, you see I wasn't getting better at the time but at least I wasn't getting worse.

The result? Initially I stayed the same, I was just grateful I didn't go backwards. Then slowly but surely I began to notice a difference. Where am I at today? Last week I went for a 5km hike had lunch then did a further 1km walk after an eventful day I got home late. The next day I left for work at 8am and my normal 3hrs hours turned into 10hrs!!! I got home at 7:45pm changed and went straight to a meeting arriving home from there at 10:30pm. No I wasn't wasted the next day, I got up cleaned my house then took off shopping! The only way I suffered was my calves were a bit sore but so were my other walking buddies. Oh, I forgot to mention I have also resumed my aerobics again, 6years on and this time I do kick-boxing aerobics!

So why the difference? I am on a liquid mineral, a multivitamin and anti-oxidant through a company called Neways. My personal opinion is the reason they work is that the mineral helps in the absorption of the other two. I know

that with my CFS my body doesn't absorb the goodness that I try to give it, so with the mineral assisting in this area I am achieving the afore mentioned results.

The company that supplies the nutritionals also offers toxic free personal care products. I know I am very chemical sensitive, so changing my toothpaste, shampoo and even my make-up has been of huge benefit to me.

I realise that with CFS what works for one patient doesn't necessarily work for another, however I wanted to tell my story so that you would have a choice. Also I wanted to share good news. As my Mum used to say:

***"Look for the light at the end of the tunnel, if there's not one there, go and flamin' well light it!"***

The supplements I'm on have turned out to be that light! There is life after CFS.

If you would like further information please feel free to contact me:

Kelly Gooch

Ph.: 07 3341 1219

Mob: 0403 152 198

Email: mgooch@mail.com

Used with Permission

ED: The ME/CFS Society (SA) Inc. enjoys publishing people's life stories related to CFS and I would certainly encourage you send in yours! Please remember that when treatments and therapies are mentioned, they are not necessarily endorsed by the Society. See the general disclaimer on page 2.

## Wahroonga Dairy Goat Farm



*Suppliers of natural, sweet tasting,  
Goat Milk Products*

All yoghurts contain Acidophilus Lactobacillus, Bifidobacterium & Thermophilus;  
yoghurts and cheeses are free of preservatives, additives, colourings and artificial flavourings.

Please contact us for more information about Wahroonga Dairy  
Products and a list of retail outlets

Back Valley, Victor Harbor Ph / Fax: 08 8554 5285 Mobile 0408 116 739

Web: [www.wahroonga-farm.com](http://www.wahroonga-farm.com)

Email: [waroonga@granite.net.au](mailto:waroonga@granite.net.au)

Licensed &  
Laboratory  
Tested  
Dairy Farm

# Medical Matters

## Q&A: Procrit Trial Focuses on Red Blood Cells

*Researchers at the University of Miami are testing the effects of the drug Procrit (epoetin alfa) on people with CFIDS. The drug, also manufactured as Epogen, increases the body's production of oxygen-carrying red blood cells. The study has received substantial coverage from national media outlets this year. As part of an ongoing Question and Answer series with CFIDS researchers, the Chronicle interviewed Barry Hurwitz, PhD, the principal investigator in the Procrit-CFIDS study.*

**Q: What is the theory behind Procrit and CFIDS?**

**A:** Procrit was developed to treat anemia. It's highly effective in inducing bone marrow to produce red blood cells. Procrit has been used on two groups of patients so far: people who have cancer and have undergone chemotherapy, and people with kidney disease who are on dialysis. To date the medication has not been used on CFIDS patients in a large clinical trial.

Our preliminary data indicated that many of our CFIDS patients who had difficulty with fainting spells and light-headedness also displayed decreased red blood cell volume. We hypothesized that the lack of sufficient oxygen supply could be a cause for these symptoms and possibly explain the fatigue as well. The study we're conducting is looking at whether increasing red blood cell volume can improve these symptoms in people diagnosed with CFIDS.

**Q: Do people with CFIDS have low numbers of red blood cells?**

**A:** We have found that 60-70 percent of people with CFIDS have low-normal, or below-normal, red blood cell volume. This was not known before we began our work. It's usually missed by standard blood tests.

The test we use is called a dual tag blood volume test. It is the gold standard, the most accurate way to measure both plasma volume and red blood cell volume in the blood. It's commonly done in the radiology departments at most hospitals.

It's important for those who are wondering if they have red blood cell volume deficit that the right test be performed. Some tests only measure the plasma volume and estimate the red blood cell volume. Those are inaccurate. For instance, there's a measure called hematocrit. The percentage of red blood cells in the blood is derived from a drop of blood, but it's really an

estimate.

**Q: How is the Procrit study being run?**

**A:** We have a randomized, placebo-controlled trial funded by the National Institutes of Health's National Heart, Lung and Blood Institute. Dr. Nancy Klimas and I are the principal investigators, and we work with a team of other medical scientists. It's a four-year study, and we're in year two. We want to enroll 150 people, and we're about halfway to that goal.

We assess individuals as to whether or not they have diminished red blood cell volume. We also give them a complete cardiovascular workup, and take other measures that will help us test what role the immune system might play in influencing red blood cell volume. The actual treatment phase lasts four months, with check-ups every two weeks. People with low red blood cell volume are randomized to Procrit or placebo treatment. People with low red blood cell volume who receive placebo will later receive an opportunity to obtain the four months of Procrit treatment and repeat the testing.

If it's determined up front that you do not have low red blood cell volume, you're given a placebo. That way we can compare people who have low red blood cell volume to those with normal blood volume levels.

The drug is administered three times a week by injection. Subjects are tested before treatment begins and after the four months of treatment. By using daily diaries, simple reflex tests and a tilt test we examine changes in CFIDS symptomatology, as well as the individual's ability to control the circulatory system. These circulatory tests are performed because in CFIDS patients the light-headedness and fainting typically occur when the person is in an upright posture, suggesting a circulatory regulation problem.

**Q: Is it too early to comment on study results?**

**A:** Yes, because it's a double-blind study. The experimenters and the subjects are unaware of the treatment assignments until after the study is finished. Then we'll be able to analyze the results. Subjects are provided copies of their test results at the completion of their testing.

(Continued on page 15)

# Research Q&A: CFIDS\* and the Autonomic Nervous System

*By Mark Giulucci*

Page 14

Talking Point 2003 Issue 1: The Official Journal of the M.E./C.F.S. Society (SA) Inc

Chronic fatigue and immune dysfunction syndrome (CFIDS) is a complex disease that involves many body systems. In their search for a cause and cure, researchers are examining how CFIDS affects the immune system, hormone systems and numerous other body processes.

Canadian researcher Ronald Schondorf, MD, PhD, and his team at McGill University in Montreal are focusing on whether CFIDS creates changes in the autonomic nervous system (ANS). The ANS controls involuntary body functions, including heart beat, digestion, gland secretions and sweating. Dr. Schondorf is looking to answer three specific questions:

- Do people with CFIDS show widespread ANS dysfunction?
- Can a questionnaire be used to identify CFIDS patients who have ANS problems?
- Does ANS dysfunction occur whether or not a person is physically deconditioned?
- 

The Chronicle asked Dr. Schondorf to explain his work, and what he hopes to find.

## **Q: What do we know about ANS dysfunction and CFIDS?**

A: We have already shown that about 40 percent of people with the disease have orthostatic intolerance, a form of ANS dysfunction. They have trouble with dizziness, lightheadedness and other symptoms when they stand up. This is related to how fast the heart beats and changes in blood pressure. These changes may also occur after you eat or when you are hot.

What's not really known is whether CFIDS affects other autonomic functions. Are these functions somehow altered in people with CFIDS? That's what we're looking to document.

## **Q: How will you conduct your research?**

A: Not everything can be studied easily. You can study the bladder or the gut, but the tests are very invasive. So we are studying sweating and cardiovascular changes while the subjects are standing. We can get at these more easily.

Some people with autonomic dysfunction sweat less in certain spots, and more in others. We already know that some people

with CFIDS get drenching sweats, while others have no problem with this at all. Our study will help us discover how widespread the problem really is in people with CFIDS. It could also give us a hint about other autonomic problems. Maybe if one part of the system gets attacked, another part will be affected as well.

## **Q: How can this knowledge help patients?**

A: It may give us insight into the underlying pathophysiology of the disease — that is, how CFIDS affects the normal working of the body. I would certainly not say that everything about CFIDS can be explained by changes in the autonomic nervous system. But perhaps studying the role of ANS dysfunction in CFIDS can help us identify groups of individuals for whom intervention can be made. In some cases, treatments for autonomic problems might help. It also can help provide objective proof that something isn't right with them. It could provide validation that they are sick, which is important to many patients.

## **Q: Are you talking about a clinical test for CFIDS?**

A: A test could be a two-edged sword. On one hand, it provides insurance companies with some degree of comfort when paying claims. But if you don't show these particular symptoms, the insurance company could use it against you. Even if a doctor with tremendous knowledge of CFIDS gives you a diagnosis of CFIDS, an insurance company could say, "Too bad, you don't show anything on the test."

## **Q: What about the questionnaire?**

A: Many tests for CFIDS and autonomic disorders, like the tilt table test, are very expensive and very invasive. A questionnaire that screens people with CFIDS for autonomic problems could be a tremendous benefit to the patient.

If you actually come up with a validated questionnaire, then doctors could screen you in the office. They could stratify patients and decide where more testing needs to be done. Physicians could avoid giving unnecessary tests. Nobody likes standing and being tested for 45 minutes. Many people have to travel great distances to get testing. They have to pay out of pocket. Maybe we could help avoid some of that.

*(Continued on page 15)*

\*NOTE: In the USA ME/CFS is known as CFIDS (Chronic Fatigue Immune Deficiency Syndrome)

(Continued from page 14)

A questionnaire has been developed by the Mayo Clinic to see if people in the general population have obvious autonomic disorders. Perhaps this is something we can use, or modify, to identify people with CFIDS who have more subtle autonomic disorders.

But this may prove very difficult. Many people with CFIDS have a lot of symptoms that are difficult to explain. Often they are much more disabled or attach a lot more meaning to certain symptoms than other people. We'll have to see how it goes.

**Q: Can you explain your third goal, to uncover what role deconditioning might play?**

A: Some people may show abnormalities in the autonomic system simply because they're de-conditioned. If you've had the flu for a few days and have been lying down most of that time, you may feel quite dizzy when you stand up. That's a very mild form of deconditioning; you have been inactive

and are not used to standing up.

We hope to see how much of a role — if any — inactivity plays in CFIDS cases. We expect that ANS dysfunction will be independent of how much activity a CFIDS patient gets. This whole area can be controversial. There's a political twist. It could be that autonomic dysfunction is a genuine problem related to CFIDS. Or maybe not — in which case some people will say that people with CFIDS are bringing this on themselves by becoming deconditioned. My argument is that the data are the data, and we'll have to see what it shows. We need to find out.

*Dr. Schondorf's research is being funded by a grant from The CFIDS Association of America.*

This article originally appeared in the Summer 2002 issue of *The CFIDS Chronicle*. It has been reprinted with the permission of The CFIDS Association of America. For more information, call the Association at 800-442-3437 or visit [www.cfids.org](http://www.cfids.org)



(Continued from page 13)

**Q: What is the best-case scenario?**

A: If individuals are fatigued, one possible cause is a lack of oxygenation in the blood, or an inability to transport oxygen. If you have diminished red blood cell volume, then you have less capability to deliver oxygen to the cells. There's a high probability that if we're able to increase red blood cell volume it will diminish fatigue, assuming that fatigue is a function of the capacity to deliver oxygen to the tissues.

**Q: If it turns out that Procrit does help, how long would treatments have to be taken for a lasting effect?**

A: That's an empirical question. First, we'll have to determine if there is a measurable change in people who take the drug — in fatigue levels, quality of life, exercise fitness, ability to sustain an upright posture, and in immune function and profile.

If there is a change, then the next question is whether the treatment has to be maintained for a long period of time. One possibility is that restoring red blood cell volume will have a positive effect on what's causing the problem in the first place. Theoretically, the treatments could end at that point. That would be a very positive outcome, because at this time Procrit is an expensive drug.

Alternatively, we'll have to keep searching for the main cause for the decreased red blood cell volume. We suspect that the immune system may be involved. That's why we're taking a number of immune system measures, to find out how the immune system might be related to the decrease in red blood cell production.

**Q: Why is there such a buzz about this study?**

A: The fact is that there's no accepted treatment for CFIDS. People are desperate to find some recognizable cause. There's obviously a strong demand for an effective treatment.

It is very exciting to have learned from our study so far that 60-70 percent of people with CFIDS have diminished red blood cell volume. We did not know that before we began the study. To me, that tells people that there's something really physically wrong with them. For individuals who have been told before that it's all in your head, that you're malingering, the knowledge that there are real physical changes going on is confirming for them.

Even if Procrit does not improve CFIDS symptoms, the information we're collecting regarding circulatory functioning and immune system interactions in relation to fatigue will shed a great deal of light on some of the important disease pathophysiology.

**Q. How can people participate in the study?**

A: We're including individuals 18-55 years of age who have been diagnosed with CFIDS by their physicians. Participants must have no diagnosed medical history of abnormal cardiovascular conditions, epilepsy, chronic respiratory conditions, alcohol or drug abuse, and must not be taking prescribed medications that would have an impact on their cardiovascular system. Participants must be willing to be available for assessments at the study site every two weeks for a seven-month period. They have to travel to Miami at their own expense. Qualifying people must fill out and submit a questionnaire on our Web site, [www.bmrc.miami.edu/research/niid/procrit.asp](http://www.bmrc.miami.edu/research/niid/procrit.asp). Other questions or comments may be forwarded via e-mail to [CFSresearch@miami.edu](mailto:CFSresearch@miami.edu).

This article originally appeared in the Fall 2002 issue of *The CFIDS Chronicle*. It has been reprinted with the permission of The CFIDS Association of America. For more information, call the Association at 800-442-3437 or visit [www.cfids.org](http://www.cfids.org)



# Sleep Dysfunction in CFS

*By Richard Podell, MD, MPH*

Page 16

Many patients with chronic fatigue syndrome (CFS) feel sleepy as well as tired. Whether or not they have difficulty falling asleep (sleep onset insomnia) or difficulty staying asleep (sleep maintenance insomnia), most CFS patients feel that their sleep is not refreshing. They wake up in the morning feeling as if they haven't really rested.

Improving sleep is a realistic goal. As clinicians know, this is often a complex and difficult task. Even modest improvement in sleep can have important positive effects on the patient's sense of well-being.<sup>1-6</sup>

Sleep studies will often disclose some abnormality. Pharmacologic and non-pharmacologic measures can be of benefit, including cognitive therapies. Complementary medications available over the counter may be of help to some patients. When sleep dysfunction remains persistent and severe, a formal consultation with a sleep physiologist should be obtained.

## Pathophysiology

We only partly understand why people with CFS lack restorative sleep. For many, especially those with fibromyalgia, the EEG shows alpha wave activity inappropriately intruding into the delta waves of deep sleep.

A significant minority have classic sleep disorders complicating their CFS: periodic leg movement disorder (PLMD) or sleep apnea. Others suffer from insomnia, hypersomnia or non-restorative sleep. The mechanisms for these aspects of CFS are not clear (see table).

## Diagnosis

When either insomnia or poor sleep is chronic, the physician should consider whether a specific and treatable sleep disorder is present. Occasionally, the diagnosis of CFS is mistaken, and a primary sleep disorder is the main cause of fatigue. More often, CFS is the diagnosis, but specific sleep disorders can complicate and exacerbate the illness. Sleep disorders can be suspected by asking patients about key symptoms, specifically about whether they snore, struggle for breath at night or have ever been told that they stop breathing, or have muscle twitching often while asleep.

Teaching a family member or friend to observe the sleeping patient for at least 30 minutes, on one or several nights, can be very useful. This is the minimum that should be done for patients with chronic fatigue without a clear-cut cause. The

observer should look for severe snoring, episodes of not breathing for 10 seconds or more, snorting or struggling for breath. Frequent gross or fine muscle or limb movements or twitches should be noted.

One may observe PLMD if there is a restless legs syndrome during the day or evening.<sup>7,8</sup> However, lack of restless legs should not deter evaluation for PLMD. Typically, patients are not aware of nocturnal muscle twitches or limb jerks. This condition is often missed unless a sleep study is done.

We cannot exclude a sleep disorder with a very high degree of confidence without professional monitoring, utilizing an overnight sleep study. We would recommend that all patients with chronic insomnia or chronically non-restorative sleep be evaluated in consultation with a sleep specialist whenever cost or third-party payment is not an issue. It is important to note that some patients with CFS have relatively normal overnight sleep tests. These patients also describe their sleep as not restful. The patient's subjective report should be respected as valid and be taken seriously.

## Treatment of Sleep Problems in CFS

Trial and error may be productive. Often long-term rather than short-term treatment may be needed, with all the trade-offs or potential medication side effects that that implies.

Even modest improvements in sleep quality can make a meaningful difference for the quality of life. However, better sleep is not, by itself, a cure for CFS.

Sleep specialists recommend an important role for sleep hygiene and behavioral techniques. Ideally, a nurse or patient educator would spend an hour with each patient to review basic sleep hygiene and relaxation skills. Attention to these details can often make a major difference. Additional and more complex behavioral techniques can often help sleep problems of any kind, especially those where the overnight sleep test fails to disclose specifically treatable pathology.<sup>9-11</sup>

If chronic pain, sleep apnea, PLMD, anxiety or depression is a dominant problem, these symptoms should be addressed with their standard treatments. Whether or not these disorders complicate sleep, pharmacologic regimens specifically for sleep can be very useful.

Sleep problems among many CFS patients are chronic, not intermittent. While limiting sleep medicine to intermittent

### SLEEP DISORDERS THAT MAY COMPLICATE CFS<sup>9,10</sup>

DISORDER	WHEN TO SUSPECT	COMMENT
Obstructive Sleep Apnea	Heavy snoring or patient experiences sudden awakenings with subjective apnea or struggling for breath.	Fairly common. Bed partner may be aware, esp. if they are asked to observe or typical signs.
Periodic Leg Movement Disorder (PLMD)	Repeated episodes of twitching muscles.	May be more common than average among patients with CFS.
Alpha-Delta Sleep Disturbance	Common in patients with fibromyalgia or other chronic pain syndromes.	Tricyclic antidepressants, cyclobenzaprine and trazadone tend to restore more normal sleep architecture. <sup>5</sup>
Anxiety, Depression and/or Chronic Pain	Often complicate CFS. Tend to make sleep disturbance worse.	Treat conditions as appropriate.

use is a desirable goal, there may be good medical and psychological reasons to encourage chronic ongoing treatment. If sleep medicines are to be used regularly, it is advantageous to use those medicines which are less likely to disrupt sleep architecture or to induce tolerance or addiction. The physician should be prepared to "test" a number of different sleep medicines, each at a relatively low dose. A few may benefit by rotating a different sleep medicine every night or every few nights. Patients with CFS tend to be very sensitive to medicine side effects, so it is often wise to start with new medicines with a very low dose.

For better sleep, the first choice should often be either antidepressants like trazadone (Desyrel) or the sedating tricyclic anti-depressants, e.g., amitriptyline. These medicines usually do not disrupt sleep, maintenance insomnia or sleep architecture, and may improve sleep. They can be useful for suppressing the alpha-delta sleep abnormality that is often seen with fibromyalgia or with chronic pain. However, because of their long action, they are often too sedating in the morning.<sup>9,10</sup>

When used for sleep, the tricyclics or trazadone usually do best at lower doses than are needed for treating depression. The most commonly used tricyclics, listed in order of sedation and increasing side effects: nortriptyline (Pamelor), doxepin (Sinequan) and imipramine (Tofranil), as well as amitriptyline (Elavil).

For the tricyclics, low doses, e.g. 10 mg, can be used at first. A few very sensitive patients might start with 1–2 mg of doxepin suspension with stepwise increases in dosage steps towards the 20–50 mg range. If also treating depression, the increase can proceed to the usual full therapeutic dose (75–150 mg). For trazadone, a starting dose of 25–50 mg qhs is adequate. If necessary, one can increase in steps toward the 150 mg range. When using these antidepressant medicines, sleep benefits are often seen the first night. This contrasts with relatively high dose range and 3–4 weeks typically needed to see effects for depression.

Antidepressants can be useful sleep aids whether or not the patient is depressed. However, some patients experience a paradoxical effect, becoming more agitated and unable to sleep. For sleep onset insomnia, consider short-acting agents such as zaleplon (Sonata) or triazolam (Halcion). For sleep maintenance insomnia, consider zolpidem (Ambien) or one of these benzodiazepines: clonazepam (Klonopin), temazepam (Restoril) or lorazepam (Ativan). Flurazepam (Dalmane), a long-acting benzodiazepine, usually leaves patients too sedated in the morning.

Benzodiazepines have a relatively high potential for tolerance, habituation and abuse. Ambien, a non-benzodiazepine, has less potential for tolerance and perhaps also less for habituation. However, Ambien is not entirely free from the risk of addiction. Transient amnesia has been reported for benzodiazepines as a class, especially with triazolam.

In PLMD, employ a very brief diagnostic trial of dopaminergic agonist, which is a moderately effective treatment for PLMD, e.g., Sinemet 25/100. If subjective sleep quality improves, consider PLMD as fairly likely. Do not continue to treat empirically. Confirm the diagnosis with an overnight sleep study. Lack of improvement with Sinemet does not rule out PLMD. Various antidepressants have been reported to exacerbate PLMD in some patients.

Almost all sleeping medicines should be used with caution for people who have to be alert when they first wake or throughout the day. Most hypnotics will also potentiate the sedating effects of alcohol and other sedating drugs. Use in pregnancy should be coordinated with an obstetrician.

## Other Therapies

There are several over-the-counter medications that patients with CFS may use as sleep adjuncts. A few are listed below.

- Melatonin may be effective for a small minority of people with insomnia, especially among the elderly. Little is known about the potential long-term side effects or drug interactions. It may be useful for delayed phase sleep disorder.<sup>12–14</sup>
- Valerian Root is a mediocre short-term sedative. However, at least three double-blind studies from Germany show benefit for sleep and for mood after 3–4 weeks or taking Valerian, 300 mg twice daily. Valerian might also help anxiety. It does not seem to be addictive. There are no substantial long-term studies of safety or benefit.<sup>15,16</sup>
- Lavender extract used as aromatherapy has been studied, showing benefit for sleep onset insomnia and accompanying anti-anxiety effects. No side effects are expected.<sup>17</sup>

All of these natural products can potentially interact with selected drugs or with specific nutrients or herbs. Books on complementary medicines and computer data bases in health food stores and pharmacies are becoming available.<sup>18</sup>

*Richard Podell, MD, MPH, is clinical professor of family medicine in the Department of Family Medicine at the University of Medicine and Dentistry of New Jersey-Robert Wood Johnson Medical School. This article is reprinted with permission from "A Consensus Manual for the Primary Care and Treatment of Chronic Fatigue Syndrome," published by The Academy of Medicine of New Jersey.*

## References

- Stores G et al. Sleep abnormalities demonstrated by home polysomnography in teenagers with chronic fatigue syndrome. *J Psychosom Res.* 1998; 45:85-91.
- Sharpley A et al. Do patients with "pure" chronic fatigue syndrome have abnormal sleep? *Psychosom Med.* 1997; 59:592-6.
- Morriss RK et al. The relation of sleep difficulties to fatigue, mood and disability in chronic fatigue syndrome. *J Psychosom Res.* 1997; 42:597-605.
- Fischler B et al. Sleep abnormalities in the chronic fatigue syndrome: A co-morbidity study. *Neuropsychobiology.* 1997; 35:115-22.
- Manu P et al. Alpha-delta sleep in patients with a chief complaint of chronic fatigue. *South Med J.* 1994; 87:465-70.
- Buchwald D et al. Sleep disorders in patients with chronic fatigue. *Clin Infect Dis.* 1994; 18 Suppl. 1:S68-72.
- Williams DC. Periodic limb movements of sleep and the restless leg syndrome. *Va Med Q.* 1996; 123:260-5.
- Ambrogetti A et al. Consideration of narcolepsy in differential diagnosis of chronic fatigue syndrome. *Med J Aust.* 1994; 160:426-9.
- Kryger M et al. Principles and practice of sleep medicine. 2 ed. PA: WB Saunders, 1994.
- Swanson J. Sleep disorders sourcebook. Detroit: Omnigraphics, 1999.
- Arnold G. Get a good night's sleep. NY: Simon & Schuster, 1996.
- Citera G et al. The effect of melatonin in patients with fibromyalgia: a pilot study. *Clin Rheumatol.* 2000; 19:9-13.
- Armstrong S. Melatonin as a chronobiotic for circadian insomnia: Clinical observations and animal models. *Adv Exp Med Biol.* 1989; 460:283-87.
- Nategaal JE et al. Effects of melatonin on the quality of life in patients with delayed sleep phase syndrome. *J Psychosom Res.* 2000; 48:45-50.
- Dorn M. Efficacy and tolerability of Baldrian versus oxazepam in non-organic and non-psychiatric insomniacs. *Forsch Komplementarmed Lass Naturheilkd.* 2000; 7:79-84.
- Donath F et al. Critical evaluation of the effect of valerian extract on sleep structure and sleep quality. *Pharmacopsychiatry.* 2000; 33:47-53.
- The Natural Pharmacy Revised. Prima Publishing. 1999.
- The A-Z guide to drug, herb and vitamin interactions: Prima Publishing. 1999.

This article originally appeared in the Fall 2002 issue of *The CFS Research Review*. It has been reprinted with the permission of The CFIDS Association of America. For more information, call the Association at 800-442-3437 or visit [www.cfids.org](http://www.cfids.org)



# Grief and Depression

by Dr Nicole Phillips, Medical Editor for Emerge,  
The quarterly journal of The ME/CFS Society of Victoria

## Grief

Page 18

Grief is the feeling generated by a loss and is a process. The typical pattern can give us a picture of "normal" depression. In the community there is still a tendency to think of grief solely as a response to death, especially of someone we love, but in recent decades the understanding of human psychological processes has grown enormously and we now know that loss of any kind can provoke a grief reaction. Loss of health such as in Chronic Fatigue Syndrome, loss of a body part due to surgery or accident, loss of a job due to redundancy or retirement are all obvious examples of loss. Less obvious losses can include infertility (loss of the expectations of rearing your own children) and divorce (loss of the expectations of a life-time shared in marriage which may also be associated with financial loss and loss of expected lifestyle).

Psychology experts have put together the following pattern of grief reactions. It must be emphasised however that your own experience is unique and there are great variations, both in the pattern of grief and in the time it takes to work through.

1. Disbelief - There is an initial response of shock, numbness and disbelief which is usually short-lived and followed by;
2. Preoccupation - Longing and yearning for what you have lost fills your mind. There may also be;
3. Denial - Acting as though the loss had not occurred (keeping a bedroom ready for a dead child) or if retrenched (getting dressed and going "to work" every morning) or in Chronic Fatigue Syndrome (pushing yourself past the point of what you know is appropriate);
4. Anger and guilt - Intense emotions which may be expressed in statements such as "Why has this happened to me?"; "It's not fair!"; or "If I had only done such and such this would not have happened". This usually settles to be slowly replaced by acceptance of the loss;
5. Acceptance of the loss - with continued grieving and, finally,
6. Depression.

The depression associated with grief usually lessens although at times it may seem that it will never lift. Anniversaries of the death or of a distressing event, birthdays and other reminders may reactivate your feelings but gradually the strands of life are picked up again and you return to normal functioning (this of course not being applicable to Chronic Fatigue Syndrome patients). This usually occurs around a period of 13 months and most people feel they are coping much better in the second year.

The important message here is that grief and the depression accompanying it should heal over time. If you remain depressed and unable to get on with life it could indicate unresolved issues related to the loss and possibly the onset of

a depressive illness.

## Depression

The number and severity of the losses that accompany the diagnosis of Chronic Fatigue Syndrome, in my experience, cause a very high incidence of co-existing depression along with the Chronic Fatigue Syndrome symptoms. Because many of the symptoms of depression and Chronic Fatigue Syndrome overlap it takes someone knowledgeable about both these conditions to tease out what is what and make appropriate diagnoses. The symptoms that overlap include fatigue, sleep disturbance, difficulty concentrating and remembering things, loss of libido, bodily aches and pains. However, in my experience the essential differences are:

1. In Chronic Fatigue Syndrome without depression the patient's mood tends to be more that of frustration and anger whereas in depression the patient's mood drops markedly and has a quality of hopelessness and negativity much more severe than in the non-depressed person. There is an overall sense of inability to cope, tearfulness, heightened sensitivity to perceived criticism and difficulties in interpersonal relationship.
2. In depression, anxiety is a major symptom and so if anxiety levels are raised substantially this is usually a good indicator of depression.
3. Thoughts of death or suicide are also a good indicator of depression. Sometimes these are more passive such as thoughts of "I'd rather not be here" or "It wouldn't matter if I was run over by a bus" rather than active thoughts and plans.
4. Importantly, in depression there is always a substantial loss of pleasure or interest in things that previously people enjoyed. The important thing here is that in Chronic Fatigue Syndrome many or most of these previously enjoyed activities can no longer be partaken in due to illness. The giveaway though is that if someone is experiencing depression they don't even have the desire to be doing these things any more such as seeing people, going to a movie or doing the things they enjoyed doing previously, as opposed to people with Chronic Fatigue Syndrome without depression who say they would still love to do these things if only they were feeling better.

From my experience if there is any uncertainty about whether depression exists or not in someone with Chronic Fatigue Syndrome a trial of antidepressants is useful as much as the emotional suffering in the illness can be relieved by the use of antidepressants if there is a concurrent depression present. If they cannot be tolerated or in fact make no difference then nothing has been lost and they can be ceased.

(Continued on page 20)

# Summary of Canadian Clinical Case Definition for Chronic Fatigue Syndrome

*A patient with ME/CFS will meet the criteria for fatigue, post-exertional malaise and/or fatigue, sleep dysfunction, and pain; have two or more neurological/cognitive manifestations and one or more symptoms from two of the categories of autonomic, neuroendocrine and immune manifestations; and adhere to item 7.*

1. **Fatigue:** The patient must have a significant degree of new onset, unexplained, persistent, or recurrent physical and mental fatigue that substantially reduces activity level.

2. **Post-Exertional Malaise and/or Fatigue:** There is an inappropriate loss of physical and mental stamina, rapid muscular and cognitive fatigability, post exertional malaise and/or fatigue and/or pain and a tendency for other associated symptoms within the patient's cluster of symptoms to worsen. There is a pathologically slow recovery period—usually 24 hours or longer.

3. **Sleep Dysfunction:**\* There is unrefreshed sleep or sleep quantity or rhythm disturbances such as reversed or chaotic diurnal sleep rhythms.

4. **Pain:**\* There is a significant degree of myalgia. Pain can be experienced in the muscles and/or joints, and is often widespread and migratory in nature. Often there are significant *headaches* of new type, pattern or severity.

5. **Neurological/Cognitive Manifestations:** Two or more of the following difficulties should be present: confusion, impairment of concentration and short-term memory consolidation, disorientation, difficulty with information processing, categorizing and word retrieval, and perceptual and sensory disturbances—e.g., spatial instability and disorientation and inability to focus vision. Ataxia, muscle weakness and fasciculations are common. There may be overload phenomena: cognitive, sensory—e.g., photophobia and hypersensitivity to noise—and/or emotional overload, which may lead to “crash” periods and/or anxiety.

6. **At Least One Symptom from Two of the Following Categories:**

- Autonomic Manifestations:** orthostatic intolerance—neurally mediated hypotension (NMH), postural orthostatic tachycardia syndrome (POTS), delayed postural hypotension; light-headedness; extreme pallor; nausea and irritable bowel syndrome; urinary frequency and bladder dysfunction; palpitations with or without cardiac arrhythmias; exertional dyspnea.
- Neuroendocrine Manifestations:** loss of thermodynamic stability—subnormal body temperature and marked diurnal fluctuation, sweating episodes, recurrent feelings of feverishness and cold extremities; intolerance of

extremes of heat and cold; marked weight change—  
anorexia or abnormal appetite; loss of adaptability and  
worsening of symptoms with stress.

- Immune Manifestations:** tender lymph nodes, recurrent sore throat, recurrent flu-like symptoms, general malaise, new sensitivities to food, medications and/or chemicals.

7. **The illness persists for at least six months.** It usually has a distinct onset,\*\* although it may be gradual. Preliminary diagnosis may be possible earlier. Three months is appropriate for children.

*To be included, the symptoms must have begun or have been significantly altered after the onset of this illness. It is unlikely that a patient will suffer from all symptoms in criteria 5 and 6. The disturbances tend to form symptom clusters that may fluctuate and change over time. Children often have numerous prominent symptoms but their order of severity tends to vary from day to day.*

\*There is a small number of patients who have no pain or sleep dysfunction, but no other diagnosis fits except ME/CFS. A diagnosis of ME/CFS can be entertained when this group has an infectious illness type onset.

\*\*Some patients have been unhealthy for other reasons prior to the onset of ME/CFS and lack detectable triggers at onset and/or have more gradual or insidious onset.

**Exclusions:** Exclude active disease processes that explain most of the major symptoms of fatigue, sleep disturbance, pain, and cognitive dysfunction. It is essential to exclude certain diseases, which would be tragic to miss: Addison's disease, Cushing's Syndrome, hypothyroidism, hyperthyroidism, iron deficiency, other treatable forms of anemia, iron overload syndrome, diabetes mellitus, and cancer. It is also essential to exclude treatable sleep disorders such as upper airway resistance syndrome and obstructive or central sleep apnea; rheumatological disorders such as rheumatoid arthritis, lupus, polymyositis and polymyalgia rheumatica; immune disorders such as AIDS; neurological disorders such as multiple sclerosis (MS), Parkinsonism, myasthenia gravis and B12 deficiency; infectious diseases such as tuberculosis, chronic hepatitis, Lyme disease, etc.; primary psychiatric disorders and substance abuse.

**Exclusion of other diagnoses,** which cannot be reasonably excluded by the patient's history and physical examination, is achieved by laboratory testing and imaging. If a potentially confounding medical condition is under control, then the diagnosis of ME/CFS can be entertained if patients meet the criteria otherwise.

*Journal of Chronic Fatigue Syndrome* 11(1), 2003 on February 1, 2003



# New Theory Links Neurotoxins with Chronic Fatigue Syndrome, Lyme, MCS and Other Mystery Illnesses

## by Patti Schmidt

[www.fibromyalgiasupport.com](http://www.fibromyalgiasupport.com) 29-11-2002

Page 20

Two doctors believe they've discovered a new brand of illness and a new way for pathogens to make people sick. They also have an FDA-approved treatment that was effective in a small, preliminary clinical trial.

neurotoxic /nōr'ò tok'sik/, anything having a poisonous effect on nerves and nerve cells, such as the effect of lead on the brain and nerves. -The Mosby Medical Encyclopedia

There are many theories and much disagreement about what causes Chronic Fatigue Syndrome (CFS), Multiple Chemical Sensitivity (MCS), fibromyalgia (FM) and some other chronic multi-symptom illnesses. Some science points to abnormalities in the immune system's viral-fighting pathways; other research to a cascading combination of genealogical, environmental, and health-and personality-related events and factors that begin with a predisposition and a "bug" and ends with someone who's chronically ill. And despite a rash of recent scientific evidence to the contrary, some out-of-touch physicians still insist sufferers are just depressed.

While some blame stress and societal ills for the widespread fatigue, depression, joint pain and cognitive problems common to these illnesses, recent research suggests these problems may instead be linked to toxins generated by cells gone awry-that many people are chronically ill due to biotoxins in their system they cannot eliminate naturally.

Two scientists - family practice physician Ritchie C. Shoemaker and EPA neurotoxicologist H. Kenneth Hudnell, Ph.D., - have collected data to back up this "neurotoxin-mediated illness" theory, and they've developed both a simple way to test for neurotoxins and a treatment protocol featuring an effective, FDA-approved prescription medicine that flushes toxins safely from the body.

Shoemaker's website features information and research as well as a way to measure toxin exposure potential. After answering a brief health questionnaire about symptoms and some

questions designed to eliminate confounding factors, it takes just five minutes and \$8.95 to take the online Visual Contrast Sensitivity (VCS) test, which measures the impact of neurotoxins on brain function.

Data from the questionnaire and vision test are analyzed immediately to determine if users are likely "positive" or "negative" for neurotoxins. The website doesn't make an official diagnosis, but gives a push in the right direction. Users can then take the test results to a physician so they can be treated if necessary.

The two say they have data to support the claim that 90 percent of the people who test positive for neurotoxins improve following their treatment protocol.

"If you have the VCS deficit, the potential for biotoxin exposure, and don't have other exposures or medical conditions that could explain the deficit, our data indicate that the response to toxin-binding therapy is over 90 percent," says Ritchie C. Shoemaker, M.D., the physician who helped develop the theory and the treatment. The story of how a small-town family practice physician and a civil servant who works for the EPA came up with that theory- and how they found a treatment for the 10 million Americans they claim it can help-is at least as interesting as the theory itself.

### The scientist

Ritchie Shoemaker always planned to have a rural primary care practice. He graduated from Duke University Medical School in North Carolina in 1977, courtesy of the National Health Service Corps, which paid for his medical education in return for a stint serving under-served areas of the U.S. In July of 1980, following a Family Practice residency in Williamsport, Pa., the NHSC sent him to its clinic in Pokomoke City, Md.

"I could hardly believe that the government was going to pay my way through a few years at Duke Medical School, in order

*(Continued from page 18)*

Making a diagnosis of depression should not in anyway take away from the concurrent diagnosis of Chronic Fatigue Syndrome. Unfortunately there are still many false and hurtful beliefs about depression such as the sufferer can pull himself or herself together which only adds to the burden of guilt that people are already experiencing or that a diagnosis of depression means that you are weak-minded or mentally incompetent or that if there is no visible problem therefore there is no problem at all. Often the depressed person feels that someone has "caused" the depression and often a parent, sibling or important role model gets the blame. Sometimes the depressed person feels that they have in fact committed an unforgivable sin

and is being punished. There are many other myths and fallacies about depression which is a treatable illness like any other medical illness.

Because depression is so common in Chronic Fatigue Syndrome sufferers and is in fact so common in the community in general, in the next issue of *Emerge* I will discuss in more detail the types of antidepressants in use currently so that *Emerge* readers can be fully informed about their possible options.

*Reprinted from Emerge, Summer 2002 with permission*

to do something I already wanted to do," he said.

Pokomoke City was then a thinly populated small town situated along the Pokomoke River, a tributary of the 200-mile long Chesapeake Bay. The Pokomoke itself flows South from Delaware, 80-miles long and just 50 yards wide in some places.

At the time they settled there, Shoemaker and his young wife JoAnn were newlyweds. Taking great pleasure in the idyllic setting, they became involved in civic activities; had a daughter, Sally; and began protecting the unique ecology of the Lower Eastern Shore, building and restoring wetland ponds, wetland gardens and a mile-long nature

trail.

"This was everything I had ever wanted," said the doctor. "I had the love of a spouse and family, the love of my practice and of my land. I was happy."

In 1996, the first reports of "sick fish" in the river began appearing in local newspapers. It wasn't long afterward that some of his friends and patients began complaining of flu-like symptoms. "They had nasty headaches, diarrhea, rash, cough,

persistent muscle aches and failures in short-term memory," says Shoemaker.

His intuition, backed by a solid grounding in science (he was a biology major in his undergraduate days) told him the sick fish and the sudden illness among his patients were related. When someone brought him a dead fish, fresh from the Pokomoke, the curious young doctor put it under a microscope.

"The link was the river," Shoemaker says in the book he wrote about these events, *Pfiesteria: Crossing Dark Water*. "Each one of them had spent time working or playing in the slow-moving Pokomoke during the summer of 1997."

He had no idea that what was under that microscope would change his life and put him at the uneasy nexus where politics, ecology and medicine meet.

### The collaborator

Meanwhile, Shoemaker's research collaborator Hilton Kenneth Hudnell, PhD, a calm, soft-spoken neurotoxicologist, was building a civil service career at the Environmental Protection Agency.

Ken Hudnell grew up in North Carolina, where the Neuse and Trent rivers join at New Bern. In a twist of fate, the Neuse was where *Pfiesteria*-related fish kills were first found - the very same organism thought to produce the devastating effects Shoemaker observed under his microscope and in his clinic.

"It's not the same river system that I played on while growing up," says Hudnell today. "Back then there were few fish kills, and people didn't associate human illness with them. My nemesis was seaweed growing on the bottom and clogging my outboard motor. Now in many places, the seaweed has been choked out by surface blooms of cyanobacteria-blue-green algae- due to pollutant runoff from massive hog farms upstream from New Bern."

A one-celled dinoflagellate, *Pfiesteria piscicida* is colloquially known as the "fish killer" in areas where it has wreaked its havoc on the local ecosystem.

*Pfiesteria* wasn't the first dinoflagellate that caught Ken Hudnell's attention. After majoring in chemistry and psychology at the University of North Carolina at Chapel Hill, he moved to the Virgin Islands for three years to start a diving business.

"I soon learned that you don't eat certain types of fish that feed around the reefs," he remembered. "Those fish ate a dinoflagellate called *Ciguatera* and accumulated their toxins. When people ate the fish, they got violently ill. Many recovered completely after a few days, but others remained chronically ill. Now I know why - they had biotoxin circulating in their bodies that they couldn't eliminate." His experience with ciguatoxins and other biotoxins in the Caribbean compelled Hudnell to return to the U.S. to enter graduate school. "I wanted to understand the relationships between neurobiology, toxic exposures and human illness," he said.

Hudnell received a graduate degree from his alma mater and is an adjunct professor there now. His work at the EPA's National Health and Environmental Effects Research Laboratory, which involves using a battery of neurobehavioral and electrophysiological tests to measure sensory, motor and cognitive functions in people affected by toxic exposures, has been recognized with two of the agency's Science and Technology Achievement Rewards.

At the EPA, Dr. Hudnell developed a theory explaining the worldwide increase in biotoxin-related events: human activities and natural events impact the earth's water, land and air, altering the habitat and promoting the development and spread of toxic organisms. Those toxic organisms, in turn, impact man as well as the ecosystem we all have to share.

It's an interdependent circle, which features mankind using up land, air and sea resources, all the while ignoring the symptoms of burgeoning environmental problems that place us in peril.

Two hundred and fifty miles north, Ritchie Shoemaker was

*(Continued on page 22)*



## Chemical Sensitivity Information

For people with

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

**(08) 83819286**

(Continued from page 21)

independently coming to the same conclusions. Chronic illness, he was beginning to believe, was partly a result of the damage we've done to the ecosystem.

Take Lyme disease, for example: As millions of people in the city moved to the suburbs- and then further out into the countryside when the suburbs became crowded- they altered the habitat to one favored by mice and deer. Houses and new landscaping provided food and cover, and eliminated the predators of a growing deer population.

Deer and mice are tolerant hosts, allowing ticks to complete their life cycle by providing a reservoir of blood-borne pathogens for the ticks to deposit into a human who happens to be in the "wrong" place (like his back yard), at the wrong time, leaving behind a tell tale trail of acute or chronic illness. If we hadn't destroyed their original habitat, in other words, we may never have gotten close enough to become a temporary feeding trough for the tick.

The doctor and the scientist met when Shoemaker, hungry for more data on Pfiesteria, called Hudnell at the EPA one July morning in 1998. "At 10:15 a.m., I read that Ken had found Pfiesteria patients showed a visual contrast deficit that lasted a year or more," remembers Shoemaker. "By 10:17 a.m., we were on the phone and working together."

Hudnell's early work as a UNC undergraduate led him to the VCS literature. He developed a VCS test on an oscilloscope screen early in his graduate studies there, soon after it was first reported in the scientific literature that the visual system was more sensitive to mid-size bar patterns than to smaller- or larger-size bar patterns. "I realized that this meant there were different processes in the eye and brain for detecting different aspects of a visual pattern, and I wanted to understand how they worked," he said. "Later I found that those processes were differentially susceptible to disruption by various toxins and disease processes."

While VCS testing had been used in neurotoxic exposure, Hudnell was the first to use it to measure the effects of biotoxin exposure and heavy metal toxicity, or as a marker for neurotoxic exposures like Pfiesteria.

## The mystery

Back at microscope in the summer of 1997, Shoemaker found a slimy fish that was the first example he saw of just how much damage a toxin-producing organism could do in the right set of circumstances.

In his search for answers, over the next few years he became intimately familiar with the habits and neurotoxic illnesses of fresh water and sea animals including fish, birds, alligators, turtles and pelicans. He studied basic and esoteric subjects, including predator-prey relationships of aquatic invertebrates; plants; phytoplankton; the pathology of invertebrate organisms in marine and estuarine environments; pesticide physiology; and the study of the rhizosphere, the interface between a root and its immediate environment.

He consulted experts in fields such as pathology; toxicology; biochemistry; geochemistry; physiology; estuarine limnology; and even membrane ionophore chemistry, the study of the passage of organisms and molecules in aqueous solutions across membranes. He learned how pesticides degrade in air, water and subsoils.

Given the intense political controversy that an environmentally acquired illness like Pfiesteria created, he needed this knowledge to piece together a mystery: Was there a link between the fish kills and the illnesses his patients were suffering? Why didn't the body rid itself of these toxins

naturally? Do bacteria, fungi, algae and other tiny organisms manufacture toxins that linger on in the human body, long after the organisms themselves are dead?

Eventually, Shoemaker figured out that his patients had a new illness, originally named Pfiesteria human illness syndrome in his 1997 article in the Maryland Medical Journal. The CDC renamed the illness "Estuarine-Associated Syndrome" in 1998, and "Possible Estuarine-Associated Syndrome" (PEAS) in 2000.

It took Shoemaker a few more years to put together his "chronic neurotoxin-mediated illness" theory and some time after that to gather the data to tell him his theory was sound. In the end, he believes he and Hudnell have discovered a new brand of illness and a new way for pathogens to make people sick. The two have continued to gather data fleshing out the theory with more clinical and molecular information.

In the meantime, Shoemaker built up his medical practice, winning the 2000 Maryland Family Doctor of the Year Award and being named one of five finalists for the National Family Practice Doctor of the Year Award in 2002. At the same time, he battled state and local bureaucrats who continued to tell people, "the river is safe," despite evidence to the contrary.

When Shoemaker went to the press with his theory and his data during the outbreak in Maryland in 1997, the bureaucrats did everything they could to ruin his reputation. One state official quoted in the local newspapers accused him of "scientific malpractice," and claimed he was "out of his field" when it came to the sciences.

Their refusal to see -and say -the truth simply drove him to work harder. When residents near the St. Lucie River near Stuart on Florida's East Coast suffered a rash of dinoflagellate illnesses in 1998, they listened to Shoemaker's theories of copper toxicity. Copper binds to pesticides, giving them easier entrance into organisms. If predators of dinoflagellates are more susceptible to the copper-pesticide toxicity than dinoflagellates, a decrease in the predator population could result in an increase in the dinoflagellate population. Also, if prey of dinoflagellates are killed at lower exposure levels than dinoflagellates, this might put pressure on the dinoflagellates to produce and release toxins in order to kill fish for a food source.

Then Florida officials earmarked \$30 million to build lagoons that filter runoff from copper-laden citrus groves, bought wetland farms to restore them and dredged contaminated sections of the St. Lucie. They levied a three-year, one percent sales tax to pay for these improvements.

The CSM treatment proved just as effective in Florida as it did in Maryland. About 15 residents and investigators working on the St. Lucie became ill with multiple systems symptoms and suffered a VCS deficit. They responded well to CSM therapy given by four local Florida physicians.

But like the guy who discovered that a bug causes ulcers, Shoemaker found the medical community in Maryland reluctant to applaud his new theory. In fact, it was met with active resistance, he said. For example, the head of ophthalmology at the University of Maryland School of Medicine dismissed the value of visual contrast testing in helping to diagnose Lyme disease by simply saying, "I don't think so."

In his spare time, Shoemaker also wrote four books: Gateway Press, in Baltimore, Md., published Pfiesteria: Crossing Dark Water, a 360-page tally of the outbreak in the waters of the Pokomoke, in 1997; Weight Loss and Maintenance: My Way Works, a 325-page explanation of a weight loss mechanism

with maintenance rates that exceed 70 percent, in 1998; and Desperation Medicine, the 519-page saga of his findings that neurotoxins are responsible for many chronic illnesses, in 2001.

His latest book, *Lose the Weight You Hate*, is a 454-page update of his earlier diet primer which adds recipes, an explanation of how neurotoxic illnesses contribute to obesity and diabetes, and a discussion of the importance of genes and how they effect weight loss.

### The test

Despite the disbelief, Shoemaker and Hudnell can point to data, accumulated since the mid-60s, that visual contrast sensitivity deficits exist in diseases like Type 1 diabetes, multiple sclerosis, and in Alzheimer's and Parkinson's disease.

In fact, experts suspect that many diseases involve deficits in visual perception, but there's little research relating toxic exposures to differences in visual function before diagnosing disease. Visual contrast sensitivity testing assesses the quality of vision. It differs from typical visual acuity testing in that it simulates "real-world" circumstances, while routine visual acuity testing measures eyesight under the best possible conditions.

"That's why measuring visual contrast sensitivity in patients who report difficulty with their vision, yet see well on the conventional visual acuity eye chart, is particularly useful," says Hudnell. The test is performed by showing the patient a series of stripes or bars that slant in different directions. The patient must identify which way each series of stripes is tilted. As the test progresses, the bars become thinner and lighter. People with excellent contrast sensitivity can discern the orientation of even very light, thin bars; patients with neurotoxic damage cannot.

After chronic exposure to many organic solvents, VCS is the most sensitive indicator of effects from many toxins, either because the visual system is highly susceptible to neurotoxins or because even small deficits can be measured, according to Hudnell.

"The visual system is the ideal place to look for evidence of neurotoxicity," he says. "The retina is a microcosm of the brain; it contains most of the cell types and biochemicals that are in the brain. So the retina is as susceptible as the rest of the brain to neurotoxic effects."

According to Hudnell, this "piece of brain," being near the front of the face, is in close contact with the environment. Chemicals may be directly absorbed from the air into the retina, so the potential for exposure to neurotoxins is greater in the retina than in the brain. But unlike the brain, he points out, the visual system has few functional outputs (pattern and motion detection, or color discrimination, for example) and we can easily measure them. The VCS test measures the least amount of stimulation needed to detect a stationary pattern.

"As neurologic function decreases due to toxicity, more and more stimulation is needed to see the patterns," he explains.

The effect can be huge; the Pfiesteria cohort in one of Shoemaker and Hudnell's studies showed a 60 percent loss of VCS on average relative to controls.

"When we see VCS drops like this following exposure, and see it recover following treatment to eliminate the toxins, we're seeing an indication of how strongly the toxins may be affecting the entire nervous system," says Hudnell. "Of course, biotoxins don't just affect the nervous system. They trigger release of inflammatory agents in the body that can inflame almost any organ and cause multiple-system symptoms."

### The theory

And that's where Shoemaker and Hudnell's theory begins, with biotoxins in the body that some people - as many as 10 million Americans - cannot naturally eliminate, resulting in many chronic illnesses.

The two men believe these poisonous chemical compounds continually circuit the human body, shuttling from nerve to muscle to brain to sinus to G.I. tract and other organs, triggering the familiar symptoms.

These symptoms are similar to those caused by infectious agents, and so is the effect they have on nerve, muscle, lung, intestines, brain and sinus, say the researchers.

Shoemaker and Hudnell say the compounds are manufactured by a growing number of microorganisms that thrive in our ecosystem due to changes in the human habitat.

"New biotoxins or toxin-forming organisms are being identified all the time," notes Hudnell.

Some, like the deer tick that passes along Lyme disease, do so directly. Toxin-forming bugs such as the fungi (*Stachybotrys* and others) that cause "sick-building syndrome" and the blue-green algae (*Cylindrospermopsis* and *Microcystis*) that poison people and animals in most of the lakes in Central Florida, do their work by releasing their toxins into air or water.

And although the pathogens differ, Shoemaker and Hudnell say the biotoxins they produce all do their damage by setting off a similar "exaggerated inflammatory response" in humans. While hiding out in fatty tissues where blood-borne disease-fighters can't get at them, they trick the body's immune system into launching attacks against joints, muscles, nerves and brain.

There is increasing evidence to show these attacks are carried out by a newly discovered group of molecules, the "pro-inflammatory cytokines," and that the destruction they cause is linked to recent surges in the rates of heart disease, obesity and diabetes. Illnesses once blamed solely on diet and lifestyle choices are now being shown to have an inflammatory basis.

And while infections cause a cytokine response from white blood cells, especially macrophages, the cytokine response to neurotoxins comes from fat cells.

"The body can turn off the macrophage cytokine response, so that the achiness, fever, headache and fatigue of a cold will go away, but there's no negative feedback that stops the cytokine response from fat cells," says Shoemaker. "So the illness doesn't self-heal." The team's research found that through typing of immune response genes, the HLA DR, they can show that individual susceptibility to particular neurotoxins is associated with particular genetic factors not found in others with a different neurotoxic illness or in controls. In other words, they're beginning to crack the code to show that some people are genetically predisposed to get certain chronic fatiguing illnesses.

But the research that links these things - the exaggerated inflammatory response, which may also involve an autoimmune response by a process called "molecular mimicry" -and its link to heart disease, for example, is in its infancy, so the medical community remains skeptical.

Nonetheless, Shoemaker thinks these provocative discoveries will eventually require researchers to confront the grim possibility that these organisms have learned how to skew immune responses by using powerful toxins to decimate the body's disease protection system. The diagnosis According to

*(Continued on page 24)*

Shoemaker, a diagnosis of chronic, biotoxin-induced illness is based on biotoxin exposure potential, multiple system symptoms, the VCS deficit discovered by Dr. Hudnell, and no

other reasonable explanation for the illness. "As opposed to illnesses which have no supporting tests or biomarkers like fibromyalgia, CFS, depression, irritable bowel disease, or just getting older, our approach gives the physician readily obtained hard data to use as a marker and, more importantly, as a monitor that changes dynamically with response to treatment," says Shoemaker. Hudnell points out that new tests for cytokine levels, hormone levels and blood flow in the microvasculature of the retina help characterize how biotoxins induce chronic illness. The new HLA genotype tests (the DNA PCR assays -not the serology or transplant tests) also help identify people who are at risk for developing chronic illness from particular biotoxins because they're unable to eliminate those toxins.

"Patients must have a compatible history, the deficit in VCS, the HLA genotype, an abnormal cytokine response, and the abnormal effects of cytokines on hypothalamic hormones, especially melanocyte stimulating hormone (MSH)," said Shoemaker. "All CFS patients should have the MSH test done."

Shoemaker and Hudnell's data show that there's a group of CSM treatment-resistant CFS patients who are coagulase negative Staph (CNS) positive and who have high leptin levels. Leptin is a hormone made by fat cells that signals the satiety center in the hypothalamus that a person is no longer hungry.

Leptin stimulates the production of alpha melanocyte stimulating hormone (MSH), which in turn controls production of endorphins (the body's natural "opiates") and melatonin (which regulates sleep) in the hypothalamus. CFS patients rarely have much MSH. Eradicating CNS does nothing to the high leptin and low MSH levels in patients with "end-stage CFS," says Shoemaker, but it certainly does in patients who are diagnosed acutely and treated aggressively, preventing irreversible damage to the MSH-manufacturing pathway.

"We must recognize that the process by which CFS develops may include an acute neurotoxic event which includes upper respiratory symptoms," says Shoemaker.

Shoemaker believes that the secondary cytokine damage from neurotoxic exposure changes the mucus membranes in the nose, allowing biofilm-forming, slow-growing CNS to release hemolysins (once called delta toxins) that in turn activate a powerful cytokine response. The boost in cytokines disrupts the leptin-MSH production link. This classic, positive feedback system increases cytokines and CNS and reduces MSH.

"While the data is certainly compatible with this model, I haven't asked for volunteers to put CNS in their noses to watch for subsequent development of CFS," says Shoemaker jokingly. But the team has found particular genotypes of the immune response genes in HLA-DR that show marked consistency within a diagnosis group and marked disparity in other diagnostic groups.

Shoemaker won't yet say that the HLA DR genes or the abnormalities in the leptin/MSH pathway are the "Holy Grail" of CFS research, but will admit that there are unique HLA genes in his CFS patients; that his Sick Building Syndrome patients have at least three unique triplets of gene biomarkers; his Post-Lyme patients have two; and that these gene-types are quite different from each other. Is CFS an illness that includes a genetic susceptibility to particular neurotoxins, which trigger cytokines associated with carrying CNS, that

produce nerve, hormone and immune system dysfunction in the ventromedial nucleus of the hypothalamus? Maybe, says Shoemaker.

"If our study shows that replacement of MSH improves many (or most!) of the abnormalities of CFS, I'll believe that," says Shoemaker. That study will be done after the animal studies required by the FDA are completed. They hope it will establish an effective MSH dose and the most effective method of MSH delivery, as well as confirm that symptoms reoccur when MSH is stopped, and then again show benefit when an effective does is reinstituted.

They'll do baseline VCS tests and MSH levels first, and will attempt to show that high levels of plasminogen activator inhibitor-1 (PAI-1), tumor necrosis factor alpha and leptin improve after treatment.

A longer trial is planned, pending initial results. That study, which will be done when funds are obtained, will also attempt to show that high levels of PAI-1 and leptin improve after treatment. Shoemaker believes PAI-1 is likely to be responsible for the extra clotting and vascular disease frequently found in CFS patients, and that once leptin levels fall, CFS patients who have gained weight will be able to lose it.

## The website

Before you can take the CS exam at Dr. Shoemaker's web site (<http://www.chronicneurotoxins.com>), you have to register and get a log-in identity and password, as well as answer symptom and medical history questionnaires. Then you can buy a VCS test for \$8.95, or a package with several tests and treatment protocols for \$49.95. The preliminary test (a free questionnaire) assesses the symptoms commonly associated with biotoxin-induced illness, as well as your potential for exposure.

"Many symptoms of and potential exposures to biotoxins are not yet well known by physicians," says Shoemaker, "So they're easily overlooked."

After you take the test, your results are available immediately. They can also be sent to your physician. If your physician isn't familiar with the theory or protocol, the website mentions a list of referral physicians across the nation, or you can request to see Dr. Shoemaker in his Pokomoke City office. (A second part to this article will detail the author's diagnostic and treatment experiences at Dr. Shoemaker's clinic.)

## The treatment protocol

Cholestyramine (CSM) is an FDA-approved medication which has been used to safely lower elevated levels of cholesterol for more than 20 years. It isn't absorbed; if it's not taken with food, it binds cholesterol, bile salts and biological toxins from bile in the small intestine, and then the CSM-toxin complex is excreted harmlessly. Science - or Shoemaker and Hudnell - doesn't have definitive answers yet as to exactly how or why CSM clears neurotoxins from the body, but a double-blind, placebo-controlled, cross-over clinical trial of eight Pfiesteria patients positive for biotoxins showed that those who took a placebo remained ill, but improved following CSM treatment. Data from 30 others he's gathered since matches the original study data.

Shoemaker says while some patients notice immediate improvements, Lyme disease patients who've been sick for more than five years usually require toxin-binding therapy for 4-8 weeks, he says. "Most patients improve in two weeks, some with complete abatement of symptoms, but depending on the amount of toxin in your body, it may take longer," says

Shoemaker.

He believes the response of these patients to CSM therapy shows the underlying common theme of neurotoxin-mediated illness, and that the proof that toxins were responsible for the illness is found when patients recover, i.e., have no symptoms following treatment with his protocol.

"The proof of neurotoxin effect comes from watching the biomarkers change with treatment and relapse with re-exposure," says Shoemaker. "There's very strong evidence, especially in the Sick Building Syndrome patients." Hudnell agrees.

"The best evidence that biotoxins are causing the illnesses comes from cases with repeated illness," says the toxicologist. "When you see patients with chronic illness recover vision as symptoms resolve while being treated with a drug that can do nothing but remove compounds from circulation, then see vision plummet and symptoms return following re-exposure to sources of toxins, and finally see re-recovery with re-treatment, sometimes for three or four cycles, you become convinced that it's the toxins causing the illness."

In another study of 51 post Lyme disease patients treated with CSM after a tick bite, both those who tested positive and those who tested negative to Lyme had the same number of symptoms after treatment as matched controls. Shoemaker says that data from more than 500 other patients he's seen since matches the study data. Prior to treatment, the chronic Lyme disease patients had a statistically significant VCS deficit. Following treatment, all patients' clinical syndrome was gone; and their VCS scores and the number of symptoms were the same as that of the controls.

Some of these Lyme disease patients, especially those who'd been sick longer than three years, suffered what Shoemaker calls "a symptom intensification reaction" early in CSM therapy, similar to, but more intense than, the Herxheimer reactions experienced previously during antibiotic treatment. The reaction was reduced with pioglitazone (Actos) therapy or prevented by pretreatment with Actos, which downregulates proinflammatory cytokine production by fat cells. Patients who weren't reexposed to another tick bite didn't relapse, though follow-up was stopped at 18 months.

There are other diagnoses- chronic Ciguatera seafood poisoning, Possible Estuary Associated Syndrome, brown recluse spider bites and mycotoxicosis-that were thought to involve biotoxins, but for which there was no known, effective treatment. Shoemaker has treated patients with these illnesses successfully with cholestyramine, too. Over the years Hudnell has done studies that linked environmental exposure to neurotoxicants like airborne solvents and metals to adverse neurologic effects in humans, including VCS deficits. But there was no treatment for it.

"There was nothing I could do to help them, and the impairments were permanent," he said. "So I was ecstatic when we found that a simple treatment, taken for a short period of time, could benefit so many people who had suffered severe chronic illness due to biotoxins." News spreading Others have gotten excited about this research: Paul Cheney has used the VCS test and a modified version of the protocol to treat patients at his Bald Head Island Clinic in North Carolina.

Chuck Lapp, director of the Hunter Hopkins Center in Charlotte, NC, also plans to put one of the machines in his office. "A number of my patients have complained that I wear loud, patterned clothing, and that it bothers their vision when I wear a patterned tie, so I think there may be

something to this," he said.

There are also almost 50 physicians in a nationwide referral network who are familiar with the VCS test and the treatment protocol; for more information, contact the website for the name and number of the doctor nearest you.

### Recent advances

In June, Hudnell and Shoemaker presented data from their latest studies on Sick Building Syndrome and Post Lyme Syndrome at the 8th International Symposium on Neurobehavioral Methods and Effects in Occupational and Environmental Health in Brescia, Italy, where Dr. Hudnell chaired a session on biotoxins. Shoemaker co-chaired. Next, they plan to conduct human studies that will more definitively characterize the proinflammatory cytokine basis of chronic, biotoxin-induced illness, and describe the permanent damage that they think has occurred in the hypothalamic-pituitary-adrenal (HPA) axis of those who had the highest exposure levels for the longest periods of time.

They also want to do the animal studies and human trials needed for FDA approval of hormone replacement therapy that they think will help those with permanent damage. To that end, Dr. Shoemaker has established a not-for-profit corporation, the Center for Research on Biotoxin Associated Illness (CRBAI).

"If the research is to get done, CRBAI needs to raise funds through grants and donations from private organizations and individuals because there is virtually no Federal funding of research in this area," said Shoemaker.

In the meantime, he still sees patients every day in his Market Street office, many suffering from chronic, neurotoxic illnesses.

Both Shoemaker and Hudnell routinely get calls from all over the world asking for advice on toxic outbreaks and how to treat them. New patients are still taking the tests on the website and beginning CSM treatment.

So as physician William Osler advocated long before the advent of the biotoxin-mediated illness theory, to find the proper diagnosis, Ritchie Shoemaker listens to the patient.

"Recognizing the pattern of a neurotoxic illness is as subtle as being run over by a steamroller, once you learn how to ask the right questions," he says.

Physicians need to learn to ask the patient a few more questions in a new order-in essence, take an organized neurotoxin history, he says. "All our biomarkers and all our data and all our nice molecular models simply provide an academic foundation for what the bedside physician already knows to be true," insists Shoemaker. "The toxins did it."

Source: [www.ImmuneSupport.com](http://www.ImmuneSupport.com). Reprinted with permission. (c) Pro Health, Inc., all rights reserved.



# Your Society Matters... ♦ ♦ ♦

## **ME/CFS Awareness Week 2003 May 10th—May 17th**

### **LEADING THE WAY: Fibromyalgia and CFS Awareness Seminar May 10th 2003**

#### **Norwood Concert Hall**

175 The Parade Norwood

**Cost**  
Members and  
Concession \$7.00  
Non-Members \$12.00



**\* Bookings Essential—  
Limited Places**  
For Enquiries & Bookings  
please phone the Arthritis  
Foundation on: 8379 5711

12:30 pm Registration and  
Trade Stalls Open  
Speakers from 1.00 pm — 5.00 pm

#### **Keynote Speaker:**

**DR DAVID TORPY**, MBBS, PhD, FRACP, Associate Professor, Adelaide  
University and Consultant in the Endocrine and Metabolic Unit, Royal  
Adelaide Hospital.

**Other Speakers Include:** Dr David Gillis Immunologist, Staff Specialist  
Immunology IMVS RAH; Peter Del Fante GP and medical advisor to the ME/  
CFS Society (SA) inc.; and Dr Richard Kwiatak, Rheumatologist  
(Our website [www.sacfs.asn.au](http://www.sacfs.asn.au) will have the latest details as additional  
speakers are confirmed)

#### **Key Features:**

- ⇒ World Class Speakers on a wide range of topics
- ⇒ Overview of CFS Research being conducted in Adelaide
- ⇒ Information about CFS and Fibromyalgia
- ⇒ Information about Self-Management Courses
- ⇒ Trade Stalls run by relevant agencies such as Centrelink, Disability Action,  
Relationships Australia

Please Allow Time for Parking & Avoid Wearing Scented Products that some may be sensitive to.  
(For example: perfumes, aftershaves, strong hair sprays etc...)

# Awareness Night

## Featuring:

### 'I Remember ME'

### by Kym Snyder

Page 27

Talking Point 2002 Issue 1: The Official Journal of the M.E./C.F.S. Society (SA) Inc

See inserts in this edition of Talking Point for booking form—  
please post along with payment to the Society.

Also see our website for more information: [www.sacfs.asn.au](http://www.sacfs.asn.au)



[www.irememberme.com](http://www.irememberme.com)

**Aims: To raise awareness  
about ME/CFS and to  
raise money for the  
Society. Bring along \$2 or  
more for the raffle!**

**Friday May 16th**  
**7:00 pm for 7:30 start—**  
**9:45 pm**

### Venue:

Mercury Cinema, 13 Morphet St,  
Adelaide South Australia 5000  
(in between the Jam Factory and the Uni SA  
City West Campus, North Tce.)

### Features

- ⇒ Drinks on arrival from 7pm
- ⇒ Brief explanation of ME/CFS
- ⇒ Film: 'I Remember Me'
- ⇒ Short Film: 'Overcoming and Managing CFS'
- ⇒ Raffle
- ⇒ Sumptuous supper
- ⇒ Bar available to purchase additional beverages

### Cost

**\$8 Members**  
**\$12 Non-members**

Bring along your friends and relatives. A great opportunity to expand your their understanding of CFS, and to raise money for the Society. And it will be a fun night.

Limited places: book early to avoid disappointment. Tickets to be pre-sold.

# 'I Remember ME' by Kym A. Snyder

## An Award-Winning Documentary Film About Chronic Fatigue Syndrome



Page 28

### Winner

#### Best Documentary

PEOPLES' CHOICE AWARD  
DENVER INTERNATIONAL FILM FESTIVAL

"A compelling documentary that combines heartbreaking and soul-stirring personal stories with investigative reporting about Chronic Fatigue Syndrome"

Fueled by the same rage at an unresponsive system that has birthed many a great social documentary, filmmaker Kim Snyder has taken up the mantle for the over 500,000 sufferers of Chronic Fatigue Syndrome (CFS) living in the United States today. Afflicted with CFS herself, Snyder interweaves her own four years of fighting with the stories of others who face the same challenges, from U.S. Women's Soccer Star Michelle Akers to filmmaker Blake Edwards to a high school senior preparing to attend his graduation after a two year absence.

Between May, 1984 and late 1986, over 300 people in Lake Tahoe, Nevada became acutely ill with a flu-like sickness. Over fifteen years later, many of them have not fully recovered, individuals across the country have become ill, and the cause remains a medical mystery. Herein begins the bizarre tale of an elusive malady that in 1988 the US Centers for Disease Control named Chronic Fatigue Syndrome (aka CFS, CFIDS, ME).

**I Remember Me** is the first full-length documentary to explore the controversial and mysterious history of Chronic Fatigue Syndrome, an illness that, according to the CDC, is now forty times greater in prevalence than previously estimated. Once dismissed as Yuppie Flu, this mysterious syndrome, for which there is not yet a universally acknowledged cause or cure, has prompted fierce debate within the medical community.

### Honorary Mention

#### Best Documentary

2000 HAMPTONS INTERNATIONAL FILM FESTIVAL  
"A compassionate and inspirational documentary forged from the center of the maelstrom, **I REMEMBER ME** is a step toward overcoming the healthcare industry's uncertainty, the government's skepticism and society's stigmatization"

"How do you come to know fact?" the filmmaker asks. Without scientific proof, she concludes "you're left with personal anecdote". So Snyder sets off on a four year journey to investigate. Through the poignant testimonies of dozens of individuals -- including film director Blake Edwards (*Pink Panther*, 10), and Olympic gold Medalist and Women's World Cup Soccer star Michelle Akers, whose brilliant career was recently cut short by the illness, (set to the evocative music of legendary jazz musician Keith Jarrett who was also sidelined by the illness for four years) -- a chilling human drama unfolds which continues to baffle scientists worldwide.

In her search for answers, Snyder unearths clusters of the illness dating back to 1936. Residents of a sleepy Florida gulf coast town are united forty years later to reflect on the illness that devastated hundreds of folks in 1956 and was never diagnosed. We hear strikingly similar accounts from local doctors in Incline Village, Nevada, the site of the original Lake Tahoe cluster, and Lyndonville, New York, a rural upstate town where more than 200 people became ill in the mid-80's.

The story builds to an emotional climax as Steven, the severely disabled Connecticut teen, attempts to make his high school graduation by way of ambulance and gurney.

More than an account of an epidemic unfolding, **I Remember Me** speaks to the universal themes of loss, human perseverance, and our difficulties in grappling with uncertainty.

[source: [www.irememberme.com](http://www.irememberme.com)]

## Editors Review

Kym Snyder is a successful film-maker having worked with Jodie Foster in the past. In the mid-nineties her blooming career was cut short, when she was struck down with CFS. This Film details some of her thoughts on CFS, parts of her life-journey, and it shows what it does to people's lives. (It is worth pointing out that this project was a labour of love. Kym, will receive royalties for our public showing of the film, and this will help her defray some of the costs she incurred along the way. If you want a copy the film can be purchased through her website: [www.irememberme.com](http://www.irememberme.com))

Along the way Kym interviews some famous people such as Michelle Akers (best female soccer player in the world at the time) and Blake Edwards (Director of movies such as *the*

*Pink Panther* series and *The Party*) who have struggled with CFS at various times. She also interviews prominent researchers and victims of CFS 'outbreaks.'

'I Remember ME' is not a point by point explanation of CFS. Nor is it a history of CFS. And it is certainly not a feel-good story. Given that governments pay CFS sufferers token respect, doctors assume the worst of patients and it has such a devastating effect on peoples lives, any realistic 'doco' is necessarily sobering in mood. I found this film powerful and uncomfortable at times. It has a couple of slow points, but picks up pace at the end. I give it 6.5/10.

## Badge Day Friday May 30th 2003

Badge Day is our major fundraiser for the year. But what is it?

Charities are allocated specific Fridays to collect money in the CBD. Almost every Friday you'll see some charity—perhaps two—collecting on the street corners.

Last year we had 25 people assisting us and we'd like to improve on that number. Quite simply, the more people, the more street corners are covered, and the more money we raise.

From personal experience I quite enjoy 'rattling tins' for an couple of hours. I often get into interesting conversations with people and generally enjoy observing humanity for that brief time.

The Society encourages members (or more probably their family / friends) to give us a hand. Given that the health our membership is not generally conducive to this sort of thing, we tend to recruit a lot of outsiders to help get the job done.

There are other ways you can help. If you would like to take a tin and some stickers to your work—to take up a collection for the Society—we'll be happy to supply you with the materials.

Please let us know if you have any sporting / social / service club contacts that might be useful to us.

Please register your interest by leaving your details with the office staff: Ph: (08) 8410 8929. Adrian Hill will get back to you with more details closer to the time.

ED.

**FOR SALE**

### Air Cleaner for Sale

Honeywell Enviracaire air cleaner 13500 model—all metal—well run in (no oil odours etc.). Plus 1 new charcoal filter plus 1 new HEPA filter (spare)  
Phone Sue: (08) 8555 2361



**Out and About:** Paul Leverenz speaks at the Mt Barker Women's Probis Club



Adrian Hill collecting at the Adelaide Railway Station

## Receive Talking Point Electronically?

Many have taken the option of receiving Talking Point in PDF document format.

Advantages to you? Receive TP ahead of everyone else and no pile of magazines cluttering up your house.

Advantages to the Society? You will save us at least \$6 in postage over the year—a significant saving!

## Stock Clearance on Efamarine Oil

**1 for \$20**  
**2 for \$30**  
**3 for \$40**



When the Society quits its current stocks it will discontinue sales of this item, due to its widespread availability in Health Food Stores and Chemists.

## SUPPORT GROUPS: METRO

### Adelaide Support Group

4th Tuesday of the month  
Venue: ME/CFS Society Office, Room 510, 5th Floor Epworth Building, 33 Pirie St Adelaide  
Time: 12:00 pm – 2:00 pm  
Best policy is to ring Support Line a few days before to confirm details.

### Glenelg Support Group

3rd Wed of the month  
Usual Venue: Cinema Centre Coffee Lounge, Jetty Road, Glenelg  
Time: 1 pm  
Please ring the Support and Information Line to confirm details: **8410 8930**.

### North Eastern Social Group: 'Better Together'

2nd Wednesday of each month  
Location: Hope Valley  
Time: 1:30 pm – 3:00 pm  
Phone: Pat on 8264 9328 or Julie on 8264 0607

## SUPPORT GROUPS: COUNTRY

### Northern Yorke Peninsula CFS Support Group

Venue: Community Health Centre Wallaroo  
Phone: Jane 8826 2097

### Southern Fleurieu Support Group

2nd Thursday alternate months  
April, June, Aug, Dec  
Phone: Melanie Stratil (Dietician) **8552 0600** for venue details.

### Central Yorke Peninsula Support group

Carer Support Yorke Peninsula, 48 Elizabeth Street Maitland SA  
Phone: Caroline 88374335

**It is good practice to call the information and Support Line for Confirmation: 8410 8930 OR 1800 136 626**

## SUPPORT CONTACTS

### SA Support Groups

Adelaide City	Support and Info Line	8410 8930
Glenelg	Marion	8234 2342
Murray Bridge	Fran	8535 6800
North Eastern	Julie	8264 0607
North Eastern	Pat	8264 9328
Northern Yorke Peninsula	Jane	8826 2097
Southern Fleurieu	Melanie	8552 0600

### Misc. Support Contacts

SAYME	Peter	0500523500
SAYME Parents	Marg	8276 5353

### Country Support Contacts

Barossa Valley	Dennis	8563 2976
Murray Bridge	Fran	8535 6800
Port Lincoln	Jade and Pauline	8683 1090
Port Pirie	Marj	8633 0867
Riverland	Ros	8588 2583
Northern Yorke Peninsula	Jane	8826 2097
Victor Harbor	Melanie	8552 0600
Whyalla	Peter	8644 1897
Yunta	Gloria	8650 5938

### Murray Bridge Group

The Murray Bridge group has been scaled back— there will now just be the occasional special meeting.  
Please ring for event times – or to register your interest.  
(Next event time not available at time of publication)  
Phone: Fran McFaul (Dietician) **8535 6800**

## YOUTH SUPPORT GROUP: South Australian Youth with ME/CFS (SAYME)

SAYME meetings are actually 2 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.

Meetings Each Month. Please call the Information and Support Line for more details or 0500 523 500



# WHAT IS ME/CFS?

(M.E.) 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 Dec. 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; unrefreshing 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 & 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<sup>1</sup> figure for the prevalence of ME/CFS is 0.2—0.7% of the population. From these figures we expect that 3000—10 500 people in South Australia have ME/CFS.

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



**If undeliverable return to:**  
**ME/CFS Society (SA) Inc.**  
**GPO Box 383**  
**ADELAIDE SA 5001**

**Print Post Approved:**  
**PP 532154/00023**

**SURFACE  
MAIL**

**POSTAGE  
PAID  
AUSTRALIA**