



WINTER GREETINGS! Here's our schedule for January 2003 through July 2003. Mark your calendars!

Jan 18 A time of sharing hope, health and healing, led by **Sandy Ryan**, support group member; *Business meeting at 9 a.m.*

Feb 15 **Carol Veldhuizen**, Staple & Spice Market, on "Aromatherapy"

Mar 15 To be announced

Apr 19 **Pam Barickman**, MS, LPC, on "Turning Misfortunes into Opportunities for Growth"
Business meeting at 9 a.m.

May 17 **Gail Bernard, MD**, Ophthalmologist, on "Learning How the Eyes are Affected by CFS/FMS"

Jun 21 To be announced

Jul 19 To be announced
Business meeting at 9 a.m.

The Paradox of Looking Good, but Feeling Bad

Written by Sherri L. Connell, BA
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www.InvisibleDisabilities.com

Surprisingly, more than 125 million Americans have at least one chronic condition. Nearly half have more than one. An illness or injury is considered chronic when it lasts a year or longer, limits activity and may require ongoing care.

Not everyone with a chronic illness has the same symptoms or degree of symptoms. Some have mild complications and with a little adjustment in their diets or schedules, they can lead a pretty "normal" life. Some have to make bigger changes, sacrificing various activities or their work situations in order to contend with their conditions. Others become so ill they are unable to work at all and struggle just to meet life's daily needs.

Just about every one of us has experienced being so sick we had to stay home from work or school because we were too sick to go. We hate being sick, because the time ticks by, the work piles up and we cannot do anything about it. We gripe and moan that we "don't have time to be sick!" even when it has only been a few hours. It is just plain miserable to be sick, in pain and debilitated - *nobody* enjoys it.

Often when we come across someone who says they have been sick and in pain for a long time, we might think they are either *exaggerating* or they are not *doing* something about it. After all, when we got sick, we got some rest, took some medication

and were soon back on our feet. Moreover, when we were sick, we were pale and droopy, but they often look "perfectly normal."

The truth is, most chronic conditions cannot be seen with the naked eye, but nevertheless are persistently keeping the person from enjoying life the way they once knew. For instance, a person can battle *extreme* fatigue, even though they may appear *healthy* and *well*. Just the same, a person can have spinal damage and *excruciating pain*, despite the fact that to the onlooker they may look *strong* and *able*.

The biggest grievance those with chronic conditions have is that their loved ones often do not *believe* what they are going through is *real*, because to others they "*look good*." Sadly, this makes the person feel as if they are being called a *liar* or a *wimp*. This can cause great strains on relationships between friends, family members and spouses. Ironically, those with chronic conditions would like nothing more than to gain complete control of their lives and not have to adjust to any limitations at all! Nonetheless, their bodies do not always cooperate with their *desires*, no matter how much they *want* it to.

Regrettably, a *travesty* occurs when the person not only has to contend with no longer being able to do what they *love* to do, but also has to *battle* for their loved one's *belief*, *respect* and *understanding*. While the person with the illness/pain is *mourning* their loss of *ability* and *freedom*, others often *accuse* them of just being *lazy* or *malingering*.

We must resist the temptation to make a *visual diagnosis* by coming to the conclusion that our

loved one must be *embellishing* their situation or trying to *pull the wool over our eyes*, because to us they “*look fine.*” After all, when we rebut what they are telling us with, “But you *LOOK* good,” our friend really hears, “But, I don’t *believe* you, because I can’t *see* it.”

Frankly, it is *impossible* for us to be compassionate, until we have *acknowledged* there is a situation for which to *be* compassionate! In other words, how can we say, “I am *sorry* you are sick,” when we are always saying, “I do not *believe* you are sick, because you don’t *look* sick!”

People with chronic conditions do not want to give up! They make efforts to laugh, smile, look their best and enjoy life, even though they know they will pay dearly for it. Because of this, we should not confuse their endeavors to *live life and be positive* with assuming they are *feeling well or doing better*. Instead, let us commend them for their incredible *courage, perseverance and persistence* that make their painful disabilities *seem invisible to us*.

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The previous article contains excerpts from the 44+ page booklet, "But You LOOK Good: A Guide to Understanding and Encouraging People with Chronic, Debilitating Illness and Pain!" written by Sherri L. Connell.

To order this booklet, please send \$3.75 each (includes postage from the US). Discounts are available for 3 or more. Make the check payable to W. Connell. Send to: IDA, 41553 Madrid Dr., Parker, CO 80138 USA. Visit IDA's website for links, support, articles and ordering information at www.InvisibleDisabilities.com!

Black Hills CFS/FMS Support Group welcomes your comments, suggestions, and ideas about our newsletter. To submit an article or other talent (artwork, poetry, etc.) to be considered for publication in our newsletter or to be added or taken off our mailing list, contact Alice James, Newsletter Editor, Black Hills CFS/FMS Support Group, 118 E. Texas Street, Rapid City, SD 57701, (605) 343-2293 or amjam5678@juno.com.



Aromatherapy can promote psychological and physical well-being

Aromatherapy is the practice of using volatile plant oils, including [essential oils](#), for psychological and physical well-being. Essential oils are liquids obtained from plants which evaporate at room temperature with characteristic aromas. They are also called "volatile oils" because of this ability to evaporate readily.

Pure essential oils are [blended](#) for harmonious, combined effect and fragrance. Skillful blending balances the therapeutic effect and aromatic quality of individual essential oils to promote calmness, emotional and hormonal balance, stress relief, rejuvenation, etc.

Aromatherapy works this way. The scent of essential oils is conveyed by the olfactory nerve to areas of the brain that can influence emotions and hormonal response. When used in a bath or massage, the oils are absorbed through the skin and carried by body fluids to the main body systems; such as the nervous and muscular systems for a healing effect.

Although aromatherapy is reputed to be at least 6000 years old, it wasn't until the 19th century that scientists in Europe and Great Britain began researching the effects of essential oils. In a recent editorial in *The British Medical Journal*, researcher Alistair Burns, a professor of psychiatry at the University of Manchester, and his colleagues said three trials done in the past year have shown the benefit of aromatherapy, particularly the use of lemon balm and lavender oil, for dementia patients. The oils contain compounds that are absorbed into the body and seem to improve some of the symptoms of the illness.

Learn more about aromatherapy and how it may benefit those with CFS/FMS at our February 15th meeting. Carol Veldhuizen, Staple & Spice Market, will be our guest speaker. This meeting may not be suitable for those with symptoms of Multiple Chemical Sensitivities because of the fragrances.

Life is not measured by the number of breaths we take, but by the moments that take our breath away.



CFS/FMS Web Corner

IMPORTANT! Before putting to personal use any health advice you find on the web, discuss it with your health care provider.

The Oregon Fibromyalgia Foundation's web site has lots of helpful information on Fibromyalgia. Visit their site at www.myalgia.com.

Visit Black Hills CFS/FMS Support Group's web site at <http://members.tripod.com/bh.cfs-fms/>. Look for the  symbol for new information.

Full body scans are popular right now, but not all doctors recommend that a healthy person have one. Ads say these powerful x-rays can reveal cancer, heart disease and other potential killers before symptoms appear. To learn more about CT scans, check the FDA's Center for Devices and Radiological Health at www.fda.gov/cdrh/ct or call 800 638-2041, ext. 141 or the American College of Radiology and Radiological Society of North America at www.radiologyinfo.org/content/ct_of_the_body.htm.

FAST HEALTH, an interactive healthcare site, has a lot of medical resources, an encyclopedia, a medical dictionary, drug search, nurse assistant, etc. Go to: http://www.fasthealth.com/index_fh.php.

CF Pen Pal Alliance brings those with CFS/ME/FMS together

The CF Pen Pal Alliance is designed specifically for Chronic Fatigue Syndrome, ME and Fibromyalgia sufferers of all ages, as well as their spouses, caregivers, children and siblings. All information is kept strictly confidential and pen pals are matched by age, gender and interests.

The CF Pen Pal Alliance was started five years ago and today they have over six hundred members worldwide! Many supportive and enriching friendships have been made through this free, international pen pal program.

Mail completed pen pal applications with a self-addressed stamped envelope to: CF Pen Pal Alliance, P.O. Box 9204, Bardonia, NY 10954. You can print the pen pal application from the Fun Wishes web site at: www.FunWishes.com. Click on Pen Pal Application.

You know you have CFIDS/FMS when...

....you look in the freezer to find your roll of scotch tape. Toni Larsen

....you notice you have two estrogen patches on and you have no idea which is the new one. Toni Larsen

....you open the microwave in the morning and find the ice cream container fully melted -- twice! Pam

....you put on your jeans backwards and wonder why they don't fit right. Toni Larsen

....your husband suggests you go for a brisk walk every morning and you'd like to hit him with a baseball bat. Sandy Meyer

Black Hills CFS/FMS Support Group Officers

Alice M. James, President
Jan Traupel, Vice President
Joyce Jobgen, Secretary
Kathryn Fullington, Treasurer

Board of Directors

Elaine Dodson	Neil Dodson
Kathryn Fullington	Alice M. James
Joyce Jobgen	Donna Martin
Connie Pich	Jan Traupel

Art group update



Rapid City artists paint at the Ben Franklin store in Baken Park on Thursday afternoons at 1 p.m. The group continues to paint boxes for the Memory Box Program (the boxes are given out by hospitals to parents who have experienced the death of an infant child). Call Pam Cranfill at (605) 348-7309 for more information about the Rapid City art group or the Memory Box Program sponsored by the Black Hills Area Decorative Artists (BHADA).

The Spearfish group meets on Wednesdays at 1 p.m. Contact Bonnie Ellingsen, (605) 722-3818, if you'd like to be part of the fun in Spearfish.

Did You Know

You can make a difference. If you would like to make a donation in memory or honor of a loved one or friend, Black Hills CFS/FMS Support Group will send an appropriate card to the honored one or to the family of the deceased, acknowledging your donation. Contact Kathryn Fullington, treasurer, 1702 East Highway 44, Lot #104 Rapid City, SD 57703-2210, at kitfull@juno.com or (605) 399-2597.

Our support group is soliciting old computer equipment. We need mice, speakers, printers, printer cables, sound cards, etc. Even if the equipment is "broken", we may be able to fix it. We rebuild, test, and sign them out to support group members who are willing to do occasional volunteer work (we have one ready now). If you are in need of a computer or have equipment to donate, contact Alice at (605) 343-2293 or amjam5678@juno.com. Your donation can be used as a tax deduction – we are a non-profit organization.

Deborah A. Barrett, Ph.D., of Immune Support, writes, "being understood, particularly by someone who shares our experience (CFS/FMS), creates a feeling of camaraderie. You do not have to explain in any detail to produce an accurate picture or evoke an appropriate response. To be understood is to be validated."

South Dakota Parent Connection (SDPC), has opened a branch office in Rapid City at 150 Knollwood Drive. SDPC is a non-profit organization providing information, training and resources, linking families, and assisting parents of children with disabilities or special needs throughout the South Dakota. Contact them at (605) 348-0305 or toll-free 1-800-44-1810.

Senior citizens (60 and older) in SD and the surrounding states now have access to a **free** "Elder Law Hotline" to provide answers to their legal questions. Michael Myers, Professor of Health and Elder Law at the USD School of Law and the USD School of Business, staffs the hotline. Voice mail is available at (605) 677-6343 or questions may be sent via e-mail to mmyers@usd.edu. You can also mail your questions to him at: USD School of Law, 414 E. Clark St, Vermillion, SD 57069.

If you had trouble voting in the recent elections in South Dakota, please call SD Advocacy Services at 1-800-658-4782. They are interested in your story.

According to the National Institute of Neurological Disorders and Stroke, 40 million Americans each year visit a doctor for chronic pain. Headache and back pain top the list of chronic pain conditions. Others include arthritis, temporomandibular joint pain (TMJ), vulvar pain, trigeminal neuralgia, and fibromyalgia.

Thanks to Kathryn Fullington, Pam Cranfill, and Elaine Dodson for proofreading the newsletter.

DISCLAIMER: The information contained in this newsletter is intended to provide education and assist those with CFS/FMS in making informed decisions about their health. BH CFS/FMS Support Group does not endorse or recommend any product or form of medical treatment. We advise that you consult with your health care professional for all health-related issues and treatments. Black Hills CFS/FMS Support Group assumes no responsibility for any treatment undertaken by readers.

New support groups forming

More support groups are forming across SD and surrounding areas every year. We've been contacted by four individuals regarding starting support groups. We are pleased that we can be of assistance. If you live in their area, please contact them through:

Belva Liggett
718 West 6th Street
Winner, SD 57580
(605) 840-1786
doubled@gwtc.net

Allison Osborne
103 E. Walnut, #78
Gillette, WY 82718
(307) 685-1430
Just forming

Sharon Zimmerschied
Spearfish, SD
(605) 722-3371
szimmers@dtgnet.com
Just forming

Nancy Patch
2216 Bridge Street
Miles City, MT 59301
(406) 232-5456
patchy@midrivers.com

The Miles City group meets the 2nd Sat. of each month from 1:30 to 3 p.m. at the 1st United Methodist Church. You may also contact Rev. Briggs, (406) 232-3502.

The Spearfish group's first meeting is Saturday, Jan 25th at 10 a.m. at Behavioral Management Systems office at 1340 10th St., Spearfish.

Symptoms of CFS/FMS include visual and/or ocular disturbances

We don't often hear about visual and/or ocular disturbances when we talk about the symptoms of Chronic Fatigue Syndrome/Fibromyalgia Syndrome, but they do exist.

According to an article written by Lesley J. Vedelago, O.D., appearing in the CFIDS Assoc. of America's web site (<http://www.cfids.org>), visual symptoms typically encountered in a study of 141 CFS patients include:

- ◆ Blurred or foggy distance and/or near vision. Blur tends to fluctuate according to the state of the fatigue at the time.
- ◆ Difficulty focusing from distance to near and/or near to distance.
- ◆ Slowness or inability to focus on objects, particularly at near.
- ◆ Difficulty tracking lines of print. Patients seem confused and distracted by the lines of print above and below where they are reading.
- ◆ Poor short-term memory and concentration (generally) with reading being markedly affected.
- ◆ Diplopia or ghosting of images
- ◆ Problems with peripheral vision, patients complain of not seeing objects in their side vision and of continually bumping into things and veering. Some say they feel like they have tunnel vision.
- ◆ Misjudging distances, clumsiness, poor balance and coordination. Difficulty driving due to problems judging distances.
- ◆ Dizziness and inability to tolerate looking at moving objects.
- ◆ Spots, flashes of light, floaters and halos.
- ◆ Intolerance to light (glare)
- ◆ Grittiness, burning, dryness or itchiness. Patients complain of sore eyes usually becoming worse as the day progresses.
- ◆ Headaches often increasing when reading, concentrating visually and driving.

Dr. Vedelago recommended utilizing the following treatment options:

- ◆ Best subjective correction for distance and near. Patients respond favorably to low power reading glasses at near.

- ◆ Prisms ground into prescription lenses. Base-in prisms, where the thickest part is placed nearest to the nose, often provides immediate relief. This is particularly true for near vision, but base-in prisms can also greatly reduce the severity of visuo-spatial symptoms, sometimes completely. Patients generally report things look brighter, they can see more, concentrate better, and neck pain and tension, including headaches, have been relieved. They often say the foggy or cloudy feeling in their head has gone and that they can read for longer periods. Yoked prisms, where the base ends of the prisms are placed in the same position for each eye, can also produce dramatic changes in some patients.

- ◆ Progressive lenses are my choice for patients with CFS. I use them as supportive lenses to reduce the effort of focusing from distance to near, providing progressive clear vision.

- ◆ Tints are regularly used because of the increased sensitivity to light.

- ◆ Ocular lubrication therapy is often needed to treat the dry eye problem and symptoms, and to eliminate the corneal staining. Warm compresses may also provide some relief. Many of these patients have significant allergy problems and I will also offer advice on relief of allergic symptoms.

◆◆◆◆◆

Members of Black Hills CFS/FMS Support Group have reported the following ocular/visual symptoms:

- ◆ My doctor has rechecked my eyes and doesn't know why I can't get used to my new prescription. I told him it was probably from my FM, tight muscles and my body not adapting to any changes very well at all. He didn't know what to tell me. Renee

- ◆ I have also been having problems with my eyes. I just don't feel like I can see well. Sometimes I even take my glasses off for close work and it seems better than with them on. I have had these glasses for over a year and never have gotten used to the "no line" trifocal. Janice

- ◆ My eyesight varies from day to day. I finally just decided to wear my glasses when I couldn't see

and the rest of the time I go without. Sometimes it is pretty good and then I will have a time when even my glasses don't help much. Joyce

♦I have trouble with my eyes changing all the time, and I think it has to do with tightness in my neck muscles. Zak

♦I know that a year or so after I was diagnosed with FM, I had to have prism added to my glasses prescription. I am able to wear contacts and get by without the prism, but not with my glasses. Before the prism, it was impossible to focus; I felt like I had no control over my eyes no matter how hard I tried. After the prism, it was like a miracle. Just an experience of mine - may not apply to anyone else. Michelle

♦I feel like I'm looking through water a lot of the time or through a film. Also, I have a hard time focusing. Mine isn't just upon waking, it's most of the time and gets much worse when I'm tired. My eyes don't seem to want to work together. I do have prisms on my lenses for that problem. The vision thing is really hard to describe. Elaine

♦I have eye problems now and it seems to be getting worse, along with blurred vision. Jan



In an article entitled *Eye Problems in ME/CFS*, Dr. Anne MacIntyre stated, "The causes of the problems may be in the eyes themselves, or in the function of the eye muscles, or from malfunctions in the brain. The abnormal easy fatigability of muscles and brain that is typical of ME/CFS may also apply to using the eyes and interpreting visual stimuli."

Dr. MacIntyre included sensitivity to light and visual patterns as also being a problem for those with ME/CFS. She noted that these problems may not always come from the eyes themselves but from some altered perception by the part of the brain that registers what we see. This is the visual cortex, which is part of the surface area of the occipital lobes at the back of the brain. Light and images may be perceived as too bright or too confused by people with ME/CFS, e.g., moving shiny lines on the steps of escalators or moving images on TV screens are a problem for many people.

Another reason for oversensitivity to light may be that when a bright light shines in the eye there is

normally a rapid contraction of the pupil to reduce the amount of light entering the eye. In ME/CFS, the light reflex may be delayed, or inadequate, due to faulty brain circuits or to weakness of the pupil constricting muscle in the iris.



Gail Bernard, M.D., Ophthalmologist with the Rapid City Medical Center, will be our May 17th guest speaker.



A Winter's Storm

by Helen Long

The icy wind blows across
the plains.
making the temperature seem

much colder than it is.

Driving on the highway is much like a skating rink
as the tires slip and slide on the icy road.

Visibility is only a few feet at best,
as blinding snow covers the windshield,
the headlights making the snow seem brighter.

It puts nerves and courage to the test.

As the north wind blows the snowbanks grow higher
and soon rocks and curbs are hidden from view,
making our way ever more hazardous.

The only sounds are the wail of the wind
and the squeak of the wiper blades
as they try to clear the window of the snow.

Up ahead the red of tail lights come into view,
giving a sigh of relief, you know someone's ahead
of you.

Traveling on at a snail's pace
tonight you have no desire to race.

Soon you arrive at your home,
you send up a prayer of thanks,
since you did not journey alone.

You can relax now with nothing to fear,
knowing that tomorrow you'll have sidewalks to clear.

Note: Helen, a member of our support group for five years, was recently able to return to work as an office manager at Life Without Boundaries and feels great. She feels her job has helped improve her quality of life. She is also director of a non-profit program for parents of troubled teens. Her hobbies include writing, helping others and reading. She and Delbert have been married for 18 years and have a 21-year old son, Patrick.