

Other Helpful ideas for wherever you live:

TROUBLE SLEEPING?

Contact your primary care doctor for a script for an air mattress to help with controlling subluxations at night.

CONSIDER SLEEPING GROUNDED

<http://www.earthing.com/Default.asp>

Throughout history humans walked barefoot and slept on the ground. But modern lifestyle, including the widespread use of insulative rubber- or plastic-soled shoes, has disconnected us from the Earth's energy and, of course, we no longer sleep on the ground. Fascinating new research has raised the possibility that this disconnect may actually contribute to chronic pain, fatigue, and poor sleep that plague so many people.

The remedy for the disconnect is simple. Walk barefoot outdoors whenever possible and/or sleep, work, or relax indoors in contact with conductive sheets or mats that transfer the energy to your body. People who do on a regular basis say they sleep better, feel better, and have more energy during the day. This simple practice is called Earthing, also known as grounding, and it is both a technology and a movement which is transforming lives across the planet.

Earthing is safe and natural, for people of all ages, young and old, but it is not medicine or a substitute for medical treatment. If you have a medical condition, see your physician or healthcare provider.

HOW TO EXPERIENCE EARTHING...NOW

Go barefoot outside for a half-hour and see what a difference it makes on your pain or stress level. Sit, stand, or walk on grass, sand, dirt, or concrete. These are all conductive surfaces from which your body can draw the Earth's energy. Wood, asphalt, and vinyl won't work. They are not conductive surfaces. Experience for yourself the healing energy of the Earth at work.

HOW I CURED MY POTS:

VECTTOR TREATMENTS – used 1-2 X's daily

Dr Donald A. Rhodes
South Texas Innovative Medicine
5833 Spohn Drive; Suite 401
Corpus Christi, TX 78414
361-992-9432; FAX 361-992-3978
cell: 361-438-8181; paindefeat.com

Feel free to contact ellen and stu smith (401-474-0115) who are both using the treatment with success. It provides circulation and calmness to the body, which in turns helps the body help itself. Through the use of the machine, you potentially can eliminate opiates and other medications while living with the pain your condition produces.

DNA DRUG SENSITIVITY TESTING –

IF YOU LIVE WITH DRUG Sensitivities – consider this test – you will know for the rest of your life what your body can metabolize.what you need to know about personalized prescribing

800-TEST-DNA ; 800-837-8362 or visit online at www.HealthandDNA.com

GeneMedRX can help you minimize the risk of adverse drug reactions

(ADRS). ADRS are the fourth to sixth greatest killer in the U.S. with more that 100,000 deaths per year. These are not errors; they occur within the FDA-approved dosage and labeling recommendations. Many may be preventable if potential drug-drug and drug-gene interaction risks

are better considered.

YouScript.com offers genetic testing for medication metabolism.

The results tell you which drugs you can and can't metabolise well.

Too slow metabolism of drugs can result in severe side-effects, and, in worst case scenarios, medication overdose.

It is covered by Medicare, and many other forms of insurance.

If not covered, it costs \$1,000. So, contact your insurance company.

NOTE: They offer payment help programs for low income patients!

Step 1: Go to their website at <http://YouScript.com>.

Step 2: CLICK ON "For Patients" on the TOP LEFT.

Step 3: CLICK ON "Talk to your Doctor"

Step 4: CLICK ON & PRINT "YouScript Prescription Request"

Step 5: Have your PCP (or other doctor) fill out this form

Step 6: Mail the form back to YouScript

Step 7: Receive your TEST KIT & SWAB YOUR CHEEK

(NOTE: Swab 1st thing in the morning, before you eat or drink)

Step 8: Mail your swabs back to YouScript & wait for your results

RESEARCH STUDY ON EHLERS DANLOS

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Camp for Kids!

We Finally Did It!!!

The Coalition Against Pediatric Pain (TCAPP), RSDSA, and the US Pain Foundation have partnered with The Center for Courageous Kids in Kentucky and have pooled all of our resources to create a camp for kids in pain. This will be a family camp that will take place at The Center for Courageous Kids in Scottsville, Kentucky from July 14-17th and is free of charge. It will be a time for families and kids that deal with daily pain to kick up their heels and have fun in a safe, accepting environment!

To learn more about the camp location and what they have to offer, please visit The Center for Courageous Kids website at: <http://www.thecenterforcourageouskids.org>.

To apply for the pediatric pain family camp, please follow the following steps: step One: Complete the Application On-Line By Clicking Here: [Pediatric Pain Online Camp Application](#)

Step Two: Print Out the Application, Sign It, Have your Physician Sign It and mail it in to The Center for Courageous Kids.

Other Option: To print out the application and fill it out by hand, click here:

[Printed Out PDF Online Camp Application](#)

All applications will be processed by The Center for Courageous Kids and campers/families will be accepted based on time of application,

lodging requirements, and room availability.

TCAPP, RSDSA, and The US Pain Foundation realize that finances are tight for most families dealing with pediatric pain and transportation to the camp may be difficult. We are all working together to fundraise and provide traveling stipends for those who need them. More will come regarding this in the future. In the meantime, we hope you will use the advance notice to plan accordingly, create personal fundraisers for travel to camp (once again the camp is free), and/or maybe include some travel gift cards on your upcoming holiday wish list.

We anticipate that this will be a great experience and an exciting time for everyone!! Let's have some fun!!! Hope to see you all there!!!

A huge thank you to The Center for Courageous Kids, RSDSA and the US Pain Foundation for helping make TCAPP's dream come true and be able to offer a camp for kids in chronic pain.

Sincerely,

RSDSA, TCAPP, & The US Pain Foundation

A sample of what I have given to a hospital to help protect myself:

Do's

- Use butterfly for taking blood Use child tubes for any intubation
- When it doubt, don't take a chance, contact one of the doctors following my rare conditions
- Insert PICC line instead of IV so it holds
- Feel free to use any meds on the page listed MEDICATIONS THAT WORK
- Honor my no resuscitation order in the copy of my Living Will

Don'ts

- NO CPR to be given – it will break my ribs and they will never heal
- No large gauge needles – easily blow veins and lose the lines
- No meds to be given on the MEDICATION REACTION LIST
- Don't use any forms of steroids; breaks down collagen rapidly with EDS

Ellen Lenox Smith was interviewed about EDS – you can listen to the tape of the show about EDS “Winning Life Through Pain”® Online Radio by Coach Marla; www.rsdcoachlive.com - to listen via computer
www.blogtalkradio.com

and

EDS Speaking series with tips on: How To Take Control Back” Living with EDS
<http://www.chronicpainpartners.com/eds-awareness-speaker-series-january-8-2014/>

Compiled by:

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A new link to turn to:

<http://www.pinterest.com/ehlersdanloseds/eds-knowledgeable-physicians-medical-professionals/>

Source: EDS Today ~ Advocates (edstoday.org); Cathy Bowen