



THE MYALGIC ENCEPHALOMYELITIS ASSOCIATION OF ONTARIO

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Agreement Number 40665071

REACHING OUT

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REACHING OUT - SPRING 2006

GREETINGS EVERYONE

As the newly appointed "Acting President" of The Myalgic Encephalomyelitis Association of Ontario, I feel very humbled in being asked to take on such a responsibility and, I feel somewhat overwhelmed, as well, as I figuratively try to fill the "big" shoes of our past president, Audrey MacKenzie.

Audrey, as most of you are aware, had put her "heart and soul" into the position of president as she grew our provincial Association to the recognized national and international organization that it is today. Unfortunately, at the beginning of this year, her health declined and she could no longer continue with those responsibilities resulting in her resignation from the Board. Although Audrey has officially resigned from the Board, she continues to have responsibility for writing our Newsletter, the web site and for liaising with the Environmental Health Clinic, part of the NEW Women's College Hospital. In addition to these responsibilities, we have often had to refer to her expertise for background information on a variety of issues involving our Association.

On behalf of The Myalgic Encephalomyelitis Association of Ontario, I would like to extend to Audrey, a heartfelt thank you for all of the time, the energy and the commitment that she has contributed (and continues to do so) to our Association.

Currently, all of the administrative work and service provided by The Myalgic Encephalomyelitis Association of Ontario is being carried out by a team of volunteers, many of whom have the illness. In our recent survey of the membership, many of you recommended that we should publicize a List of Available Volunteer Jobs. You spoke...we listened. In this Newsletter you will find such a list. We will update and improve on this initial list in subsequent publications.

Recently, you may have learned that the Ontario Medical Association (OMA), after issuing a "Diagnostic Code" for ME/CFS, this year, felt it appropriate to issue a corresponding "Time-Based Billing Code" for ME/CFS. This is great news. The new time-based billing code not only, publicly acknowledges that ME/CFS patients require more medical attention and, that doctors currently treating such patients should not be monetarily penalized for providing such service but, it encourages, as well, other and/or new doctors to begin treating ME/CFS patients given that they will now be monetarily compensated for their

time spent with such patients. Also, through both of these codes we should, in the future, be able to gather accurate annual statistics on how many people in Ontario are being "diagnosed" and "treated" for ME/CFS. This will be very valuable information.

As some of you may be aware, the Association has, for the past two years, worked towards submitting a Grant Application to the Ontario Trillium Foundation - a grant that would enable us to hire some full-time, paid staff to help coordinate the work of our volunteers and to help expand the organization in those areas of the province where we are currently underrepresented and are thus not able to provide the level of service that we provide in other larger centres. On July 4th of this year, we did submit such an application to the Ontario Trillium Foundation given the very valuable assistance of a new volunteer and an experienced writer of such applications. Thank you so much Theresa for coming forward and agreeing to take the lead role in preparing this lengthy and detailed application for submission. We should hear back from the Trillium Foundation in three months. We will try to keep you informed.

Margaret Parlor, our Coordinator for Youth and Education Issues who has been liaising with the Ontario Human Rights Commission on behalf of the Association and Youth with ME/CFS, has recently requested to speak to the Standing Committee on Justice on August 9th re Bill 107 (a bill recommending changes to the Ontario Human Rights Commission). The Attorney General has apparently proposed additional changes to the bill and has referred it to the Justice Committee. We, as an Association, would like to express our support for the Commission who has previously spoken out for Youth with ME/CFS whereas, other government branches have been slow to carry through.

These are only a very few of the initiatives that are being carried out by our volunteers. Let me end this greeting by expressing to all of them, on behalf of the Association, my sincerest thanks for their steadfast commitment and hard work.

I look forward to meeting many of you at our public events and wish all of you an enjoyable summer.

Sincerely,
Anthony Rovito, Acting President
The Myalgic Encephalomyelitis Association of Ontario.

If all our misfortunes were laid in one common heap,
most people would be contented to take their own and depart.

- Author unknown

M.E./CFS EDUCATIONAL VIDEOS AND DVD:

Video #1: Sept. 12, 2001 M.E./CFS Medical Information Session with **Dr. Alison Bested F.R.C.P. (C), Dr. Alan Logan ND and Lawyer, Russell Howe** as speakers.

Video #2: June 21, 2003, M.E./CFS Medical Information Session with **Dr. Alison Bested F.R.C.P (C), Dr. Alan Logan ND and Dr. Peter Powles**, Past Chief of Medicine, St. Joseph's Health Care, Toronto and Sleep Disorder Specialist. Dr. Powles also speaks on the possibility of mitochondria dysfunction in M.E./CFS. Videos #1 and #2 are \$20.00 for members and \$25.00 for non-members. S&H and tax included.

Video #3 and DVD- Dr. David Bell: Dr. Bell is an Internationally known expert on children/youth and adults with M.E./CFS. Question and Answer session provided by Dr. Bell and Dr. Alison Bested (see video #1). Video #3 and DVD are \$15.00 for Members and \$25.00 for non-members. S&H and tax included.

MEMBERSHIPS: Our Annual Membership is \$20.00 and donations are greatly appreciated, as they are crucial in increasing the education and awareness of M.E./CFS throughout Ontario. Charity receipts are issued for income tax purposes. If someone is experiencing financial difficulties and would like to be a member, a complimentary membership is available.

M.E./CFS BROCHURES: Our M.E./CFS Brochures, containing the Canadian M.E./CFS Definition, are now available in ENGLISH and CHINESE. The FRENCH and PORTUGUESE will soon be available and all new translations will be posted on our web site.

UPCOMING EVENT

ANNUAL GENERAL MEETING

THE MYALGIC ENCEPHALOMYELITIS ASSOCIATION OF ONTARIO

Date: Saturday, November 25, 2006

Time: 1:00 – 4: 00 PM

**Place: Auditorium, the New Women's College Hospital
76 Grenville Street, Toronto**

(closest subway station is Queen's Park on the University Line)

1:00- 1:45 PM – Annual General Meeting

1:45- 2:00 PM - Break

2:00 – 4:00 PM – Speaker – DR. ALISON BESTED F.R.C.P. (C)

Dr. Bested will discuss the following:

- Her book "*Hope and Help for Chronic Fatigue Syndrome and Fibromyalgia*" books will be available for purchase**
- Latest research studies**
- Coping mechanisms**
- Take questions from the audience**

SCENT FREE POLICY

RESEARCH

A NEW APPLICATION OF SOUND RESONANCE TECHNOLOGY THERAPY FOR THE TREATMENT OF FIBROMYALGIA

A retrospective analysis

Complement Ther Clin Pract. 2006 Aug;12(3):206-12. Epub 2006 Jun 15.

Cogan J, Camus M, Saucier JF, Arsenault P, Demers J.

Department of Anesthesiology, Montreal Heart Institute and Universite de Montreal, 5000 Belanger Street, Montreal, Que., Canada H1T 1C8.

PMID: 16835032

OBJECTIVE: Chart review to evaluate the effectiveness of a three-phase sound resonance technology therapy (SRTT) protocol for the treatment of fibromyalgia.

RESULTS: Initial FIQ scores of 159 consecutive patients ranged from 24 to 80 (mean=58). After Phase 1, (approximately 1 month into the protocol), FIQ scores had decreased on average by 26 points (n=128, 95% CI 23-30, p<.001). After phase 3 of the protocol 53 patients completed an FIQ questionnaire and the mean decrease in FIQ score was 38 points (95% CI 32-44, p=.004).

CONCLUSIONS: This retrospective analysis suggests considerable and rapid relief of the symptoms of fibromyalgia following the use of the three-phase SRTT treatment protocol, which appears to be maintained over several years. Although these results are not conclusive they are remarkable as no other therapy reported in the scientific literature seems as efficacious for fibromyalgia. A follow-up study using an RCT design is warranted.

FIRST BIOMEDICAL RESEARCH IN CHILDREN WITH M.E.
A GROUNDBREAKING STUDY OF BIOCHEMICAL MARKERS IN THE
BLOOD OF CHILDREN WITH ME

- * Children with ME may have signs of a chronic inflammatory disorder.
- * ME could result from a continuing challenge to the immune system, such as a persistent viral infection.
- * Study findings could become the basis for future treatment interventions.

Three years ago on 11 January, the Report of the (UK) Chief Medical Officer's Working Group on CFS/ME stated that research in children with ME was an urgent priority. This is the first biomedical study in children.

Two (UK) ME charities, MERGE and The Young ME Sufferers Trust are delighted to announce a unique study into biochemical markers in children with ME. The investigation will be based in the Vascular Diseases Research Unit at the University of Dundee. Funding for this study has been provided by MERGE (the ME Research Group) and The Young ME Sufferers Trust (the Tymes Trust) in conjunction with the Scottish charity 'Search ME'.

ME and CHILDREN

ME (also called ME/CFS) is a disabling condition of unproven cause affecting all age groups, but it represents a substantial and widespread problem in the young. Estimates vary but there are probably around 20,000 children with ME in the UK alone, yet some doctors still refuse to recognise the problem, let alone investigate it. Attitudes are changing, however, and in a recent report, the UK Chief Medical Officer highlighted the fact that research in children with ME was an urgent priority.

The scientific study of ME in adults is sparse given the extent of the problem, but in terms of children it is almost non-existent. MERGE and The Young ME Sufferers Trust believe that work in this area is crucial, as studies suggest that ME is the commonest cause of long-term sickness absence from school in previously fit children.

THE STUDY

Title: An Investigation into Biochemical and Blood Flow Aspects of ME/CFS in Children

Researchers:

The study will be under the direction of Dr Gwen Kennedy (Research Fellow) and Professor Jill J F Belch (Professor of Vascular Medicine) at the Vascular Diseases Research Unit, University Department of Medicine, Ninewells Hospital Medical School, Dundee DD1 9SY. In the past 15 years, this research group has published more than 250 peer-reviewed scientific papers relating to inflammation and vascular disease, and over the past 4 years has been investigating ME/CFS in adults. The study on children is an extension of this work on adults.

Background and Aim:

Previous work by these researchers, using sophisticated vascular imaging techniques, has shown biochemical abnormalities in the circulation of adult ME patients, suggesting that ME might result from a continuing challenge to the immune system, such as a persistent viral infection.

The aim of the newly-funded study is to investigate a group of children with well-defined ME/CFS (in whom there is the possibility of long-lasting chronic ill-health) to see - for the first time - if similar biochemical abnormalities exist as those already observed in adults with ME. If they do, children with ME/CFS may have signs of a chronic inflammatory disorder associated with increased risk factors for cardiovascular disease, but encouragingly, the findings might become the basis for future treatment interventions.

UNIQUE

This study is unique in that it is the first to investigate biomedical markers in children with CFS/ME and fits in well with the UK Chief Medical Officer's call in 2002 for further research in this field.

EXPERIMENTS

The study will recruit 25 children with well-defined ME/CFS along with 25 age- and gender-matched 'control' children. Each child will have a) A medical examination; b) Blood tests consisting of a standard full blood count, measurements of oxidative stress (eg oxLDL and plasma isoprostanes in the blood), cholesterol measurements (HDL, LDL & triglycerides); C-reactive protein (an indicator of inflammation will be measured by a high sensitivity ELISA) and apoptosis measurements. In addition, blood flow responses to acetylcholine will be measured using a scanning laser Doppler imager.

TIMESCALE

Recruitment for the study began in the Spring of 2005, and results should be available about 18 months afterwards.

Charity details:

MERGE <http://www.mereseach.org.uk/index.html>

The Gateway, North Methven St, Perth PH1 5PP

The Young ME Sufferers Trust (Tymes Trust) <http://www.tymestrust.org>

PO Box 4347, Stock, Ingatestone, Essex, CM4 9TE Tel/Fax : 01245 401080

Editors note: When available, the research findings will be published in a future Newsletter.

DE PAUL PAEDIATRIC HEALTH QUESTIONNAIRE

The De Paul University (US) wants children and adolescents between the ages of 5-17 and their parents/ guardians to complete the De Paul Pediatric Health Questionnaire (DPHQ) to assess chronic fatigue. If you would be willing to participate, please contact Michelle Choi, MS, RN.

Her email is: <mailto:mchoi7@depaul.edu> or telephone her at 773-325-4976.

De Paul University previously conducted and published the research on the prevalence of CFS in Chicago. (422 per 100,000 population)

SPECTROSCOPIC DIAGNOSIS OF CHRONIC FATIGUE SYNDROME BYVISIBLE AND NEAR-INFRARED SPECTROSCOPY IN SERUM SAMPLES

Journal: Biochem Biophys Res Commun. 2006 May 22

Authors: Sakudo A, Kuratsune H, Kobayashi T, Tajima S, Watanabe Y, Ikuta K.

Affiliations: Department of Virology, Center for Infectious Disease Control, Research Institute for Microbial Diseases, Osaka University, Yamadaoka, Suita, Osaka 565-0871, Japan; Department of Physiology, Osaka City University Graduate School of Medicine, Abeno-ku, Osaka 545-8585, Japan.

NLM Citation: PMID: 16730652

To investigate visible and near-infrared (Vis-NIR) spectroscopy enabling chronic fatigue syndrome (CFS) diagnosis, we subjected sera from CFS patients as well as healthy donors to Vis-NIR spectroscopy.

Vis-NIR spectra in the 600-1100nm region for sera from 77 CFS patients and 71 healthy donors were subjected to principal component analysis (PCA) and soft

independent modeling of class analogy (SIMCA) to develop multivariate models to discriminate between CFS patients and healthy donors. The model was further assessed by the prediction of 99 masked other determinations (54 in the healthy group and 45 in the CFS patient group).

The PCA model predicted successful discrimination of the masked samples. The SIMCA model predicted 54 of 54 (100%) healthy donors and 42 of 45 (93.3%) CFS patients of Vis-NIR spectra from masked serum samples correctly.

These results suggest that Vis-NIR spectroscopy for sera combined with chemometrics analysis could provide a promising tool to objectively diagnose CFS.

ADVANCES in ME/CFS
Highlights from Dr. Kenny De Meirlier's
Lecture – Calgary, Alberta, April 2, 2006

By: Marjorie van de Sande, B. Ed, Grad Dip Ed, National ME/FM Action Network, Advisor & Webmaster, Conference Planning Committee.

Dr. De Meirlier is a world renowned researcher and is professor of Physiology and Internal Medicine at the Free University of Brussels in Belgium. Dr. De Meirlier recently published his 600th peer-reviewed paper. He is co-author of 'Chronic Fatigue Syndrome: A Biological Approach', co-editor of the Journal of Chronic Fatigue Syndrome and reviewer for more than ten other medical journals. Dr. De Meirlier was one of four international experts on the panel that developed the Canadian Consensus Document for ME/CFS. He assesses/treats 3,000 to 4,000 patients annually.

Normal Response to Infectious Agents

Numerous infectious agents can trigger ME/CFS. Infectious agents that invade cells release ribonucleic acid (RNA) or deoxyribonucleic acid (DNA) when they reproduce. Normally when a virus infects a cell, an enzyme called Ribonuclease L (Rnase L) is activated and cuts the RNA of the infectious agent so it cannot replicate itself. The Rnase L molecule also cuts the RNA of the infected cell, which triggers the cell's death and removal. Then the Rnase L molecule "switches off" and remains inactive so that it doesn't damage health cells.

Abnormal RnaseL Molecule Found in ME/CFS Patients

The normal weight of the Rnase L molecule is 80 kilo Daltons (kDa). In ME/CFS patients, the Rnase L molecule is being cut and weighs 37 kDa – less than half its normal weight. The low molecular weight (LMW) Rnase L molecule can

discriminate ME/CFS patients from healthy people, and illnesses such as fibromyalgia, multiple sclerosis, cancer, AIDS and depression. The Centers for Disease Control (USA) sent 100 blood samples to Dr. De Meleir. Using the test for LMW Rnase L, Dr. De Meleir was able to identify which blood samples came from ME/CFS patients with 99% accuracy. These findings confirm an organic origin on ME/CFS and validate the diagnosis.

Abnormal Rnase L Molecule Causes Chronic Dysfunction of the Immune System

The damaged Rnase L molecule is not able to kill infectious agents and it keeps damaged cells alive. The body is unable to “switch off” these abnormal Rnase L fragments so they continue to cut the RNA of normal cells. The destructive Rnase L fragment is six times more active than normal and consumes approximately 70% of the cells’ energy (ATP). Rnase L fragments destroy normal protein synthesis, enzyme production and other vital cellular functions. They inhibit respiratory muscles, and cause hyperventilation, metabolic alkalosis, sleep disturbances, and central fatigue. There is sodium retention, low magnesium levels and dramatically low levels of potassium. Natural killer cells, which protect against viruses and intracellular infections, are also being damaged. Thus, the immune system is in a state of chronic dysfunction.

Testing for ME/CFS

Dr. De Meirleir is co-founder of REDLABS <http://www.redlabsusa.com/> which recently opened a lab in Nevada, USA. This lab offers diagnostic and treatment tests for ME/CFS patients. Although each patient’s profile is unique, patients tend to fall into three groups with different causes and treatments. Based on the results of six tests, Dr. De Meleir was able to predict patient’s symptoms with 95% accuracy while the remaining 5% had overlap features. Symptoms severity rises in correlation to the rise in the level of LMW Rnase L.

.Group Profiles

- **Group 1: (15-20%)** This group has high levels of LMW Rnase L and elastase, low levels of protein kinase (PKR) and uric acid, and low to normal levels of nitric oxide. Spinal taps indicate elevated levels of lymphocytes and proteins in the spinal fluid and there is increased pressure upon opening the lumbar puncture.

These patients have a chronic low-grade viral infection and inflammatory reaction in the brain. Many micro-organisms are associated with this profile. Heavy metals, pesticides and other triggers may also be involved. Approximately 20% of this group has low-grade Herpes Virus 6A (HHV6A) encephalitis.

The prominent feature is neurocognitive problems such as confusion and impaired concentration and memory. Fatigue originates in the brain. Pain is not prominent. Patients exhibit symptoms that have some similarities to multiple sclerosis (MS).

- **Group 2: (10-15%)** Patients have very high levels of LMW Rnase L and elastase, high protein kinase activity, severely low natural killer cell activity and very low serum uric acid levels.
This group of severely ill patients has bacterial infections originating from animals such as pets, rodents, ticks, etc. These patients have severe bowel problems. The gut is an important part of the immune system because 70% of the immune cells are in the digestive tract. When a patient has leaky gut syndrome, the gut has become permeable and foreign proteins enter the blood and tissues and inflammation results. Dr. De Meirleir tests for 12 pathogenic gut bacteria.
- **Group 3: (60-70%)** The majority of ME/CFS patients are in this group. This profile is basically similar to Group 2, but not as severe. Generalized pain originating from dysfunction in the pain processing areas of the brain and CNS is a prominent feature. These patients have gastrointestinal infections and bacteria are in the blood.

Some other Areas of Investigation

- **Infections:** Part of the immune system is activated and part is suppressed, leaving the patient vulnerable to opportunistic infections. Patients may have one or a number of infections. Serum Immunobilan tests are done to identify which ones are active. Suspect microorganisms include viruses, bacteria, and mycoplasma. A chlamydia pneumonia infection is often found in patients with chronic sinus infections. Approximately 8 – 10% of ME/CFS patients have infections of animal origin such as Rickettsiae, Coxiella, Bartonella, and Borrelia.
- **Heavy Metals:** Exposure comes from many sources including food, insulation, air, etc. ME/CFS patients have increased sensitivity to chemicals, environmental pollutants and heavy metals, particularly mercury and nickel. Toxins can trigger an inflammatory response.
One of the Rnase L fragments has a structure that is almost identical to a protein involved in the removal of heavy metals and toxic chemical from cells. When this protein is blocked by the Rnase L fragments, the cells become more sensitive to mercury. Now a tiny amount of mercury that would normally kill 10% of the cells can kill 50% to 100% of the cells.
- **Mycrotoxins:** Fungi such as Aspergillus Niger and Candida can contribute to ME/CFS symptoms. Candida is a yeast fungal infection that changes sugars to aldehydes, a toxic form of alcohol.

- **Digestive Tract:** Gastrointestinal problems are a serious concern in ME/CFS patients. 70% of the body's immune cells are found in the gastrointestinal tract. These immune cells prevent bacteria and foreign protein from entering the blood stream. When the gut become permeable and foreign protein enters the blood stream, elastase is produced. Elastase is the enzyme that is responsible for cutting the Rnase L molecule into fragments. Elastase breaks down elastin, which gives elasticity to collagen. As a result, there is pain and loss of elasticity in ligaments and tendons.
- **Peripheral Resistance to Thyroid Hormone:** Most patients have normal results to common thyroid tests. However, ME/CFS patients have a much higher level of a protein that is 98% identical to T3, which is the active form of thyroid. Because this foreign protein can bind to T3 receptors, T3 cannot find receptors and is therefore ineffective in its role of activating cellular metabolism.

Treatment Summary

Some of the psychiatrists advocate that no tests or lab work be done on ME/CFS patients because testing will reinforce delusions of physical illness. Given the wealth of confirmed biochemical abnormalities, such rationale is ludicrous. Dr. De Meileir stressed that tests must be done in order to determine the origin of the problem. Then treatment can be prescribed to eliminate the cause. A "clean-up" of all the consequences of the problem must also be undertaken. Therapies and the order of treatments vary according to the patient's unique test profile.

Treatment includes:

1. Restoring immune competence.
2. Removing microorganisms.
3. Restoring hormonal balance
4. Restoring intestinal flora
5. Decreasing prostaglandins and protein kinase activity.
6. Removing heavy metals and toxic chemicals.

Dr. De Meirleir describes various treatments therapies in his lecture, which is available on DVD.

New ME/CFS DVD Resources – Prices include shipping & handling:

Dr. Kenny De Meileir:

Physicians' full day workshop - \$80.00

Dr. Kenny De Meileir:

Patients' lecture - \$25.00

Dr. Pierre Flor-Henry's lecture: very technical (limited time offer) –qEEG studies (current density source) & psychophysiological studies - \$20.00

Dr. David Bell's lecture: (emphasis on chronic orthostatic intolerance) - \$ 25.00

Note:

- Please send order ASAP so they can determine the number of DVDs to have made.

- Dr. De Meileir's DVDs will be delayed until June, 2006
- **Payment:** must be by **check** or **money order** payable to:
Marjorie van de Sande – Mail it to her at: 151 Arbour Ridge Circle NW,
Calgary AB T3G 3V9
- Please be sure to indicate which DVDs you would like.

[Dr. De Meirleir also spoke in Quebec, hosted by the Association quebecoise de l'encephalomyelite myalgique (AQUEM).]

“Summaries of the lectures will be published in the Association's newsletter *Le Ruban bleu*. Videos of the lectures in French will be available later through the Quebec ME Association. Tel: 514-369-1689; Tel: Sans frais: 1-877-369-1689
Website: <http://www.agem.org> email: <mailto:agem@spq.qc.ca>

Source: National ME/FM Action Network's *Quest* Communication #71
3836 Carling Avenue, Nepean, ON K2K 2Y6
Tel: 613-829-6667 Web: <http://www.mefmaction.net>

Editors note: The Rnase L test that is performed in Reno, Nevada, USA, costs approximately \$570 US dollars. Please see the Lab's web site for further instructions.

The cost of the test is not covered in Canada.

PLACEMENT OF THE JOURNALS OF CHRONIC FATIGUE SYNDROME

STRATFORD WALK-IN CLINIC

In the months of June and July the new Hospital Interns and Residents 'hit' the Hospital wards. During this time, their attention is focused on learning the basics and becoming familiar with their duties. For this reason, we have delayed sending out Journals to Hospitals until August. In the meantime, we have targeted the medical staff at Stratford's only Walk-In Clinic.

Dr. J. Bandey, Dr. P. Brooks, Dr. E. Flowers, Dr. P. Hades, Dr. G. Langford,
Dr. J. McArthurs, Dr. D. Parratt, Dr. W. Parsons, Dr. J. Spers, Dr. E. Thomas,
Dr. D. Thompson, Dr. B. Tomlinson, Dr. D. Tomlinson, Dr. P. Weir,
Dr. M. Wilkinson, Dr. M. Maclsaac.

Nurse Practitioner: Zoe Ross, Dietician: Deb Northmore, Medical Receptionists:
Jane Crawford and Erin Jurjens.

HURON PERTH HEALTH ALLIANCE

In August, we will be placing the Journals of CFS within Huron Perth Health Alliance which includes Stratford, Seaforth, St. Marys and Clinton Hospitals with the following:

Chief of Medicine; Dr. Nancy Whitmore, Medical Program Director, Medicine

Chief of Surgery: Dr. Nancy Whitmore

Chief/Head of Family Practice: Dr. Doug Thompson

Chief of Psychiatry: Dr. Marilyn Marshall

Chief of Emergency Dept: Dr. Miriam Mann

Chief of Pediatrics: Dr. Shamin Tejpar

Chief of OB/GYN: Dr. Cherly Hillyer, Medical Program Director, Maternal/Child

Chief of Pathology: Dr. Malcolm Carlson, Medical Program Director, Pathology

Chief of Anaesthesia: Dr. Richard Branson

Chief/Head of Urology: Dr. Andrew Hussey

Director of Nursing: Donnalene Tuer-Hodes

Employee Health Services: Gladys Brindley

Manager of Staff Physicians' Lounge and Resource Library: Jimmy Trieu

Huron Perth Health Alliance Chief of Staff: Dr. Laurel Moore

Site Chief: Clinton Public Hospital: Dr. Maarten Bokhout

Site Chief: Seaforth Community Hospital: Dr. Dan Rooyakkers

Site Chief: St. Marys Memorial Hospital: Dr. Fred Jewson

ENVIRONMENTAL HEALTH CLINIC

Dr. Lynn Marshall and Dr. Riina Bray worked together as Co-Medical Directors of the EHC in May and June to assist Dr. Bray in assuming the position of Medical Director on July 1, 2006. Dr. Marshall will continue with the EHC in the role of Medical Education Liaison.

We extend a warm welcome to Dr. Riina Bray as EHC's new Medical Director, and look forward to continuing to collaborate with the EHC Team.

M.E./CFS ARTICLES IN NEWSPAPERS AND Ms MAGAZINE

HOSPITAL NEWS **Canada's Health-Care Newspaper**

Hospital News, is a very popular newspaper that is available at the first of every month in Hospitals in Toronto and the Greater Toronto area and may also be

available across Canada. This newspaper is available to Hospital Staff and the general public. In their 2006 issue, there is an extensive article written by Dr. Alison Bested F.R.C.P. (C) on M.E./CFS, FM and MCS. As this newspaper is very popular, it is an excellent way of educating hospital staff and the general public on these illnesses.

Several months earlier, The Myalgic Encephalomyelitis Association of Ontario mailed multiple Journals of Chronic Fatigue Syndrome Volume 1 (1) to the editorial staff of *Hospital News*.

ST. CATHERINE'S STANDARD NEWSPAPER

Our member, Sarah and her mother were interviewed by the St. Catherine's Standard for an article on M.E./CFS that is expected to be published on July, 31, 2006. We very much look forward to reading her article. Thank you Sarah for spending your energy to do this. We have been speaking with the author of Sarah's story and we are hopeful that the entire article will be published in our September Newsletter.

Future Youth Writers?

If other youths would be willing to share their story of their experiences with M.E./CFS, we would be pleased to publish them in our Newsletter and/or on our web site and share them with the National ME/FM Action Network. If you are uncomfortable with using your name, then a 'pen name' would be fine.

Ms. MAGAZINE

Be on the lookout for an article by Dr. Nancy Klimas in the Summer issue of Ms Magazine. Dr. Klimas has been involved in M.E./CFS research for many years. <http://www.msmagazine.com/press/2006-summerissue.asp>

Editor's note: It is very encouraging to see so many main stream magazines and newspapers publishing articles on M.E./CFS.

CHANGES TO THE INSURANCE ACT

In Richard Bogorach's L.L. B. newsletter, it stated that there were changes to the Insurance Act that took place on **March 1, 2006**. "the Designated Assessment Centre (DAC) system has been abolished which allowed for an insurance company to refuse a treatment plan, deny a benefit or terminate a benefit based on the decision of a DAC. The new system that will take its place, "significantly limits the options that are available to the Insured and what is ultimately required by the Insurer". "It is important that Insured individuals understand the different procedural steps that have been put in place".

Please discuss these recent changes with your lawyer **if** your Disability Insurer has requested an Insurance Examination.

DR. BESTED F.R.C.P (C) - SUPPORT GROUPS, TORONTO

EDUCATIONAL SUPPORT GROUP

Dr. Bested F.R.C.P. (C) and Tracey Beaulne, Doctor of Naturopathic Medicine, will be leading 8 Week Educational Information Sessions for M.E./CFS, FM and MCS which include, Education about these illnesses, Nutritional instruction, Guidance with dealing with Disability Issues and much more. Dr. Beaulne & Dr. Bested are graduates of the Harvard Medical School's 'Mind-Body Course' and have based their course on these concepts.

Location: 3600 Ellesmere Road, Unit 4, Toronto

Time: 1:00 PM – 3:00 PM – every other Friday – SCENT FREE POLICY

Date: First course commenced again on July 28th, 2006.

Cost: \$150.00 which includes the Working Manual, Handouts and the ND's time.

To attend present or future sessions, please Call Dr. Bested's office at:
416-283-0007

SUPPORT THERAPY GROUP

COVERED BY OHIP

Dr. Bested will be leading a Supportive Therapy Group commencing again on September 8, 2006. The sessions will include learning coping skills to live with having the chronic illnesses of M.E./CFS, FM and MCS. Among the variety of coping skills that will be taught, is how to learn cognitive behavioural therapy to manage stress and to conserve your energy. Dr. Bested was on the Expert Review panel for the Canadian M.E./CFS Definition, Diagnostic and Treatment Protocols, is a Staff Physician at the Environmental Health Clinic and Lecturer at the University of Toronto.

Location: 3600 Ellesmere Avenue, Unit 4 (Ellesmere Rd and Morrish), Toronto

Time: On-going - Fridays - SCENT FREE POLICY

Fee: Covered by OHIP

To attend: Please call Dr. Bested's office at 416-283-0007

DR. BESTED'S BOOK SIGNING

HOPE AND HELP FOR CHRONIC FATIGUE SYNDROME AND FIBROMYALGIA

by Dr. Alison Bested F.R.C.P. (C), Alan Logan ND and Russell Howe L.L.B.
Dr. Alison's Book Signing at the New Women's College Hospital was a success!
It was wonderful that so many came out to support her. Thank you for your effort.
The Book is available on <http://www.amazon.ca> and in local bookstores.

Pictures from the event:.



Dr. Kitty Kerr, Dr. Alison Bested and Dr. Lynn Marshall



left to right - Debbie, Dr. Alison Bested's secretary and receptionist, and
Dr. Alison Bested



left to right - Maries and Diane (Board members) with Dr. Bested's
book, standing in front of our Educational Display Board.



Dr. Bested and Acting President Anthony Rovito

TRAPPED IN BED FOR 14 YEARS WITH CFS

By GILL SWAIN

She can't swallow. She can't speak. She's in constant pain. Yet some doctors say Lynn's illness is all in the mind. Read her story and you'll never be flippant about 'yuppie flu' again:

For years many doctors dismissed ME, also known as Chronic Fatigue Syndrome, as 'yuppie flu'. But last month a coroner gave ME as the official cause of death for the first time in the UK - raising hope among campaigners that the condition is about to be taken seriously at last.

Here, Kay Gilderdale tells GILL SWAIN the heartrending story of her daughter, Lynn, 28, who was struck down by the illness 14 years ago...

The soft cotton curtains are permanently drawn to cut out the summer glare. On the bed in the gloom lies a beautiful young woman with skin so pale it is almost translucent. She is stretched out flat on a sheepskin to prevent bedsores, her head resting on a towel. There is a tube down her nose delivering liquid food, and an intravenous line pumping drugs straight into her chest.

Her name is Lynn Gilderdale, she is 28 years old and this has been her life for 14 years. Apart from stays in hospital when she develops an infection, Lynn never leaves her bed in the small bedroom at the back of her mother's bungalow in the village of Stonegate, East Sussex.

Her legs are paralysed and without feeling, she cannot sit up without passing out and her neck is too weak to support her head. She has lost more than half the bone density in her spine and went through the menopause at the age of 20. She is in constant pain. She cannot swallow. She cannot speak. Her mother Kay, who cares for her, has not heard her daughter's voice since she fell silent in August 1992.

Lynn is suffering from ME - Myalgic Encephalomyelitis - once sneeringly dubbed 'yuppie flu' and suspected of being a psychological affliction that struck mostly people who couldn't cope with the stresses of modern life. Anyone who ever thought that way would find a visit to Lynn a deeply shocking and humbling experience. 'It's like she's in limbo,' says Kay, 52. 'If someone dies, you mourn them, then you get to a stage where you know that person is gone and you move on. But Lynn is neither one nor the other.

'She is stuck in that room, not dead, but not alive properly. If I didn't believe, and she didn't believe, that one day she would get better then I don't think it would be right for her to go on suffering like this for a whole lifespan of 70 or 80 years.'

It is estimated that a quarter of the 240,000 ME victims in the UK suffer severe symptoms such as paralysis and the inability to speak or swallow for months or years, and there are probably several hundred as terribly ill as Lynn. Dr Anne MacIntyre, who wrote one of the first self-help books for ME sufferers and has known Lynn since 1993, says: 'At one time Lynn was so sick she recognised nobody, not even her parents. It is absolutely dreadful. These cases are mostly of people who fell ill in their teens, but they are hidden because no one ever sees them.

'They are too ill to get to a clinic and they are cared for at home by parents or other family. Their GPs have mostly given up on them because no one really knows what is going on with this illness', though only able to turn her head weakly from side to side and move her arms.

Lynn's strength of character is unmistakable. She expresses herself through a sign language that she has developed with Kay, and smiles and makes jokes whenever she can. Kay invites people into her daughter's small room, which is cluttered with soft toys, to meet her and take photographs to convince the world this is a real illness and to encourage more research to find a cure.

To describe the pain she is in, Lynn makes stabbing gestures and points to the left side of her chest, sweeps her hand across her forehead to indicate her persistent headache and twists her hands around each other to represent the churning agony in her stomach.

Asked if she is fed up with being like this, she looks both angry and exasperated and holds her thumb and forefinger emphatically an inch apart, meaning: 'Just a bit!' She is very sad, she indicates, but never depressed. I am not brave, I have no choice but to be hopeful, otherwise I would just give up,' her mother translates.

The family's ordeal has been made worse by the fact that, because there is no diagnostic test which can detect the cause of ME's symptoms, many people - including doctors and nurses - persist in believing it is self-induced. But Lynn was a lively, intelligent, popular teenager who enjoyed a happy life with her family. 'We didn't realise how happy until we lost it,' says Kay.

With her mother, older brother Steve and father Richard, a former police inspector who now works for the force as a civilian, Lynn would go sailing and on family cycle rides.

She played the piano and clarinet, won prizes for ballet, and loved swimming and going to the youth club with her friends. Then in November 1991, when she was 14, she had a TB vaccination and immediately felt unwell. Lynn struggled in to school the next day but was sent home and never returned.

Lynn developed flu, bronchitis, tonsillitis and glandular fever, one after the other. 'By February she was really very ill and we were beginning to realise it wasn't just normal bugs,' says Kay.

'Her legs would give way, her memory was getting very poor, she was having awful pains all over her body and a constant, dreadful sore throat and she would often faint.'

Because of her weak legs, she had to start using a wheelchair, then the top half of her body became floppy. By May 1992, ME had been diagnosed and Lynn was bedridden, had difficulty swallowing, couldn't recognise people and her voice had reduced to a whisper.

Frequently, she would fall unconscious while every muscle twisted in violent spasms. 'That first year was so terrible, when we knew she was extremely ill but the tests didn't show anything,' says Kay. 'The first paediatrician we saw said: "It's OK, you've got a fashionable illness. It will go away in time."

'With every other disease you get kindness and sympathy, but though Lynn was very frightened and we were desperate for help, all we got was accusations that she was pretending. It was hugely upsetting.'

Cruel, if well-meaning, experiments were conducted on her in hospital to 'force' her to admit she was making it up. Nurses left her unattended for hours in the theory that she would get up to use the bathroom. This had humiliating results.

'Making it up'

Doctors once administered a 'truth drug' and questioned her over whether she was being abused at home. There was a suggestion Lynn had school phobia and Kay once overheard a nurse speculating that it was Munchausen's Syndrome by Proxy - when a mother induces symptoms in a child to draw attention to herself.

'One consultant was convinced Lynn was orchestrating her spasms at certain times of day so they took away her clock, the radio and TV and the nurses lied to her about the time. She still had the attacks at the same times.

'They abused her verbally, calling her a "silly little girl", saying "Of course you can do it" and telling her to fetch things herself. Sometimes she was in such pain and felt so terribly ill she would ask us: "What is going to happen to me?" But we had no answers for her, and neither did the doctors.'

Medical opinion now mostly concurs that ME is caused by a virus, but there is still no treatment for it besides controlling the symptoms.

At first, however, Kay was advised to make Lynn stick to a timetable of study, rest, socialising and exercise. So she would make Lynn walk down the road even when she felt weak - then had to half-carry her back when her legs gave way.

Kay had trained as an auxiliary nurse and it made sense to her at the time to keep Lynn moving. Now she bitterly regrets it, as she is convinced it caused Lynn more harm.

Soft-spoken and mild-mannered, Irish-born Kay is determined to stay positive, but she had to struggle to come to terms what she saw as her own role in Lynn's suffering. 'I don't beat myself up about it any more because that would be a waste of energy and I need every atom to cope,' she says.

Nine months after she fell ill, Lynn could move no part of her body except her little finger, could not speak and had to be fed through a tube. But Kay and Richard made the courageous decision to take her home.

'They said if we did, there was a risk she would die, but we felt there was a greater risk if she stayed in hospital and didn't get the peace and care she needed.

'For two or three years afterwards she would wake up screaming from nightmares of things that happened to her in hospital. She is still scared of doctors and nurses and I won't have anything to do with anyone who doesn't believe in ME.'

Kay left her job in accounting to look after Lynn and has never left her side for more than two days. Her marriage broke up - she says not because of Lynn's illness but unrelated problems. However, Richard still helps care for his daughter.

Lynn's brother Steve did well at school despite his family life disintegrating and now works in IT and is due to become a father in August.

Kay was only 37 when Lynn fell ill. But for her, too, normal life came to an end then. She has a carer in twice a week so she can go shopping and see people.

'I don't resent what it has done to my life but I do resent whatever has made her so ill. It's been heartbreaking to watch my child lose her faculties one by one.

'It is still very hard for me to see mothers and daughters together or groups of teenagers dressed up and laughing or to hear a family in the garden having a barbecue with children running around.

'If I lived somewhere like a high-rise flat, I don't think I could have coped. And at least I can walk in my garden.'

Every birthday and Christmas has been sad as the years have passed with no improvement, though Kay tries to make them special. 'For her 18th, I wrapped 18 little presents and put them in a biscuit tin which I iced and put candles on. Lynn said it was a lovely cake but she couldn't eat it, then I showed her what it really was.'

In her late teens, Lynn's body stopped producing oestrogen and she was diagnosed with premature ovarian failure. She has been on HRT ever since, but the lack of hormones contributed to her severe osteoporosis. She is on 24-hour pain control, plus drugs to prevent sickness and spasms.

Light and noise

Lynn is hyper-sensitive to light and noise and for years could not bear to watch television or listen to music. Now she has forgotten how to read. She has a hamster with which she plays in the afternoons and she watches the darting movements of the tropical fish in a large tank beside her bed.

She loves make-up and jewelry and choosing presents from mail-order catalogues. At her strongest she can make cards for friends. But she suffered a knock back in October. Her lung was punctured while she was having her Hickman line - a semi-permanent catheter through which she receives medication - replaced and she is now sleeping nearly 15 hours a day.

Asked what she would like to do if she recovered, Lynn signals that she just wants to do normal things. And she folds her arms together in a rocking motion to indicate her yearning for a baby.

'She has always loved children and I've told her there are many ways to have a baby even if you can't give birth yourself,' says Kay. 'But I am really hoping that once the virus which caused her ME has finally burned itself out, everything else will start working again.'

'People do get better, even those as ill as Lynn. Every time I read of such a case I am pleased for them, but I can't help wondering when it will be her turn.'

'If she could come out of that room, it wouldn't matter where we went. It would be enough just to feel the air on our faces, see the sky, be part of the world. Lynn tells me she feels it is all out there, waiting for her to step back into.'

'It is not that she doesn't want to. She wants to so much. Who would choose to lie in bed and be injected with drugs so many times your veins collapse over the life she had as an active teenager?'

'We need to find the cause'

'Yet the [UK] Government is putting money into treatments such as graded exercise and cognitive behaviour therapy - which don't help those most severely affected by ME - rather than into research to find the cause.'

'Until a cure is found, the thing which would make the biggest difference to our lives would be for everyone to realise it is a real and terrible illness.'

'But a lot of people still say to me they thought ME was "just tiredness". And people like Lynn are still being told: "Pull yourself together." '

There is a web site for the severely affected with ME: <http://www.25megroup.org>
or Action for ME: <http://www.afme.org.uk>

Source: co-cure (UK) Newspaper, the Daily Mail, 4 July 2006

MEMBERSHIP SURVEY

We have been conducting a survey of our members to evaluate how well we have been serving your needs and what we can do to serve you better.

You may have already been contacted by us. If so, we sincerely thank you for your participation. We appreciate the time you so generously shared with us and the many innovative suggestions you have given.

We may have lost touch with some of you either because you have moved or changed your telephone number or simply through clerical errors. If we have not, as yet, contacted you by the end of July, please call our Help-Line and leave a message indicating you would like to participate in our survey and one of our volunteers will call you back.

When we complete the entire survey, we will communicate all of the results to you. One of your suggestions, thus far, was that we provide specific job descriptions when we ask for volunteers. Great idea! You spoke... we listened - such a detailed Volunteer List is provided in this Newsletter.

- A Big Thank You to our Volunteer who is conducting our Survey. So far, she has placed over 600 telephone calls to try to reach everyone!!!

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Did you know that ALL the work for our Association is done by Volunteers?

Our Newsletter, Website, Membership Coordination, Board work, Education Awareness and Youth Programmes are all the result of the generosity and efforts of our volunteers.

MANY, MANY THANKS TO YOU ALL!!!

We know from talking with you during our Membership Survey that many of you would like to see more information on volunteering. We have compiled a list of available volunteer jobs. If you are interested in any of the jobs on our list, please call our Help-Line at 416 222-8820 or 1 877 632-6682 and provide us with your name, your daytime telephone number and the particular job for which you would like to volunteer. Our Volunteer Coordinator will contact you over the next month.

Brochure Distributors: These positions will require that you distribute and / or post our brochures at local pharmacies, libraries, community centres, etc. A car would be helpful, but not necessary. This job would require a minimum of 1 hour per month, as we ask you to replenish the brochures at these local distribution centres. (We are especially interested in people from communities in Ontario that need more M.E./CFS information.)

MORE VOLUNTEER JOBS!!!

Chocolate Fundraisers: We need people to help our volunteer sell an excellent line of chocolates throughout the year, but especially in the months before the Christmas. The amount of time you dedicate to this activity is optional and would be negotiated with Diane, our Volunteer Team Leader of Chocolate Sales.

Spreadsheet Administrator: This position requires someone experienced in data entry and generating form letters and statistics. Our current excel spreadsheet needs updating which may take several hours. From then on, it would require about 2 hours per month to maintain.

Education Displays: This position requires a person who can carry a poster and help in the set up of a small display which we use at hospitals and public events in Toronto. It also requires someone who is comfortable talking with the public about CFS and about our Association. The Association sets up this display several times a year, and each display lasts 4 - 8 hours. We are looking for several people for this position so that each person could commit to 1 - 2 Education Displays per year, for a minimum of 2 – 4 hours. We need other people to help book the displays at various Toronto venues. Our Education Display Coordinator would be in attendance during these events.

The Association wishes to hold these displays outside Toronto. For this, we need volunteers from cities outside Toronto who would help us locate appropriate venues and help set up the displays.

Graphic Artist: This position would be filled by an experienced graphic artist. We are planning to revamp our current brochure, and someone with this type of experience would be ideal. The number of hours for this project is unknown.

Help-Line Volunteers: This position would require you to pick up messages left on our Help-Line, to call back those callers who need to talk to someone and / or to send out available information as requested. You need to be a good listener, patient, mature, compassionate and be knowledgeable of Chronic Fatigue Syndrome. We would train you and provide you with support materials. This job would require about 1 hour of time per week and can be done from your home. (If you feel that 1 hour per week is, at this time, too much for you, we would try to reduce it.)

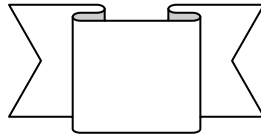
TWO MORE!

Print Materials Coordinator & Distributor: This position would require a reliable, mature person with a car who would be responsible for the printing of all Information Package materials and brochures. This person would also be responsible for mailing out our brochures to the Brochure Distributors throughout the province. This position would require about 4 hours per month and would likely be shared by 2 volunteers.

Writers and Researchers: As the information and research now available on M.E./CFS steadily increases, we need volunteers who can write, organize and present this information well to give to the media and the general public. Also, we need researchers who can contribute to both our Newsletter and our Website. These positions would probably require a minimum of 4 hours per month.

We look forward to hearing from you.

VOLUNTEER RECOGNITION



Our first 'official' recognition goes to not one, but three Volunteers!

They are two adorable little dogs called Muffin and Hershey... and of course, I can't forget their sidekick, Carlos Rajkumar. Their Volunteer Assignment is getting the Newsletter out to everyone.

Muffin and Hershey never complain, when at the last minute, they have to rush to Staples to have the Newsletter printed between Christmas and New Year's Day - and then assemble the Newsletters, print out the labels and put them on the envelopes - and then rush to the Canada Post Distribution Centre in order for the Newsletter to meet the end of the year deadline....not one little bark from them in protest... not one! And then, they have to send out the email Newsletters.

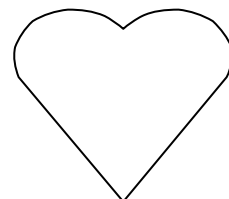
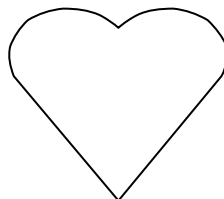
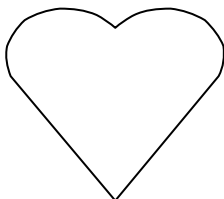
I neglected to say that in addition to the above, they have to read the Newsletter scanning for typos...of which, there are usually plenty for them to correct. But

they sit at the computer and with their little paws, they work and work until they are satisfied with the final version. Are they not just the most adorable little creatures that exist? ...all this time and effort they freely give to our Association - and it is all volunteer work!

I forgot to tell you that with the last Newsletter, Muffin and Hershey may have received a C+ for their work. Somehow they took a liking to the pictures and decided to chew them...just for the fun of it. But their sidekick, Carlos, came to their rescue and patched up the pictures...could you see where they chewed the pictures? Probably not...Carlos, their sidekick, worked tirelessly to glue the pictures back together.

The Myalgic Encephalomyelitis Association of Ontario is very, very grateful and appreciative of Carlos Rajkumar and his 'buddies' who for many years has given so much time and effort to our Association in 'getting out' our newsletters - and always with such good humour, endless patience and kindness.

Thank You Carlos!



CONTINUING MY JOURNEY WITH M.E./CFS

Sometimes we get really stressed out and need “grounding’. One easy method is to simply lie down on the floor for awhile - or cup your hands over both eyes for a few minutes.

GENERAL INFORMATION

WEB SITES

1. Chronic Fatigue Syndrome Web Site for Gay People:

http://health.groups.yahoo.com/group/Gay_Chronic_Fatigue_Syndrome_Group/

E-Mail: mailto:Gay_Chronic_Fatigue_Syndrome_Group-owner@yahoogroups.com

Source: Co-Cure

Announcing a new e-mail group: Gay Chronic Fatigue Syndrome Group:
“Chronic Fatigue Syndrome is a difficult and challenging illness that affects every aspect of our lives. Gay people with CFS also face additional challenges added onto what others with this illness have to deal with. Finding support and other people with this illness to feel connected to can be difficult. I am hoping gay people and others in their lives will find it safe in this moderated private online support group to discuss anything they like. You don't just have to talk about the illness itself all the time. I know the group may start out small, but I am hoping as time goes on it will grow. Regardless of the number of people in the group, I am hoping that by joining, members will find support, information and companionship with others who share their illness and face its challenges on a daily basis.”

The following Environmental web sites were published in the Environmental Health Clinic's *Environmental News*, Spring 2006

2. Canadian Partnership for Children's Health and the Environment

<http://www.healthyenvironmentforkids.ca/imgupload/13297cd6a147585a24c1c6233d8d96d8/Primer.pdf>

3. The Canadian Lung Association, Pollution and Air Quality, indoor Air-Your home 2006

http://www.lung.ca/protect-protegez/pollution-pollution/indoor-interieur/home-chevzvous_e.php

4. Dieticians of Canada

www.dieticians.ca

Offers answers to nutrition questions. It is the most trusted source of information on food and nutrition for Canadians.

THE COOK'S CORNER

Jello Snack

A cool and refreshing snack - even good for breakfast.

Lime Jello

1 - 398 ml can of Pineapples Tidbits

Cottage Cheese

Walnut pieces.

1- Lime Jello (or whatever flavour of Jello you prefer)

1 – cup of Pineapple Juice (or whatever fruit juice you prefer)

1 – cup of Pineapple Tidbits (or whatever fruit you prefer)

1 cup of Cottage Cheese

½ cup of finely chopped or crushed walnut pieces

Add one cup of boiling water to your favourite Jello flavour, stir until the powder is dissolved and then add one cup of Pineapple juice. Place in refrigerator until partially set. Remove, and add 1 cup of Pineapple Tidbits, 1 cup of cottage cheese and ½ cup of finely chopped or crushed walnut pieces. Return to the refrigerator to fully set.

COOKING WITH RUBS

Rubbing meat with a flavourful blend of herbs and spices before cooking works like a dry marinade”, providing great flavour and sealing in moisture.

As a guideline, use about 1 tbsp.(15 ml) to season a pork chop, chicken leg, steak or fish fillet. Use about 2 to 3 tbsp. (30-45 ml) to season a rack of ribs, whole chicken or a roast. With fingers, rub seasoning mixture evenly into meat. For lean meats, such as skinless chicken, fish and pork chops, mist or lightly brush seasoned meat with vegetable oil before cooking.

Cook initially at high or medium- high heat to sear both sides of meat, then reduce to medium or low. Close lid to retain heat.

When cooking meat or fish, don't flip or fuss excessively. Cook on the first side long enough so meat will release from the grill. Undercooked meat has a tendency to stick, so let it cook a little longer. Use a flat, wide metal spatula to make turning easier.

Tip: Store rubs in a tightly sealed jar in a cool, dry place, away from sunlight, for up to 3 months.

Cajun Seasoning:

This mixture is good on just about anything: beef, pork, chicken, fish, shrimp and even potato wedges.

½ cup (125 ml) paprika
2 tbsp. (30 ml) each cayenne, dried minced onion and garlic powder
1 tbsp. (15 ml) each of salt and lightly crushed fennel seeds
2 tsp. (10 ml) each- dried thyme and oregano leaves
1 tsp. (5 ml) black pepper

Combine all ingredients in a jar with a tight fitting lid. Shake well to blend thoroughly. Makes about 1 cup (250ml).

Jerk Seasoning Rub

Go beyond the traditional chicken and pork and try this rub on fish or shrimp.

2 tbsp. (30 ml) each dried minced onion and dried thyme leaves
1 tbsp. (15 ml) each garlic powder, cayenne and granulated sugar
2 tsp. (10 ml) each ground allspice and black pepper
1 tsp. (5 ml) salt
½ tsp. (2 ml) cinnamon

Combine all ingredients in a jar with a tight fitting lid. Shake well to blend thoroughly. Makes about ½ cup (125ml).

Latin Rub

A flavourful mix that works well on pork chops, steaks, ribs and chicken.

½ cup (50 ml) ground cumin
2 tbsp. (30 ml) each ground coriander and black pepper
1 tbsp. (15 ml) each salt, chili powder, cinnamon, red pepper flakes and brown sugar.

Combine all ingredients in a jar with a tight fitting lid. Shake well to blend thoroughly. Makes ¾ cup (175ml).

Source: *Homemakers* magazine

BRAISED BEEF

Beef – an inexpensive cut of beef can be used for this recipe.

½ half pound of beef
salt and pepper
2 cups of orange juice
2 tea bags
2 Tablespoons brown sugar
2 cinnamon sticks
1 small chopped onion
6 Star Anise (licorice flavour – available in bulk stores and supermarkets).

Salt and pepper beef on all sides. Brown the beef in pan on the stove-top – pour off any fat. Then add the 2 cups of orange juice, 2 tea bags, 2 Tablespoons of brown sugar, the chopped onion, 6 Star Anise, and the 2 cinnamon sticks. Bring to a boil and then reduce heat and simmer the liquid until the beef is thoroughly cooked and still tender. Remove beef from the pan to a serving dish.

Bring the liquid in the pan to a boil and keep boiling until the liquid is reduced to 1/3.

Strain the liquid to remove the cinnamon sticks and the star anise and pour over the beef.

Variation: sprinkle fresh chopped tarragon over the meat just before serving.

Serve on rice.

DISCLAIMER

As a resource group, the function of our organization is to provide you with current information on M.E./CFS. As we are not medical professionals, we accept no responsibility for how this information might be applied. We urge you to discuss all aspects of your illness with your attending physician.
