



Painting by Beth Politano

# inforME Magazine

InforME Magazine is an informal publication for people concerned with ME, CFS and CFIDS.

(ME: mylagic encephalomyelitis, CFS: chronic fatigue syndrome, CFIDS: chronic fatigue & immune dysfunction syndrome)

Spring 2011

## Inside this edition:

Green Smoothies and a Raw Food Diet.....1

Editor's Letter.....2

Raw Truffles and Fruit Balls .....4

Why Raw Food: The Liver and Nutritional Healing .....4

Sweet Green Rollups ..6

Guai Protocol: A Letter.....7

Changing & Steady ....9

The Guaifenesin Protocol.....9

FM Symptom Map.....14

\*\*Upcoming Events....15

Art Show Poster .....16

## Green Smoothies and a Raw Food Diet

By ZL

My personal green revolution has been all about having a nutritious diet and enjoying it too. While it's been a huge learning curve I've happened upon the right guidance just at the time I've needed it so I've not been too overwhelmed.

Are you wondering how you could start your own journey? I recommend you simply start each day drinking a green smoothie.

We have all heard that we are what we eat. Over the years I've had a growing concern about how our food is processed and what we are putting into our bodies to nourish them. However struggling with fatigue if I don't give food prep a priority then I'm too tired to prepare something healthy and then would graze on what ever was most convenient and not necessarily what was most nutritious. And so the cycle continued...fatigue and unhealthy food choices leading to more fatigue and so on.

I kept hearing: "your body will tell you what it needs". I guess my body's needs kept falling on deaf ears since I continued to fuel myself with foods that only seemed to make me feel worse: bloated, lethargic and gaining weight. Is any of this sounding familiar to you?

It's so overwhelming to sift through all the information out there regarding what is good for you and what to avoid: no sugar, less meat, more fish, watch out for pesticides, don't eat anything white, always eat your breakfast, watch your fats and on and on. What's a chronically fatigued and over whelmed ME person to do? I've discovered green smoothies and I want to tell you about them.

There is a Green Revolution happening and it's all about adding a lot more nutritious food into your diet by consuming leafy greens. Greens contain vitamin B's, iron, dietary fibres and so much more. Drinking green smoothies increases your digestive efficiency, boosts your immune system, helps with your blood sugar management and overall

I have had a dream that I have been pondering in my heart for some time now. I was inspired by my two friends Beth and Nancy. I have been enjoying their art for so long and I was hoping one day that I would be inspired to help show off their talent in some way. I have also discovered the talents of so many of our MEVA members! I had a dream of having an ART SHOW and I shared that dream with Lyrica and Tina. They too were excited about the idea and together we are making this dream a reality! We haven't seen the end of this project and we were hoping that you would give us your support by coming to the opening reception on Friday, March 4th from 6:00-9:30. If you are unable to come, the art will still be hanging on the walls of Serious Coffee in the Cook Street village, for the whole month of March. The details are on the back page, you can't miss them. We hope that you will benefit from this experience because the art show has also been arranged for YOUR enjoyment. I love mingling with our crowd and it is a major bonus for me to be enjoying your company surrounded by art and live entertainment! We have many fabulous works of art, from a collection of artists with an invisible disability. Our goal is to raise awareness about Invisible Disabilities and 30% of all sales will be donated to MEVA and ME/CFS/CFIDS research and education. The three of us feel privileged to be a part of this project.

Last year my pal Deb asked me to meet a friend of hers, who has FM. Deb kept telling me how sick her friend was and that she tried something new and it has changed her life. Keeping in mind that we have all heard this story before, MANY TIMES! I kept putting Deb off and then one day I met this friend and then I met her again and again.

So I decided to give her a chance to tell me her story, thinking this could be published in the InforME Magazine. As it turns out she didn't even want to tell me her story, but decided to any way. When I met her to get details, I found myself, inviting myself, to go along with her to see her doctor. This Dr. happened to practice in L.A. It sounds a bit impulsive doesn't it? Well my husband thought I had lost my mind.:-) I called him at work from Anne's house to tell him what I had learned, that I was going to get better, that I had made an appointment to see this Dr. St. Amand, that the hotel was booked and that we needed to get flights organized for me right away! His answer to me was whoa! Whoa! Whoa! So we talked and I went. It was a great experience, well everything but the projectile vomiting I experienced on the plane and on the first bit of the trip. My new found friend happened to be a nurse, so I was well cared for. This is a really great story, I will have to tell you just how funny and how wonderful it was! The short story is that I had an appointment with Dr. St. Amand. He is wonderful! He and his children also have FM. I have started the Guaifenesin protocol and it is working for me! The purpose of this drug is to reverse all the ME/FM symptoms. It's not a cure but it will improve your life until they find one. Look inside for more details. So much to say, so little paper.

Maybe I will see you at the art show? Maybe I will see you at another function? When ever we meet, it will be my pleasure. My kindest regards to you all!

## InforME Magazine

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### Publication Disclaimer

The purpose of InforME Victoria is to offer a wide variety of information about coping strategies, research issues and possible treatments for ME, CFS and CFIDS. There is yet no agreement in the scientific and medical communities with regard to the causes and optimum treatment for conditions. We make every effort to use only responsible sources but some information may be speculative. We recommend that readers consult with a health professional with regard to their own treatment plan.

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*continued from front page*

reduces your bad food cravings.

Besides being nutritious and easy to digest, the best thing is that green smoothies are so easy to make. You can even make a big batch on a day you are feeling more energetic and it will last you 2 to 3 days. This is a great way to start your day and to keep on a healthy track on those days when you can barely lift a finger in the kitchen.

A green smoothie drink is simply a smoothie made in a blender that has a proportion of 60% fruit to 40% leafy greens. For example my current favourite recipe is one banana, an orange and a handful of frozen blueberries. I add several cups of water a couple of dates and several handfuls of greens.

The combination of fruits to leafy greens is endless. I usually like to have a very ripe banana as one of my fruits. Let your bananas ripen until they have dark spots on them. I then add one other fruit to this such as an orange, blueberries or pineapple. Keep to 2 or 3 varieties at the most.

For the green leafy vegetables I have been using all of the following: chard, kale, beet greens, spinach, romaine lettuce, other lettuce greens and collard greens (these are a new discovery for me and very delicious). With spring approaching I also look forward to adding dandelion greens, miner's lettuce and stinging nettles. These are harvested either in my yard or on walks in the woods.

The most important thing with eating so many greens each day is to make sure you have variety. Plants have their own group of naturally occurring organic substances called alkaloids, which if ingested in excess can be toxic to us. An easy way to avoid this is to simply rotate the greens you are drinking. Keep rotating your selection of leafy greens and you will be just fine.

Using a regular blender works well for starters. It does not get the greens completely smooth so in time you may want to invest in a high-powered blender. That's what I did and have not looked back. My blender has a counter on it

and already I have used it over 1100 times! This has been the best health investment I have ever made. A powerful blender actually breaks down the cell walls of your food so that makes it much easier to digest your foods.

For those of you that have a computer there is a wealth of information out on the Internet by Goggling green smoothies. Here's a website to give you some recipe ideas. <http://www.rawfoodtalk.com/showthread.php?t=54452>

For those of you who don't have access to the net you can rarely go wrong by using 60% ripe fruit and 40% leafy greens. Have fun experimenting.

Once you are enjoying starting each day with a green smoothie the next step to adding more raw food to your diet is simply having a delicious vegetable salad for lunch. For dinner you can eat another salad or sliced raw vegetables before your cooked food. Eating even a little raw vegetables before cooked food boosts your digestion. Another way to add more raw food to your diet is by making each meal 50% raw.

Are you wondering how this has changed my life? Well I'm not expecting this to be a magic bullet but I am giving myself some time to observe the benefits that are happening. For instance I can finally say for the first time in my life I have no food cravings and no bloating after eating. I really enjoy my food now knowing that I am being mindful and making healthy choices. An unexpected result has been that I now love being creative in the kitchen and sharing my healthy meals with family and friends.

Following a 100% raw diet may sound quite drastic to many of you. By having a green smoothie each day is an excellent start and easy way to add more raw and nutritious food into your diet.

Here are two raw treats that are not only very yummy but good for you too. I find they taste better when kept in the freezer. It's a good place to hide them too from others especially if you label them as a science experiment.

## RAW TRUFFLES

... so delicious its hard to believe that they are good for you too!

2 cups raw Macadamia nuts  
1.5 cups Medjool dates pitted and chopped  
¼ cup unsweetened cocoa powder  
(such as Cocoa Camino)  
½ cup goji berries (soaked for an hour or so)  
Salt to taste, anywhere from a pinch to a ½ tsp.  
Vanilla powder, to taste  
(or use extract if you must)  
Maca root powder (Good for supporting the adrenal glands. Can be found at Lifestyle Market  
No change in flavour if you omit this entirely)

Process the nuts first in a food processor until fine but not butter. Then add the rest of the ingredients. Put in the refrigerator for an hour or so. This makes them easier to roll into balls. You can then roll the balls into cocoa powder, grated coconut or some nuts. Try one immediately or put into the freezer for a firmer texture.

## DRIED FRUIT BALLS

...recipe from Nomi Shannon

1 cup dried apricots soaked for 20 min.  
1 cup pitted Medjool dates soaked 20 min  
(reserve the water)  
½ cup dried figs soaked 20 min  
1 cup dry raw almonds, walnuts or pecans  
½ cup unsweetened dried grated coconut

In a food processor process the almonds until fine but not a powder. Gradually add the apricots, dates, figs and coconut. Process until well mixed using 1 to 2 tbsp of date soak water if necessary to create a dough-like consistency. Refrigerate for several hours and then roll into small balls. This makes about 30 pieces. You can keep them in the refrigerator for up to two weeks. I put them in the freezer and found they still had a creamy consistency and were not frozen solid at all. Try adding a bit of raw carob or cocoa powder to make a chocolaty treat.

## WHY RAW FOOD: THE LIVER and NUTRITIONAL HEALING

*By Jen Nemeth*

When I acquired M.E. many years ago I was lucky enough to have a very gifted and prescient physician who used nutritional methods although they were deemed unorthodox - liver detoxification, and Magnesium and Vitamin C infusions.

So when I recently enjoyed a relapse - recurring attenuated flu-like symptoms and irritable bowel - I determined to redress my diet, in particular eliminating wheat, sugar, and dairy.

When I saw a four-week raw food course advertised I felt it was a sign. [www.rawteacher.com/shawnab](http://www.rawteacher.com/shawnab) My first degree was in science and one of my first jobs was in food and nutrition research. I am always keen to learn more. My hopes were pretty modest - to reduce the symptoms of IBS (Irritable Bowel Syndrome). What I did get from a month long course and a raw food liver detoxification regime (and I am still monitoring this because I am so surprised) was relief from irritable bowel, a surprising relief from musculoskeletal pain, clearer skin and increased mental acuity. Oh yes and my nails stopped breaking off and I lost weight too! Because I am frequently asked "Why raw food?" I thought it might be useful to share how I try to explain 'living food' to others. Zosia is covering the practical aspects of raw in another article.

The theory behind consuming raw food is relatively simple. Raw food is more digestible. It delivers more nutrition to the body and allows the liver to heal and cleanse thereby allowing HEALING at a cellular level.

### RAW FOODS ARE LIVE FOODS

Raw foods could more appropriately be called living foods. Technically, raw foods are not heated above 112 degrees and therefore enzymes are not destroyed. A living diet consists of fruits, vegetables, nuts, and seeds, which contain

vitamins, minerals, phytochemicals and enzymes. Enzymes are food's life force. Uncooked plant foods packed with nutrients not destroyed by heat are naturally very nutritious. High levels of enzymes aid digestion and absorption, thereby reducing the load on the liver, allowing it to heal and to detoxify. Moreover, raw food diets typically contain lower levels of trans fats, saturated fats and cholesterol, and higher levels of fiber. All good!

After a heavy meal of cooked food do you feel fatigued, lethargic? This may be due to poor digestion, the excessive use of energy and excessive toxin production

A cooked diet, low in enzymes, can hamper digestion and cause the production of toxic chemicals. In any case, with aging or chronic illness, the body tends to produce fewer enzymes and its stores are depleted. Cooking also leaches out water-soluble vitamins such as C and destroys heat sensitive vitamins.

On the other hand, if the body is not required to supply enzymes for digestion energy is freed for other processes such as healing, cell rejuvenation and fighting foreign invaders. The alkaline PH of raw foods promotes optimal health. Most people with acute or chronic illness have an acidic body.

### POOR DIGESTION AND FOOD SENSITIVITIES

Most common food allergies are actually food sensitivities caused by the protein content in food that the immune system identifies as harmful. Wheat, rye, dairy, eggs, peanuts, shellfish, soy, fish, and pork commonly cause reactions.

When food is poorly digested, large undigested protein particles pass through the gut and enter the bloodstream where they act as allergens prompting allergic reactions as the immune system tries to fight them off. Inflammation ensues. Thus the treatment for a leaky gut syndrome is abstinence from protein rich foods including wheat and milk and their products.

### THE LIVER

Weighing just over 3 pounds, this reddish brown largest gland and largest organ, is fascinating. It is a powerhouse, a complex chemical factory mediating over 500 functions.

My liver processes everything I eat, drink, breathe in or rub on my skin. Working 24/7, it processes food once it has been digested, provides me with energy, fights off infections, disease and toxins, helps cleanse and clot the blood, destroys poisons and drugs including alcohol, controls cholesterol levels, helps rid the body of waste, regulates hormones and much, much more.

Nearly all the blood leaving the stomach and small intestine passes first through the liver to deliver its nutrients. The liver filters this blood and performs many vital nutritional functions. First, enzymes and bile help digest food as one of the liver's first steps in converting food into the building blocks for life and growth and breaking it down to turn it into energy. It processes digested food from the intestine and controls the levels of fats, amino acids and glucose in the blood. It stores iron, vitamins and other essential chemicals. It makes enzymes and proteins too, which are responsible for most chemical reactions such repair of tissue and blood clotting.

Of a myriad of my liver's functions two predominate - producing energy and fighting infections.

#### **Producing quick energy**

One of my liver's most important jobs is breaking down food and converting it into energy when I need it. Carbohydrates are broken down into glucose molecules and stored primarily in the liver and muscles as glycogen. When quick energy is required the liver responds by rapidly converting its store of glycogen back into glucose, ready for the body to use.

#### **Fighting infections**

My liver plays a vital role in fighting infections, particularly those arising in the bowel. It does this by mobilizing part of my body's defense mechanism - the macrophage system. The liver contains over half of the body's supply

of macrophages that literally destroy any bacteria that they come into contact with.

### MY LIVER AND THE FOOD I EAT - FOOD FOR ENERGY

What I eat gives me the energy and material to sustain myself. Food is broken down in my stomach and intestine (gut) into three main nutrients - carbohydrates, fat and protein - absorbed into the bloodstream and carried to my liver.

**Carbohydrates** (sugar and starch) are absorbed through the intestinal lining, transported by blood vessels to the liver, which breaks it down to glucose, a form of sugar used to make energy. The excess glucose is stored as glycogen. Between meals stored glycogen is broken down and released as sugar to prevent hypoglycemia (low blood sugar levels). My liver stores glucose and helps control my blood sugar levels.

**Fat**, which provides the fat-soluble vitamins A, D, E and K and essential fatty acids, can also be used as a long-term energy store.

The production of bile by the liver makes it possible for dietary fat to be absorbed. In addition the fat-soluble vitamins are dependent on bile from the liver for absorption.

### MY LIVER AND THE FOOD I EAT - FOOD FOR REPAIR AND GROWTH

**Protein** is made up of units called amino acids and when these reach the liver they provide building blocks to make cells and tissues throughout the body.

My body carries out millions of chemical reactions every day. To do this it needs a mix of **vitamins and minerals** in addition to the essential nutrients, carbohydrate, fat and protein.

### THE POETRY OF THE LIVER

The poetic, metaphysical and symbolic aspects of the wonderful organ called the liver attract the artist in me. It is very appealing to think of caring for the health of this organ by eating living foods.

Medical terms for the liver often feature ‘hepato’ or ‘hepatic’ originating from the Greek

word for liver ‘hepar.’ The Greeks considered the liver the heart of the emotions, viewing it as the organ closest to divinity and practicing hepatoscopy, investigating the livers of slain animals to predict the success of military campaigns.

In certain Middle Eastern cultures the liver is thought to be the seat of the soul. Thus it may be crooned. “I love you with all my liver!”

The philosopher Rudolph Steiner describes the immune system as that which distinguishes the Self from non-self. For those of us who enjoy metaphysics or Jungian psychology here is much food for thought.

### GOING RAW

It is not easy, no big change is. But it is so interesting. For now, try this yummy snack and see how simple it can be!

#### Sweet Green Roll-Ups!

a.k.a. The Raw Foodies Oh Henry Bar

Spread one of these combos on a lettuce leaf or half of a collard leaf and roll it up:

1. Carob spread (almond butter, carob powder, honey), banana, sunflower seeds, sea salt
2. Tahini, banana, dates, sunflower seeds, sea salt
3. Banana, sunflower seeds, dates, carob sauce (carob powder, maple syrup or honey), sea salt
4. Tahini, sea salt, sunflower seeds, chopped Medjool dates

~ adapted from *Gaia's Living Foods*

### DEFINITIONS -

#### COURTESY OF THE BRITISH LIVER TRUST

Bile – a yellow/green fluid made by the liver to help digest foods containing fat and cholesterol. Carbohydrates – substances that give energy, such as starch (found in bread, rice and potatoes) and sugars (found in fruit, honey and jam).

Enzyme – a substance, usually a protein, produced by the body to help speed up a chemical reaction (which can be measured with liver function tests).

Glucose – a simple sugar and main source of

‘quick’ energy for the body and is the sole source of energy for the brain.

Glycogen – stored in the liver and muscles, glycogen is the way the body stores carbohydrates. It is easily changed back to glucose when the body needs energy

Hepatic – anything relating to the liver.

Nutrient – something that must be eaten in the diet to provide energy or material for growth. Carbohydrates, fats, proteins, minerals and vitamins are all nutrients.

### REFERENCES

[www.britishlivertrust.org.uk](http://www.britishlivertrust.org.uk), [www.liver.ca](http://www.liver.ca)  
[www.rawbc.org](http://www.rawbc.org), [www.vivaraw.rd123.ca](http://www.vivaraw.rd123.ca)

Do you love your liver as much as your liver loves you?



## Guai Protocol: A letter

January 2011

To my fellow FM Sufferer,

Before I tell you my story, I feel compelled to tell you some of the Absolutes of this Protocol. Without following these necessities, you will fail in your recovery, add to your frustration and waste time and money — we have enough of that already! So please, do not even think about trying this Protocol until you KNOW these facts:

1. DO YOUR OWN RESEARCH: READ the books and the website. Learn ALL that this Protocol entails and what it demands of you.

Why? The going can be tough. You **will** go through painful times.

This is **not** a magic pill – if that is what you want – this protocol is NOT for you!

2. There are NO “Million dollar Evidence-based Studies”: and I doubt that there ever will be... Why? Because there are no ‘millions of dollars’ to be made by promoting Guaifenesin: this drug is an old one, and it is cheap! Therefore,

who would be interested in funding expensive studies that will not result in a financial benefit to their investment? Dr St Amand states clearly that he does not personally receive any moneys from this either, other than, his medical practice.

3. And, Here is THE BIG ONE: You MUST NOT use ANY topical products [stuff on your skin], which have Salicylates; including mint toothpaste! Eliminating these products is a HUGE learning curve but is ESSENTIAL to success, and requires HUGE EFFORT.

5. Your course of ‘reversal cycles’ can be heavy and painful.

BUT there are many people who are now enjoying improved Health and Life!... I am one of them... therefore I am happy to tell my story:

For most of my 60 years of life, I have been ‘weaker’, ‘sickly’, prone to infections, with multiple periodic “arthritic type flares”. These ‘life altering’ challenges have cost me my marriage, friendships and my career.

I have the ‘distinction’ of having 8 diagnoses: All of which are under the Chronic Auto-Immune Umbrella. Multiple labels, tests, medications, programs, disappointments, pain, dysfunction and well-intended efforts at good health, litter my history.

The fact that I also had a diagnosis of FM, *well really now*... there is ‘nothing of substance’ which can be done! So my self-care efforts were directed at the more ‘important’ diagnosis – more than enough to keep me busy and ‘spinning’.

Then ‘it’ happened.... April 2010: I met my new neighbour. She had said that she had FM, and chatted about her walk along the beaches of Victoria that morning, for 13 km!?!

I grabbed my pen and paper!

This was the first time I had ever heard of Dr St. Amand and the “Guaifenesin Protocol”.

So my research began. I read and re-read all of the books [ordered from Bolan’s]. Asked questions: Spoke to my ‘Medical Crew’: Felt disbelief, puzzlement and struggled against my medical self over the fact that this protocol had “no scientific evidence.”

I discovered that my pharmacist knew all about it [?], and knew of those who were benefitting! He has spoken with the Pharmacy at Marina Del Rae and he produces the same product [!] Costs about \$80 per three months supply.

My doctor and my physiotherapist also had to start learning of this 'strange new' concept.

My doctor was supportive as "It is a patient's job to research all new 'ideas' that come along". He approved my trying this protocol, and wrote out my prescription! He stated that this medication was "so safe". My Respirologist, who does not support the concept, did feel confident enough in the medication to say, "Sure, give it a try, it can't hurt you!"

My physiotherapist needed no convincing. Each week she has marveled at the change in my body condition. We look forward to our monthly "Mappings" which shows the on-going changes! Then we cheer at the amazing improvement! She now has a family member on the protocol as well.

**But be Warned:** Each person's response to the protocol is unique and there is no way of forecasting how you will react. The Reversal Cycles can hit hard and progress can be slow.

It is interesting to note that those who do NOT have FM, and who take the Guaifenesin, DO NOT show the reactions that we 'FM-ers' get!

I commenced Guaifenesin in June 2010. Expecting great pains and troubles for the next few years.... But....

My reaction is now called "Rapid Responder". I have quickly felt the 'improved energy', and less pain. Although I am still 'cycling' through some painful times as I go through the 'reversals', these are getting less painful and less incapacitating with each re-visit. But during these times I have the encouragement of the "Mapping" which continues to show improvement – I am 'clearing'. Improved Health is happening!

How much? Well my fatigue level, which was crushing before, is now allowing me to do about 2 hours of 'something' each day! I am so enjoying going out for a coffee with a friend! Going to pick up milk, by myself!! The lessening of fatigue is such an improvement ---- it is a wonderful gift.

In September 2010, I went to see the good doctor, Dr St Amand in Marina Del Rae, CA. He is an endocrinologist, who has faced much condemnation by the medical community for his stand on this protocol with "no scientific evidence".

But please note: Dr St Amand has FM himself! As well does his own children and grandchild. No doubt this is what fuels his strength in facing medical rejection! Although there are specialists who now support his work and use it to treat their own patients.

My Best Award for trying this and continuing on? I asked my adult son, who has had a sick mother all of his life, what he thought of this course of treatment... He paused for a while, then quietly said, "I have my Mom back."

So will I continue? You bet!

Does this fix all of my diagnosis? No!

Is it worth a try? What do you have to loose?

Can this hurt you? NO! The drug is safe!

Is this a 'wild ride'? Indeed it is! Your own path, frequency of 'reversals' and speed of response is unknown until you start.

Is being "Sal-Free" a pain? Initially YES! But after you find your array of favourite 'sal-free products', it becomes your new 'normal'.

Is there support? Yes! The books, the monthly newsletters, the online support group, and especially the website.

### ***But, what about that 'Lack of Evidence'?***

.... I just look in the mirror!!!

Here is the website: [www.fibromyalgiatreatment.com](http://www.fibromyalgiatreatment.com) : You will find here all the information required to make your own informed decision. Estevan Pharmacy" 250-598-2517 and Physiotherapist: D Arslan: 250-812-8912

My best wishes to each of you for Courage and Strength in your personal journey.

~Anne

## **Changing and steady** *from THE DAILY MOTIVATOR* by Ralph Marston

For life to move forward, some things must change. For life to have meaning, some things must endure.

It is good to embrace change, because growth, progress and value creation are impossible without it. At the same time, it is wise to be wary and careful with change, for a solid, steady foundation contributes greatly to life.

In fact, new and valuable changes are made possible by the very fact that some things do not change. When the ground beneath your feet holds steady, you can reliably build many new and useful things upon it.

Make the most of the opportunities to change, to grow, to improve, and to move forward into new territory. At the same time, protect and preserve the fundamental, enabling values upon which your life is built.

A successful, fulfilled life is at the same time changing and steady. Understanding what must change and what must not is a key life skill, one that is well worth the time and trouble to develop.

Be ever willing to change some things in life while being reliably able to hold firm in other things. It is a powerful combination that will take you far.



## **The National ME/FM Action Network**....would like to appeal to you for

help in raising funds for the IACFS/ME research and clinical conference that they are hosting September 22nd - 25th, 2011 in Ottawa. This is a four day medical conference with work shops and meetings being lead by expert researchers and professionals. There will also be a one day patient conference on September 22nd

For more information call 613-829-6667 or fax 613-829-8518.

Email: [ag922@ncf.ca](mailto:ag922@ncf.ca) ~ [www.mefmaction.net](http://www.mefmaction.net)

## **The Guaifenesin Protocol** by R. Paul St. Amand, M.D. and Claudia Craig Marek

Fibromyalgia is a legitimate, common entity. It is a cyclic and progressive disease, which affects millions of patients, primarily women, regardless of race. Manifested by multiple symptoms that may initially last only a few days, it eventually progresses to affect multiple areas and bodily systems until patients simply cycle from bad to worse. At present, there are no diagnostic laboratory tests for fibromyalgia. Our recent research paper reported several abnormal cytokines that change during the course of our treatment.<sup>1</sup>

Patients are often referred from one doctor to another, and told that they have *chronic fatigue, systemic candidiasis, myofascial pain, irritable bowel or vulvar pain syndrome*. Too often, physician and patient focus on symptoms and fail to perceive the much larger problem. These dead-end diagnoses result in the treatment of symptoms, which is only partially effective and at the same time ignores the underlying cause and the disease that continues to worsen over time.

The American College of Rheumatology recommends searching for tender points at eighteen predetermined sites on the body to establish a diagnosis of fibromyalgia. However some patients simply have higher pain thresholds so while they complain of body aches or stiffness, they focus mainly on fatigue and cognitive impairments. These so-called Chronic Fatigue Syndrome patients suffer from the same metabolic abnormality. Since pain perception varies greatly, we urge physicians to seek objective evidence instead of the purely subjective response to variably tender points. The confirmation of fibromyalgia is far more secure when using our method of palpation that we call mapping (see page 14).

Fibromyalgia has no set symptoms and many combinations from the following list are interwoven:

**Central Nervous System:** Fatigue, irritability,

nervousness, depression, apathy, listlessness, impaired memory and concentration, anxieties and suicidal thoughts. Insomnia and frequent awakening due to pain result in non-restorative sleep.

**Musculoskeletal:** Pain and generalized morning stiffness could arise from muscles, tendons, ligaments and fascia of the shoulders, neck, entire back, hips, thighs, knees, ankles, feet, inner and outer elbows, wrists, fingers, and chest. Injured or old operative sites are commonly affected. Though fibromyalgia is described as a “non-articular” disease many know better: Joint pains with or without swelling, redness and heat are frequent. The litany includes foot or calf cramps, numbness and tingling of the face or extremities. Irritable Bowel: (Often called leaky gut, spastic colon or mucous colitis). Symptoms include nausea (often brief, repetitive waves), indigestion, gas, bloating, pain, cramps, constipation alternating with diarrhea and sometimes mucous stools.

**Genitourinary:** Common are pungent urine, frequent urination, bladder spasms, burning urination (dysuria) with or without repeated bladder infections and interstitial cystitis. Vulvodynia (vulvar pain syndrome) includes vaginal spasms, irritation of the vaginal lips (vulvitis) or opening (vestibulitis) and painful intercourse (dyspareunia). It typically mimics a yeast infection but without the cottage-cheese discharge. Intense PMS and uterine cramping are common. Symptoms of fibromyalgia are worse premenstrual.

**Dermatological:** Various rashes may appear with or without itching: Hives, red blotches, itchy bumps or blisters, eczema, seborrheic or neurodermatitis, and rosacea. Nails are often brittle and of poor quality and hair falls out prematurely. Strange sensations are common such as cold, heat (especially palms, soles and thighs), crawling, electric vibrations, prickling, super-sensitivity to touch, and flushing that is sometimes accompanied by sweating.

**Head, Eye, Ear, Nose, and Throat:** Headaches (migraines), dizziness, vertigo (spinning) or imbalance; dry eyes as well as itching and

burning with or without sticky or crusty discharge upon awakening; blurred vision; nasal congestion and post-nasal drip; painful, burning tongue, mouth and abnormal tastes (scalded, bad or metallic); ringing in the ears (tinnitus) or lower-pitched sounds; ear and eyeball pain; sensitivity to light, sounds and odors.

**Miscellaneous Symptoms:** Weight gain; low-grade fever; lowered immunity to infections; morning eyelid and hand swelling from fluid retention that gravitates to the lower extremities by evening where it stretches tissues causing the restless leg syndrome.

**Hypoglycemia Syndrome:** This is a separate entity. Thirty percent of female and twenty percent of male fibromyalgics suffer both conditions (fibroglycemia). Symptoms greatly overlap those of fibromyalgia, but sugar craving accompanied by tremors, sweating, anxiety, panic attacks, heart pounding, faintness, and frontal headaches, especially if hunger induced, are solid clues to the diagnosis. *Hypoglycemics must follow a prescribed diet or recovery will not be complete even with the reversal of fibromyalgia.* (See <http://fibromyalgiatreatment.com/hypoglycemia.htm> for more information.)

Trauma, infection or stress can aggravate or tip susceptible individuals into fibromyalgia but are not the basic causes. It is generally accepted now as an inherited disease and preliminary results from our research team at City of Hope support this belief. We have treated family members that spanned three generations including four two-year-olds as well as patients who became symptomatic only in their seventies. This age spread strongly suggests a multi-genetic disease in various combinations. Boys and girls suffer equally before puberty but females predominate (85% to 15%) thereafter. Forty percent of our patients recall “growing pains” in childhood that disappeared during the true growth spurt of puberty. Untreated fibromyalgia ultimately leads to a “tartar of joints” that we recognize as osteoarthritis.

Over forty years ago, one of my patients taking gout medication observed he could peel tartar (calcium phosphate) off his teeth with his

finger nail. This observation indirectly led me to study an unrecognized systemic problem reflected by deposits from the disturbed saliva. We now postulate that a defective metabolism, possibly a kidney enzyme, forces a minuscule retention of phosphate, which gradually accumulates to detrimental levels in many tissues. The excess results in inadequate energy formation (ATP), cellular fatigue and other malfunctions that explain all the symptoms of fibromyalgia. Our physicians’ paper for interested professionals defends that theory can be found here: [http://fibromyalgiatreatment.com/Research\\_Urico.htm](http://fibromyalgiatreatment.com/Research_Urico.htm)

We no longer prescribe gout drugs (uricosurics). We now use **guaifenesin** for fibromyalgia because it has no side effects and is even safe for children. It is marketed for respiratory mucus problems and is available without prescription in various strengths, though some brands may not be effective for fibromyalgia. Currently, we can only advocate three products: the long-acting 600 mg Mucinex also sold by Pro Health under their label, and a 600 mg. tablet compounded by Marina del Rey Pharmacy. Capsules and 400 mg. tablets may be added to boost the basic dose as short acting compounds.

We begin patients with 300 milligrams of long acting guaifenesin twice a day for one week. Feeling distinctly worse suggests adequate dosage and patients remain on that amount. This suffices for only 20 percent of patients; if symptoms do not worsen, we increase to 600 mg. twice daily. Reversal begins for 80 percent of patients at one of these two levels leaving 20 percent who will need more.

During reversal, symptoms are intensified and new ones may be experienced. These are **not** side effects, but signal that reversal is underway. Better hours eventually appear and then cluster into days and finally weeks. The palpable lumps and bumps soften, fragment and gradually clear. Recovery is more rapid than the time it took to develop the illness. Even genetically-slower responders, may clear one year of metabolic debris every few months. Newer lesions clear first and the oldest ones last. The original description

of fibromyalgia as “rheumatism with hard and tender places” has certainly been forgotten. Tender-point examination limited to a few preordained parts of the body has less value than our totally objective body mapping.

The original description of fibromyalgia as “rheumatism with hard and tender places” has certainly been forgotten. Tender-point examination limited to a few preordained parts of the body has less value than our totally objective body mapping. We use our finger pads as though we were trying to iron out underlying tissue and thereby find the swollen places within muscles, tendons and ligaments. We record their location, size and degree of hardness on a body caricature that becomes a baseline for future comparisons. Unless swollen, the purely subjective tender spots are excluded in mapping. Subsequent examinations and patient inputs readily determine drug dosages and sequential disease regression. We hide previous maps until we complete the examination and only then compare them to confirm progress. ***The most important site for confirming the diagnosis and assuring future success is the left thigh. The outside of the quadriceps muscle (Vastus lateralis) and the front part (Rectus femoris) are involved in 100% of adults and clear within the first month upon attaining adequate dosages.***

***Ignoring the following will guarantee treatment failure. All salicylates including aspirin completely block the benefits of guaifenesin for fibromyalgia. This occurs at a kidney site—something well documented with uricosuric gout medications.*** Salicylates are often found in pain medications and exfoliating products. Less appreciated is the fact that all plants manufacture them in quantities that vary with genus and from crop to crop. They are stored in bark, leaves, roots, and seeds where they serve to repair damage or as weapons against soil bacteria and fungi. Salicylates are readily absorbed through the skin and intestine when introduced from medications and supplements including plants oils, gels and extracts. Individual genetics determine ease of blocking but all patients should assume a high

level of susceptibility and take no risks. New or replacement products should be carefully inspected for changes made by manufacturers. Items on Salicylate-free lists should be double checked for accuracy before purchasing.

The following is a partial guide to natural and synthetic salicylates that must be avoided:

**Medications:** (1) Pain products containing salicylate or salicylic acid, for example, aspirin, Salflex, Anacin, Excedrin, Disalcid. (2) Herbal medications such as St. John's Wort, ginkgo biloba, saw palmetto, Echinacea; vitamin supplements with alfalfa, rose hips or bioflavonoids (quercetin, hesperiden, rutin). (3) Wart or callus removers, acne products and dandruff shampoos may contain salicylic acid. (4) Pain creams, balms and lotions such as Ben Gay, Myoflex or Salonpas. (6) Medications such as Pepto Bismol, Asacol, Alka Seltzer or Urised that contain the word salicylate as part of their generic names.

**Cosmetic and Topical Products:** (1) Skin cleansers or exfoliants that use salicylic acid. (2) Hair shampoos, conditioners or sprays with plant extracts or salicylic acid (3) Bubble baths and lotions containing aloe, ginseng, lavender; almond or grape seed oils etc. (5) Sun screens or tanning lotions with aloe, octisalate, homosalate, mexoryl or meradimate. (6) Lipsticks, balms, or medicated topicals with ingredients such as aloe, camphor, menthol, or castor oil. (7) Deodorants with castor oil. (8) Sticky plant juices or saps adhere to the skin while gardening or weeding (Patients should wear waterproof gloves when gardening). (8) Beware of tissues, toilet paper and baby wipes with aloe.

**Shaving Aids:** (1) Shaving creams with aloe, mint, menthol or mentholatum will block. (2) Razors with aloe strips adjacent to the cutting edge deliver salicylates through microscopic cuts. Vitamin E, lanolin, and mineral oil are all acceptable.

**Oral Agents:** (1) Most mouth washes contain mint, wintergreen or salicylate (Listerine). (2) Toothpastes contain salicylates, as well as fresh or artificial mint, often unlisted. Use Cleure toothpastes, the non-mint ones made by Tom's

of Maine or others listed on our website. Baking soda and/or peroxide provide good cleansing and whitening. The non-mint pre-brushing rinses are acceptable as are Cleure Mouthwashes. (3) Use no lozenges, dental floss, breath fresheners or chewing gums with any mint flavor, including menthol, wintergreen, peppermint or spearmint. (Fruit/Cinnamon flavors may mask mint hidden by the stronger flavors.)

PHYSICIANS CANNOT BE EXPECTED TO RECOGNIZE OR KNOW ALL THE INGREDIENTS IN TOPICAL PREPARATIONS. DOCTORS WILL ASSUME GUAIFENESIN HAS FAILED IF PATIENTS DO NOT COMPLETELY PURGE SALICYLATES. ***IT IS YOUR RESPONSIBILITY TO FOLLOW OUR PROTOCOL EXACTLY.***

Dictionaries or online references can help identify ingredients. When calling manufacturers ask for a list to check yourself because often personnel do not realize that plants make salicylates This web site: <http://fibromyalgiatreatment.com/groups.htm>, can connect you to a support group to help with updated safe-product listings and answer questions. FAQs and lists are at: [www.fibromyalgiatreatment.com/board](http://www.fibromyalgiatreatment.com/board).

**No diet is required for fibromyalgia since the liver alters food salicylates.**

Do not use decongestants or cough medicines to get guaifenesin. There are potential side effects from various additives. Single ingredient guaifenesin has no side effects (save rarely mild, but transient nausea) and no known drug interactions. Using it with salicylates causes no ill-effects, it simply negates the drug's effectiveness for fibromyalgia.

Pain medications such as acetaminophen (Tylenol), Ultram, Darvocet-N, Imitrex, non-steroidal drugs such as Advil, and Aleve, will not block guaifenesin.

Our treatment is not for those lacking courage. It calls for patient skills and, hopefully, physician assistance. Remember, reversal of the disease reproduces past symptoms and may cause new or long-forgotten ones to re-surface. The intensity of these early cycles often causes concern during the

initial weeks of treatment. ***Such symptoms are not guaifenesin side effects.*** Patients realize they were getting steadily worse long before starting our protocol despite medicinal Band-Aids used to mask symptoms. We offer hope to those with determination to try once more despite previous failures. This is a highly-effective protocol.

***Important: Do not assume fibromyalgia is the cause of all symptoms.*** When in doubt or confronted with new problems, please consult your personal physician or appropriate specialist.

#### **Addendum:**

• Fibromyalgics with hypoglycemia must follow a low carbohydrate diet as prescribed, or they will not feel better, even when guaifenesin clears the lesions of fibromyalgia. Though ***not mandatory***, fibromyalgics with carbohydrate craving will get a "jump-start" with similar dietary modifications for the first thirty days of treatment. Carbohydrates (sugars and starches) release insulin. This hormone not only induces kidney reabsorption of phosphate but also drives it into various cells and intensifies symptoms. Elimination of the following foods prevents the wide fluctuations of blood sugar that allows a surge in energy and lessens bouts of fatigue.

• *Foods to Avoid Strictly: All alcohol, dried fruits, fruit juice, baked beans, refried beans, lima beans, barley, black-eyed peas (cowpeas), lentils, garbanzos, rice, bananas, pasta (all types), flour tortillas as in burritos, tamales, corn, potatoes, sweeteners of any kind including dextrose, glucose, hexitol, maltose, sucrose, honey, fructose, corn syrup, starch. Caffeine and alcohol are permitted for those without hypoglycemia.*

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#### **Other Information:**

• This is not the full bibliography in support of

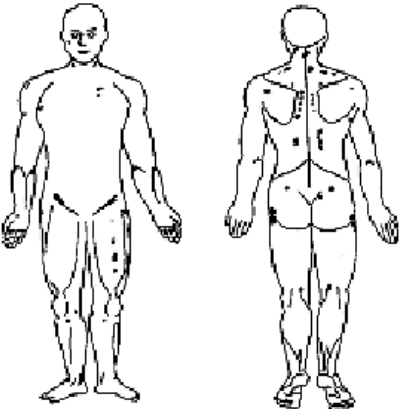
our theory. (Interested physicians may contact us for a theoretical, more technical, paper or consult the Technical Appendix of our book)

- Online Guaifenesin Support group: <http://www.fibromyalgiatreatment.com/newsgroup.htm>
- Cleure Salicylate Free Products. A full line of dental, personal and medicinal products: [www.myfibrosmile.com/ftc](http://www.myfibrosmile.com/ftc) or (888) 883-4276. All purchases benefit The Fibromyalgia Treatment Center
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- St. Amand, MD, R. Paul and Marek, Claudia: A Description of Fibromyalgia and Hypoglycemia: Their Combined Morbidity and Therapy with Guaifenesin and Diet. AAEM Symposium Syllabus, 1998.
- "What Your Doctor May Not Tell You About Fibromyalgia" (ISBN 0-446-675-121),
- "What Your Doctor May Not Tell You About Pediatric Fibromyalgia" (ISBN 0-7595-5002-6),
- "What Your Doctor May Not Tell You About Fibromyalgia Fatigue" (ISBN 0-466-67730-2) by R. Paul St. Amand, M.D. and Claudia Craig Marek, all published by Warner Books.
- "Fibromyalgia: The First Year. A Patient Expert Walks You Through Everything You Need to Learn and Do" by Claudia Craig Marek. ISBN 1-56924-521-5 published by Avalon Books.

- All are available in bookstores, online booksellers and from the website below.
- *DVD* of Dr. St. Amand's method for diagnosis, treatment, and mapping is available from The Fibromyalgia Treatment Center P.O. Box 64339 LA, CA. 90064 for \$25.00 including shipping and handling. Copies of this paper and others available free of charge.

R. Paul St. Amand, M.D. Assistant Clinical Professor Medicine Endocrinology--Harbor-UCLA  
and Claudia Craig Marek Medical Assistant fmsnurse@aol.com

PATIENT: \_\_\_\_\_ DATE: \_\_\_\_\_



**FM Symptom Body Map**  
(not exactly as shown - altered to fit space)  
<http://fibromyalgiatreatment.com>

fatigue	hunger tremors	eye irritation	bloating	itching
irritability	palpitations	nasal congestion	constipation	rashes
nervousness	panic attacks	abnormal tastes	diarrhea,	sensitivities
depression	frontal headaches	a)bad	dysuria	a)chemical
insomnia	occipital headaches	b)metallic	pungent urine	b)light
impaired concentration	general headaches	ringing in ears	bladder infections	c)sounds
impaired memory	dizziness	numbness	vulvodynia	d)odor
anxiety	a)vertical	restless legs	weight changes	allergies
salt craving	b)imbalance	leg cramps	brittle nails	growing pains
sugar craving	c)faintness	nausea	bruising	pain
sweating	Blurred vision	gas	skin sensations	

## UPCOMING EVENTS!

The **MEVA AGM** will be held on **April 27th**  
1908 Stanley Ave. at 2:00 pm  
All members are welcome.



You are welcome, to join us in June for a lovely  
**Garden Party**

The setting is peaceful, the flowers are beautiful and  
the people are wonderful.

This is a good place to tell your stories and ask your questions.



The date has not been set for our  
June event yet.

For more information please go to  
**members.shaw.ca/me.victoria**

Or you can find us at our  
**NEW WEB SITE**

**me-cfsvictoria.org**

the site is not complete, but it will  
be soon!

You can also call 250-370-2884

Friends and snacks to share are  
welcome at all events.

I decided  
not to have bad days  
anymore.  
Just good days and  
recovery days.  
~Lorraine



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M.E. Victoria Association

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**Sculpture · Collage · Photography**

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[me.victoria@shaw.ca](mailto:me.victoria@shaw.ca)