Quest 32

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FIBROMYALGIA/CHRONIC FATIGUE SYNDROME/

ENVIRONMENTAL HYPERSENSITIVITY CONFERENCE

(Reviewed by Dr. Alison Bested)

On Saturday**,** October 3, 1998 The Environmental Women's Health Clinic, Women's College Hospital hosted an organized and informative conference for doctors entitled "Chronic Fatigue, Fibromyalgia and Environmental Hypersensitivity-Practical Pears". This conference was part of The University of Toronto's Continuing Medical Education Series, Department of Family and Community Medicine, held in downtown Toronto.

The majority of the participants in attendance were doctors interested in learning the latest diagnostic techniques and patient management strategies for patients suffering from Fibromyalgia, Chronic Fatigue syndrome and/or Environmental hypersensitivity.

The list of accomplished speakers was impressive. Dr. Frank Foley, Medical Director of The Environmental Health Clinic provided the introductory comments and introduced the speakers. Presenting doctors were: Drs. Alison Bested, Lorenz, Lynn Marshall, Gerald Ross, Paul Sterling and Beverly Tomkins. Unfortunately, Dr. Susan Tainsh was unable to attend the conference.

Other informative speakers were: Mr. Leo Phillon (speaking on medical-legal issues), Mr. Russell J. Howe of Boland & Howe, Barristers & Solicitors, Mr. Masandorl Ishise (speaking on the triple-headed Spect Brain Scan - Mount Sinai Hospital) and a presentation from The Community Indoor Air Quality Work Group - South Riverdale, Toronto, Ontario.

In his opening address, Dr. Frank Foley described having Fibromyalgia as being similar to a doctor "going on call for three days straight". He emphasized that doctors should be asking their patients presenting with these diagnosis, "How can we help"" and "How did we do". Dr. Foley also mentioned that the medical community is "very conservative", saying that doctors' understanding of multiple chemical sensitivities is in the same position as Fibromyalgia was twenty years ago.

Three hundred patients have been seen at The Environmental Health Clinic at Women's College Hospital,

and in terms of their medical histories, his patients' stories are often similar. In the Fibromyalgia patients, they have altered neuro-chemicals. The physiology is "out of whack" in Fibromyalgia and Chronic Fatigue Syndrome patients.

Dr. Alison Bested, a Toronto Hematological Pathologist, aptly described her initial impression of her CFS patients as looking like "a puddle on the floor". She requests bloodwork to rule out other diseases that can cause fatigue on a new patient and notices the following upon physical

examination of her patients: red crescents at the back of their throats, swollen lymph nodes, a "puffiness" in their faces, and a positive Romberg test.

Dr. Bested indicated that it is important for family doctors to listen to their CFS patients, as these people have been "sick for a long time". CFS patients do have a sleep disorder, and this fact has been well documented. Sleep studies can be important documentation as these patients are very disabled. Dr. Bested refers patients to a relaxation centre in Toronto - Dorothy Madget's Clinic.

Independent Medical Examinations set up by Insurance Companies were also discussed by Dr. Bested. She commented that their tests are not designed for CFS patients, and need to be modified. For example, the lifting of weights during these examinations make the patient worse. Concerning I.M.E.'s and F.A.E.'s the family doctor has a right to ask: 1. What is included in the I.M.E./F.A.E.? and 2. What are these tests going to do?

For her patients, Dr. Bested suggests not going beyond daily energy levels, or they will crash. Lifestyle changes are also required. Smoking, alcohol, tea and coffee consumption must be stopped.

Dr. Gerald Ross, originally from Nova Scotia, now works at The Environmental Health Clinic in Dallas, Texas. He considers CFS, FM and MCS "a spectrum". Dr. Ross speaks from first-hand experience as he has CFS and MCS himself.

CFS patients are low in magnesium and nutrient-depleted. They do not regulate body temperature regularly, and their detoxification mechanisms are significantly impaired. Dr. Ross has published a paper entitled "Neurotoxicity in Metabolic Brain Scans of Patients Reporting Chemical Sensitivities".

Dr. Beverly Tomkins runs a CFS/KFM Rehabilitation Clinic in Calgary, Alberta. Dr. Tomkins explained in depth the importance of a proper physical examination for these patients, and also commented there are approximately 200 tender points throughout the body. For an appropriate tender point examination, the examining doctor must clearly say to the patient for each of the 18 tender points, "Does this hurt?". Four kgs. of pressure must be applied, and the doctor must get the correct location of the tender points within 5 mm.

Other symptoms Dr. Tomkins cites are as follows: eyes are dull, sclera - yellow/blue; sinus congestion; chronic allergies; pharynx-pale tissue, red rim (red crescents); tongue pale, coated, fissures, rough; tender cervical lymph nodes; cold extremities; low resting blood pressure; and flax, external jugular veins. 10 minute standing test; globally tender abdomen; possible tender liver, spleen, stomach; voices are flat; memories are poor; difficulties giving detailed histories; and rashes.

Mr. Russell J. Howe of Boland & Howe, Barristers & Solicitors in Aurora, Ontario spoke about Insurance Companies. He is well informed in this area.

Doctors' medical-legal reports should include these points: 1. arrival of the diagnosis; 2. comment on treatment given; 3. identification of findings that give credence to a patients' credibility; 4. have a strong opinion!; 5. estimation of long-term effects of the injury in functional terms; and 6. use doctor's language in terms of function that is understood.

If a doctor is filling out a questionnaire for the insurance company, and feels that a yes/no box is not sufficient information, then the best thing to do is add his/her own comments alongside the box.

Another comment for doctors is to check any in-coming information sent to them as a result of a meeting with an insurance company representative for accuracy in statements before signing the report.

For Independent Medical Examinations, the patient can take a witness with him/her, plus a recording device. (A hand-sized tape recorder can be purchased at Radio Shack etc.). Take notes immediately after the assessment.

LTD. CLAIMS: TWO RECENT BRITISH COLUMBIA COURT DECISIONS - PART II

By: Brad D. S. Garside, Barrister & Solicitor, Vancouver, BC - Tel. (604) 683-1211

EDDIE v. UNUM LIFE INSURANCE COMPANY OF CANADA

"Quite a different result emerged from another British Columbia Supreme Court decision handed down less than three months after the Mathers decision. In Eddie v. Unum the issue to be decided was whether the claimant was disabled due to "injury or sickness".

Ms Eddie claimed she was disabled from continuing to work due to fibromyalgia.

The insurance company had denied the Plaintiff's claim for disability benefits on the basis that there was no "objective" medical evidence to support the Plaintiff's disability, and further, that the condition known as fibromyalgia is not one recognized by medical science.

At trial, the insurance company raised a number of arguments.

First and foremost, the insurer pointed to the report of an "independent medical examiner" retained by them to examine the claimant (an internal medicine specialist). This physician did not think that the Plaintiff had fibromyalgia. He alluded to "psycho-social" factors for the Plaintiff's absence from work. The doctor suggested that the Plaintiff did not want to continue working due to a variety of vague personal problems unrelated to any objective medical condition. This medical examiner was clearly biased and there was no evidence to support his opinions. Accordingly, the court rejected his opinion.

In contrast to Mathers, the trial judge in the Eddie case was impressed by the credibility of the claimant. The judge gave the benefit of the doubt to the claimant on every point raised by the insurance company's lawyer.

For example, Unum argued that the claimant Eddie failed to try hard enough to get back to work due to her obesity and addiction to tobacco. But the trial judge accepted that obesity and tobacco addictions are difficult to solve. The judge refused to penalize the claimant for these reasons.

The judge was impressed by the Plaintiff's work record. He accepted that the claimant was a dedicated, hard-working youth care worker who enjoyed her job and that she did not stop working for reasons unrelated to her fibromyalgia.

When Unum rejected Ms Eddie's application for benefits, the reason given was that the medical documentation did not provide "objective clinical evidence" of disability due to sickness. Unum argued that fibromyalgia was merely a label which did not fit any definition of "sickness" or "illness".

The trial judge rejected Unum's arguments.

First, the judge noted that the Unum insurance policy did not require "objective medical evidence of continuous total disability" in order to establish entitlement to disability benefits under the policy.

Second, the judge entered into an involved discussion of the policy wording, particularly what was meant by the term "sickness". The judge quoted at length from a medical article analyzing the concept of "illness" because he felt it gave expression to what was meant by "illness" and "sickness" in the context of insurance disability claims.

That paper distinguished between illness and disease, concluding that they can exist quite independently of each other. The article said that "illness" relates to the patient's sense of sickness, whereas "disease" has a narrower definition, relating to an objective medical condition that can be determined by scientific medical tests, (i.e., blood tests, x-rays, etc.).

From this, Mr. Justice Fraser concluded that the meaning of "sickness" or "illness" in a disability insurance policy "...includes the condition of a person who genuinely wants to continue in his or her employment but, because of the claimant's perception based on symptoms that something is wrong with his or her body, genuinely and reasonably feels unable to continue working."

The judge noted that this is a subjective test which depends on the credibility of the claimant.

Mr. Justice Fraser stated "...that the fundamental misconception of the insurance company was that it was necessary to be able to identify the cause of a condition before benefits are allowed." He rejected the insurer's approach, saying that "...while insurers may be more comfortable when they have objective medical evidence of disease, it is the fact of sickness, not its explanation or cause, which governs."

Accordingly, the judge concluded that Ms Eddie is disabled due to "sickness" and therefore entitled to disability benefits.

In deciding that Unum wrongly required Ms. Eddie to produce objective clinical evidence supporting her claim, Mr. Justice Fraser awarded additional aggravated damages of $15,000.00 to compensate for the mental distress suffered, in addition to the disability benefits under the policy.

The Eddie v. Unum decision is apparently being appealed by the insurance company.

DISCUSSION

For lawyers, the interesting legal issue posed by Mathers and Eddie is: how to reconcile the trial judges' different approaches as to what evidence is required to prove "total disability" in a case involving subjective conditions where there is little or no objective medical evidence to establish the existence of the condition.

This presents a continual challenge for disability claimants and their lawyers, although the recent Alberta decision in Baie v. Crown Life certainly offers some encouragement. In Baillie, the Alberta Court of Queen's Bench found that chronic fatigue syndrome is an organic disease rather than a psychiatric illness.

Nonetheless, for the most part, medical science has not yet been able to explain the cause of chronic pain conditions like fibromyalgia and chronic fatigue syndrome. Reliable tests have not yet been developed to verify the diagnosis and to assess disability for people with these conditions. These recent British Columbia court decisions demonstrate the difficulties involved in proving that claimants with these conditions have a medical condition, illness, or sickness resulting in disability which prevents them from working.

The courts have often expressed caution in accepting disability and motor vehicle/personal injury claims based on subjective medical conditions in the absence of objective medical evidence. The credibility of the claimant is critical in such cases.

In the Mathers case, the court seemed to have the impression that the claimant was "self-limiting", in the sense that he had made a personal decision to stop working which was not justified by the medical evidence. The court was not willing to allow the claim for LTD benefits based purely on the subjective belief of the Plaintiff that he was in too much pain to work in the absence of objective medical evidence to verify his condition.

By contrast, in Eddie the Court felt that the claimant genuinely wanted to keep working but was unable to do so due to her fibromyalgia condition, even in the absence of objective medical evidence to support the nature and severity of her condition.

The court found that the Plaintiff's subjective feeling that she was too ill to work was sufficient to establish her entitlement to long term disability benefits.

The difference between the two judgments seems to come down to the trial judges' different views of the credibility of the claimants, in terms of their desire to get better and their willingness to return to work.

Courts are generally more impressed by people who are forthright in giving their evidence, by people who are trying their best to rehabilitate, and by claimants who genuinely wish to return to work.

Whatever the British Columbia court of Appeal may eventually have to say about the Eddie decision, future court decisions in disability cases involving claims for fibromyalgia, CFS, and other chronic pain problems will be determined largely according to the trial judge's assessment of the claimant's credibility.

INDEPENDENT MEDICAL EXAMINATION: UPDATE

As you know, we are presently collecting information on people who have gone for an I.M.E. and the results thereof. We have contacted all known ME/FM support groups across Canada so that we may get as much feedback as possible on this important matter. Please contact **Mary Ellen** to send completed questionnaire or to obtain a questionnaire:

The following report outlines how Colorado U.S.A. solved its problems of unfavourable and biased I.M.E. reports. If you have not already done so, please complete the questionnaire concerning the results of your "Independent Medical Examination" or "Functional Abilities Evaluation" and send it to: **Mary Ellen**, **P.O. Box 66172, Town Center Postal Outlet, 1355 Kingston Rd., Pickering, ON L1V 6P7 - Tel. (905) 831-4744 - E-mail: marye@pathcom.com.** You can contact Mary Ellen or our Network if you would like a copy of the questionnaire.

MAKING "INDEPENDENT MEDICAL EXAMS" INDEPENDENT -

By: George V. Rossie, Ph.D., Clinical & Consulting Psychologist, R. Daun Gretzinger - IME Administrators, LLC, Denver, Colorado, U.S.A.

Many insurance claimants complain, perhaps with good reason, that the "Independent Medical Examination" (IMEs) upon which their insurers rely to determine benefits are unfair. Insurance company adjusters typically send claimants to medical examiners who can be counted on to issue reports favorable to the insurer's position. Doctors who routinely side with the company can expect to have an unlimited supply of referrals and can expect an appreciable income flow from their efforts.

In Colorado, the practice of certain insurance companies using just a handful of notoriously biased doctors to perform IMEs in auto accident cases became so predictable that those doctors became known by the not-so-affectionate name, "the 'A' Team." Generally, an "A Team" report did not have to be read for one to know its contents and conclusions precisely. For example, one of the members of the "team", a psychiatrist who also sat on the board of directors of a major insurance company, performed over 200 consecutive auto IMEs in a several-year period, without ever finding a single case of emotional or intellectual problem that he could attribute to the motor vehicle accident. The vast majority of patients were labeled "malingerers", and the rest had "pre-existing psychiatric disorders." In at least one case, this included a young man who had crashed his motorcycle into the side of a truck and lay in a coma for two weeks.

Fed up with such abuse, a grass-roots effort to change the way IMEs in Colorado were conducted for auto accidents sprange to life in 1996. The initial driving force behind the effort was a legislative aide to a state senator who had been in an auto accident, and then "re-victimized" when her insurer sent her for IMEs that determined that she was no longer in need of treatment, despite being unable to resume her legislative duties. With the help of several of her therapists, and with the support of the senator, legislation was drafted and introduced into the state legislature which essentially would have prohibited insurance companies from using IMEs at all to determine benefits in auto cases. Prior to the bill's introduction, the therapists had contacted every other treating provider they knew, encouraging them to write or call their own representatives in support of the measure, and also asking them to alert other professionals and victims of IMEs of the effort and the process. The insurance industry's initial attempts to kill the bill were blocked because by that time legislators from all over the state had been barraged by doctors and patients who wrote or called expressing their support for the need of reform, and the bill was allowed to proceed to the committee stage, where public hearings were scheduled. Now, the organizing therapists began enlisting auto accident patients to show up for the hearings to tell their stories of how they had been treated by their insurers. The response was overwhelming, to the point that one critical hearing had to be moved out of the normally used hearing room into an assembly hall to accommodate the huge crowd. Faced with this massive show of opposition, the insurance industry dropped its outright resistance and agreed to work on compromise legislation which they agreed would "dispel the misperception that the IME process was biased."

The resulting legislation, Senate Bill 96-78, made several important changes to Colorado's No-Fault law. First, a new program was created under the direction of the state insurance commissioner which provides the exclusive mechanism in this state for resolving disputes over the reasonableness, necessity, and relatedness of treatment following motor vehicle accidents. The program (the Personal Injury Protection or 'PIP' Examination Program) makes available a group of licensed health care providers, experienced in the treatment of MVA issues and actively engaged in clinical practice, who have not earned more than half their income or spent more than half their professional time performing IMEs, to examine patients when a dispute with the insurance company arises. A list of five qualified practitioners in the same specialty as the treating doctor whose opinion or bills are disputed is the same specialty as the treating doctor whose opinion or bills are disputed is prepared and within five days of the request, sent to the party disputing the claim (usually the insurance company, but maybe the patient in the case that there was a dispute over an earlier IME). If neither side can agree on one person from the list to conduct the exam, the insurer and the patient each strike two names, and the remaining practitioner performs the exam. The examiner is required to address in a written report the issues in dispute, and the insurer is required to pay the benefits if the examiner agrees with the previous treatment rendered or medical conclusions of the treating doctor. If either party is dissatisfied with the findings, that party may request and pay for a second IME under the same procedures of selection. In this case, the conclusion of two out of the three practitioners (the two examiners and the treating provider) is binding. The examiner must physically examine the patient and review the records, which must be supplied by the insurance company. The patient may augment the records as necessary. The requesting party is obligated to pay the examiner's fees. The whole process is designed to be completed within 45 days of when the insurer initially disputes the claim.

The legislation also allowed the Insurance Commissioner to contract with an outside source to create and run the program. Through the normal state bidding process, IME Administrators, LLC, contracted with the Division of Insurance to administer the program, create the provider registry, process the requests, establish the reporting standards, train the panelists, and prepare the lists of five examiners. To accomplish this, IME Administrators first recruited over 1400 providers in approximately twenty-five specialties, including chiropractors, psysiatrists, orthopedists, surgeons, psychologists, dentists, optometrists, and others, from throughout the state to serve on the panel. A detailed list of biographical and practice information was gathered from each provider, and this data was entered into an automated database which was developed to generate the list of five providers from the country in which the patient resides, in the same specialty as the treating doctor whose care was disputed. The database automatically produces a "dossier" on each of the five candidates, incorporating the extensive educational, business, and personal information already supplied by each recruit, and that information is sent on to the insurer and the patient, to aid them in making the appropriate selection of the best candidate to perform the exam. The automated database "revolves through" all available blocks of five members of the specialty within each county, then randomizes the names and creates new blocks of five, as the demand for exams dictate, so that the same five examiners are not always paired against each other. IME Administrators monitors the flow of the examination process and tabulates the outcome of the exams in terms of conclusions, costs, and time to completion. The proprietary automated database then produces summary reports regarding the utilization of the program.

The PIP Examination Program went into operation on January 1, 1997. By June 30, 1998, over 4600 requests for IMEs had been processed. Approximately 75% of the IMEs completed to that point indicated that the prior treatment rendered or the medical conclusions of the treating provider were reasonable, necessary, and accident related. Approximately 20% found that the care was only partly reasonable, necessary, or accident related, and generally in those cases an apportionment was made. Five percent found that the care was not reasonable, not necessary, or not related to the accident. At the present time, more detailed data analysis is not generally available.

For the most part, the response to the program from patients, attorneys, and treating doctors has been overwhelmingly positive. Insurance company response has been less enthusiastic, but still positive. Major complaints center around their opposition to the "same specialty" review requirement, especially when chiropractors are involved. Most insurers strongly favor allowing M.D.'s, especially psysiatrists and orthopedists, to review any treating doctor's work, regardless of the specialty. Obviously, the other independently licensed practitioners oppose this type of oversight. Also, there have been some complaints of overcharging for the exams, and some unsuccessful efforts to establish a uniform fee for IMEs. Finally, some conflicts have surfaced when the patient has multiple providers from various specialties, and the insurer or the patient doesn't want to pay for or undergo multiple IMEs. Despite this, there is broad consensus that the process is an inherently fair one, and the frequency of suits alleging bad faith breach of contract is reportedly down in the state. To date, there has been virtually no "second guessing" of the IME by patients or attorneys, who could demand a second exam when the results are not in accord with the treating provider's opinion, and almost no cases in which the patient has failed to cooperate with the examiner. Fears that examiners would abuse their discretion by "retaliating" against insurance companies have not been borne out. It would appear that many treating doctors have become more conscientious in their record keeping and their treatment planning, knowing that their work may be evaluated by a competent peer.

IME Administrators, LLC, believes that the process it has created could be successfully exported to many other geopolitical settings and could be applied to any situation in which an insurer requires an independent medical exam, including worker compensation injuries, general medical conditions, or disability cases. The principal rate-limiting factor in its application to other conditions is strictly political. It appears that the process, the technology, and the philosophy for providing truly "independent" IMEs now exist.

(The authors are available for training and consultation, and can be contacted at 4200 West Conejos Place, Suite 111, Denver, Colorado, 80204; tel 303-893-9300 or 303-628-9338; fax 303-893-4384; e-mail gvross19@idt.net)

THOUGHTS ON THE AACFS CONFERENCE IN BOSTON: By: Mary Robinson

This was my first AACFS conference. I am the mother of 2 children with CFIDS, and I volunteer my time to work with Dr. David Bell as a research assistant. I am the editor and one of the co-authors of a book with Dr. Bell titled "A Parent's Guide to CFIDS: becoming an advocate for your child with Chronic Fatigue Immune Dysfunction Syndrome", due out early in 1999, by Haworth Press. I traveled to Boston with Dr. Bell and the staff from his office. It was wonderful to be in the company of these wonderful people whom I admire.

The Research Conference began first thing on Saturday morning. It was amazing to be sitting in a room of hundreds of others who are working on this illness. In a world where we all see so many disbelievers, it was wonderful to be in a place where so many are fighting for a cure. Each presentation offered another view of the cause, another approach to how to deal with this and another opinion about its prevalence. One could quickly see that with so little known in this illness, it is no wonder there is so much disagreement on the etiology of this syndrome. But what was fascinating to hear was the overall agreement that this illness is REAL, and much more prevalent than previously thought. It is not a psychological problem, but a real illness that deserves much more attention than it has been given.

It gave me a sense of belonging to sit in the audience next to so many specialists who I have only known by name up to this point. It was fascinating to hear one after another share their views and their research. Turning my head I would see one or two huddled together in the corner of the room to share private thoughts and notes and it made me feel I could be at the edge of something big. Here were the leading researchers standing next to me excitedly sharing their theories and views. At the very least, it made me see these very special people as a group of very passionate, understanding, gifted professionals who I am proud to have in our corner. I may not agree with everyone's theories on the illness, but I do feel that they are all following their hearts to do what they feel is best for their patients. I know this may be seeing the world through rose-colored glasses, but there was a sense I got from these people that we are all in this together.

My favorite session of the conference was Saturday night. A small discussion group met to discuss Pediatric Issues of this illness. I loved being a part of this conference session where my ideas as a parent were as valued as the leading researchers sitting next to me. While much time was spent discussing the importance of socialization and academics for these children an important point was made about acceptance. If Doctors do not accept this illness, the parents will continue to have problems getting the school to accept it. If medical journals continue to refuse to publish articles related to CFIDS then how are doctors going to see the validity of this illness? As was pointed out, this may continue to be a problem until a discipline claims the illness. If it is not a pediatric illness then pediatric journals will say it is not fit to publish in their journals, if it is not a cardiology problem then that journal will say it is not the place to publish, and so on and so on. As long as it remains an orphan illness with no place to call home, it will have problems being published, and therefore informing the medical community. We agreed that while this is reality it is not an excuse to not publish articles on CFIDS. Doctors in all areas of medicine need to be reading about these studies, and the journals need to stop passing the buck on who should be publishing, and begin educating their readers on this illness and the current research.

Sunday was the day I was looking forward to, as it was the clinician's conference and more my speed. I enjoyed hearing the session on children. Dr. Jim Jones spoke first. He conceded that adolescents do get CFS and "may" benefit from a diagnosis, but not children. In his opinion there are so many other things that could be causing the symptoms that every possible avenue should be tested. He insinuated that children's descriptions can not always be believed. He stated that children are just not old enough to articulate how they are "really" feeling.

I sat there with my nails dug into my palms seething with a picture in my head of my little girl on the couch at home articulating quite clearly how she feels. And it occurred to me that if you have a doctor who is unwilling to diagnose children then these youngsters aren't going to talk clearly about their problems. What child wants to talk to someone who is going to tell then they are really fine? But with a doctor who will listen and believe, as our doctor, Dr. David Bell does, children will learn to describe their symptoms in a way clearer than many adults can articulate.

Dr. Allen Gurwitt, a psychologist spoke next and he stated that in his opinion there was a real problem with children and this illness. Here he is settled in boston and NO ONE there will treat this illness in young people. He has to send children to Dr. Bell or Dr. Lapp. He felt strongly that children with CFS need to be seen by an understanding clinician. Dr. Gurwitt continued on to talk about young people in a very moving way. He told a story of a girl in a High School who wrote to him saying she had been questioned on her need to use a handicapped parking space in the school's parking lot. She had to go before the transportation board to defend her right to use it. She stated that while she usually liked the invisible nature of the illness, because she could hide behind it, on this particular day she wished more than anything to be covered in purple spots, so she would not have to try to explain it to them. She wanted some visual symptom for these disbelievers. Dr. Gurwitt went on to conclude that iin a time when these teenagers want to fit in, to be a part of things, this illness keeps invading that right, and getting in the way, and they have to struggle to be themselves. (I wish I had taped it as his words escape me. All I know is I was leaning forward on my elbows and suddenly my eyes were all teary. I wasn't going to cry in the midst of 100's of people, and then I heard the sniffles of the women next to me and knew I was not alone.) My son was now whom I pictured before me and I vowed to look up Dr. Gurwitt and tell him how much his talk had moved me. (I did!)

Then the sessions moved on to the psychological side, which actually left me laughing. One doctor got up and went on about how every CFS patient he has seen had psychological problems before the onset of CFS. I was going along with what he was saying, not agreeing but following him. This was a sincere approach and he asked people to consider his perspective and not judge him. He said no one wants to even consider or admit this side as it is seen as a weakness somehow. Well, like I said, I didn't agree, but I kept an open mind. Then the next speaker, Dr. Gurwitt, got up and said in all the cases he has seen NONE would fit the criteria for depression or other psychological problems that were there before the onset of CFS. I just laughed to myself and thought who knows anything? It all depends on who you listen to, and no one really knows anything!!

The other sessions were good, but not earth shattering. They talked of treatments, nothing new there really.

Then Sunday evening was the formal banquet. We heard a keynote speaker talk on the similarities of FM and CFS. The night ended with the video presentation of a work in progress "Remember Me" by Kim Snyder. It was a moving, tremendous, video. I had seen it several times before and each time it moves me more.

Monday we had to rise early for our 9:30 AM flight home. We were all exhausted, and HATED to be leaving as the patient conference was just beginning. But at least we were able to come. The experience was one I will not soon forget. I feel more impassioned than ever to fight this illness. I feel honored to work as a volunteer for Dr. David Bell. I feel rejuvenated when counseling parents on the phone about ways to cope with the family, to deal with the schools, and just get through another day. I felt blessed that in this world of uncertainty, I have met people who are fighting for my children, and me and will continue to fight until a cure is found.

[Ed.Note: We are presently developing a website for Youth, and we welcome Ms Kate Anderson, M. Ed. who has joined our team as a Youth Consultant.]

NATIONAL DOCTORS' ROSTER - UPDATE

J.A. SHERKEY, MD, C.C.F.P. - ME/FM diagnosis & Treatment

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NATIONAL LAWYERS' ROSTER - ADDITION

ALLAN BAYDA - ME/FM - free initial consultation

Duchin, Bayda & Kroczynski

Barristers & Solicitors

2515 Victoria Ave.

Regina, SK S4P 0T2

Tel. (306) 355-3131 - Fax (306) 359-3372

E-Mail: abayda@cableregina.com

RUSSELL J. HOWE - ME/FM - 2 hours free initial consultation

Boland Howe

Barristers & Solicitors

14996 Yonge Street

Aurora, ON L4G 1M6

Tel. (905) 841-5717 - Fax (905) 841-7128

U.S. LAWYERS' ROSTER - ADDITION:

CYNTHIS RIXEY SCOTT - ME/FM - Initial Consultation Free

Attorney at Law

Holland & Scott

3515 So. Tamarac

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Tel. (303) 773-3600 Fax (303) 689-9627 E-mail: Cindirixey@aol.com

INTER-GROUP/CONTACT COMMUNICATIONS:

The **BC Coalition for People with Disabilities** is a well-known advocacy organization which has fought and won many causes for Canadians with disabilities. In this month's issue of its newsmagazine, a"TRANSITION", the BCCPD features an article entitled "Research Project Needs People with ME or FM". The article was written by Shelley Hourston. Shelly highlights and explains the illnesses of ME/FM and describes the important research project about insurance companies requesting an independent medical examination which is being conducted by the National ME/FM by our Network.

Its next issue of "TRANSITION" coming out in February 1999 will focus on ME/FM and will also include an update on the I.M.E. Registry. This special ME/FM issue will also include the case study of Mary Ellen who had her disability benefits stopped following an unfavourable I.M.E.

We thank BCCPD for assisting our Network to further our mission of creating more awareness of the experiences of people with ME/FM in Canada.

To subscribe to "TRANSITION", membership is $12.00 per year which includes the newsletter. Please send cheque payable to Transition, c/o BCCPD, 204-456 W. Broadway, Vancouver, BC V5Y 1R3

BOOKS/NEWSLETTERS/REPORTS/VIDEOS ETC.

Policy Directives for CPP Staff re: Medical Determination of Disability under the Canada Pension Plan. (1997 & 1995). Both years are needed for cross-reference purposes (**45 pages**). Please send your request & cheque for **$8.00** payable to **National ME/FM Action Network** to cover photocopying and mailing charges etc.

MAKING CHANGES - By: J.A. Spiegle & R.A. van de Pol (Brookline Publishing 1993) A collection of self-reports that illuminate the changing conditions of the lives of people with disabling conditions and their family members. **$17.96 U.S. plus shipping charges**. To order call: **1-800-686-6049**

MUSCLE PAIN SYNDROMES AND FIBROMYALGIA - Edited by Andrew A. Fisher, MD, PhD. Pressure Algometry for Quantification of Diagnosis and Treatment Outcome - Price: **$39.95.** Published by: The Haworth Medical Press, 10 Alice Street, Binghamton, New York 13904-1580 U.S.A. **Phone: 1-800-HAWORTH - Fax: 1-800-895-0582 - Email: getinfo@haworthpressinc.com**

CFS FAR MORE COMMON THAN AIDS, HIV INFECTION OR LUNG CANCER - By: The CFIDS Association of America (4 pages) - Please send stamped ($0.45) self-addressed envelope to our Network to obtain a copy of these statistics.

OUR WORLD

NAUSEA - Being constantly on a merry-go-round

INSOMNIA: Night yawning non-stop!

'HASTI NOTES' - A QUICK WAY TO SEND A MESSAGE

A package of four different cards was designed for us by Mary Harris of Peterborough, a ME person. The front of the card shows a picture of a turtle and the back of this card contains information on who we are and how to obtain information on ME/FM. **Cost: $4.00 per package**. Contact us for ordering these 'Hasti Notes' and have the satisfaction of helping our organization at the same time .

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WEB: http://www3.sympatico.ca/me-fm.action/

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