

# Connections

*"To Improve the Lives ... While We Find the Cure"*



## Ten Steps to Better Health

by Gerard L Guillory, MD

Over the past few years, I have helped a number of employer groups educate employees on 10 simple but often-overlooked steps toward better health. Here's a brief overview:

**1.** Add probiotics to your diet. If you find your digestive tract grumbling more than you think it should, you might want to replenish your gut's probiotics.

Probiotics are living, beneficial bacteria that occur naturally in the human intestinal tract and are essential to healthy digestion. A growing body of evidence suggests that probiotics help treat and prevent various forms of diarrhea, ulcerative colitis, Crohn's disease, irritable bowel syndrome, small-bowel bacterial overgrowth, and lactose intolerance. Probiotics also may help prevent colon cancer.

Probiotics are essential to the maintenance of the lining of the intestine, as they block the invasion of disease-causing bacteria. When an imbalance between "bad bacteria" and "good bacteria" exists, the lining of the intestine allows larger food and bacterial particles to be absorbed into the bloodstream. The immune system activates as the body fights these invaders. Many people who report apparent food intolerances may be experiencing symptoms arising from an imbalance of bacteria.

Replenishment of the gut with viable, beneficial bacteria—a number of affordable commercial products are available at health-food stores—may have multiple positive effects. Check with your doctor to find a good probiotic that works for you.

MSG is commonly found in packaged gravies, readymade salad dressings, flavored chips, canned soups and many other highly processed foods.

**2.** Beware MSG and aspartame. If you regularly experience severe headaches, dizziness, muscle aches and digestive discomfort, the cause may lie in your diet.

continued on page 4

## Ask The Experts

Questions and Answers

**Question:** When a person is told a syrinx is too small to be causing symptoms, what should they look for?

**Dr Vez:** Size of syrinx has no bearing on cause, ie, a small syrinx can certainly be the result of a Chiari and is often the case early on in the evolution of a syrinx.

**Question:** What is the proper follow-up for a patient diagnosed with Chiari who only has mild or no symptoms?

**Dr Vez:** My practice is generally annual MRI for first 5 years or sooner if symptomatic.

**Question:** What can a person do who has been diagnosed with Chiari, has progressive symptoms but chooses not to have surgery?

**Dr Vez:** In general, if symptoms are progressive, the result is likely permanent deficits. No mechanisms prevent [progression] other than surgery. Whiplash-like motions should be avoided, ie, roller coasters, chiropractic manipulation, etc.

**Question:** If a patient had surgery and was decompressed, how would you suggest she deliver a baby? If not decompressed?

**Dr Vez:** In general, an untreated Chiari [patient] should have C-section, and if treated, a vaginal delivery is usually well tolerated.

### About the Experts:

Erol Veznedaroglu, MD, FACS, FAHA; Director, Capital Institute for Neuroscience; Chairman, Department of Neurosurgery, Stroke and Cerebrovascular Center of New Jersey; Chief, Cerebrovascular and Endovascular Neurosurgery, Capital Health System

**SAVE THE DATE**  
**ASAP's Chiari & Syringomyelia**  
**Conference**  
**July 18-21, 2012**  
**Washington DC Metro**

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**A**merican  
**S**yringomyelia  
 & Chiari  
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**P**roject, Inc.

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# ASAP Contact Us

## ASAP

### American Syringomyelia & Chiari Alliance Project

Address: 300 North Green Street, Suite 412  
Longview, Texas 75601

Phone: 903-236-7079

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Toll-free: 800-ASAP-282 (800-272-7282)

Staff: **Patricia Maxwell & Jamie Mayhan**

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[Patricia\\_Maxwell@ASAP.org](mailto:Patricia_Maxwell@ASAP.org)  
[Jamie\\_Mayhan@ASAP.org](mailto:Jamie_Mayhan@ASAP.org)

## Save Your Cancelled Postage Stamps

For years ASAP members have been collecting cancelled postage stamps. Maynard and Flora Guss would prepare the stamps for auction through the Hollywood Florida Stamp Club. Maynard passed away in May, and Flora is no longer able to continue this project.

We are looking for a volunteer to take over the fundraiser. You would work with your local stamp club to turn the used stamps into a donation to support ASAP programs and research projects. If you or someone you know belongs to a stamp club and would like to continue the project please contact the ASAP office.

If you have been collecting stamps, you can send them to the ASAP office and we will store them until a volunteer is found to continue Maynard's legacy.

**Please Note:** Articles in this newsletter are not intended as a substitute for medical advice and do not necessarily represent the viewpoints of the editor, Medical Advisory Board or Board of Directors. Please contact your doctor before engaging in any new therapy or medication.

## Spread Awareness with an ASAP Business Card

Don't Just Tell People About  
CM/SM... Show Them!

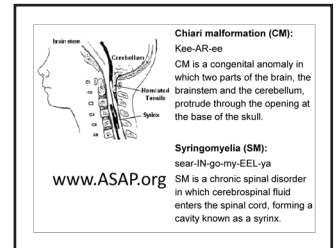
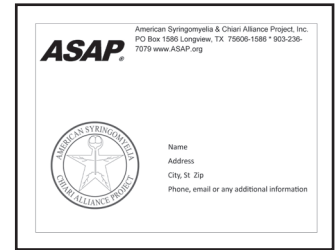
Order personalized ASAP  
business cards with a brief  
description of Chiari and  
syringomyelia on the back.

To place an order, include  
the information (i.e., name  
address, phone, email) you  
would like on the front of the  
card; it may also be left blank.

20 cards - \$5.00  
40 cards - \$10.00

Mail to: ASAP  
PO Box 1586  
Longview TX 75606

If you have questions: call 903-236-7079 or email [info@ASAP.org](mailto:info@ASAP.org)



## Awareness and Fundraising

Share your ideas and experiences with others. Email a short story to [Patricia\\_Maxwell@ASAP.org](mailto:Patricia_Maxwell@ASAP.org) or mail a typed or clearly written article to:

ASAP  
PO Box 1586  
Longview TX 75606-1586

Interested in hosting a fundraiser to support ASAP programs and research? We are here to help and guide you to ensure a positive experience.

ASAP has items available to help with spreading awareness in your community. Bookmarks, cards and brochures explain the disorders in varying detail allowing an easy and convenient way to spread awareness. Supply your physician's office with brochures. Hand out bookmarks to neighbors and friends. Include awareness cards when sending holiday cards this year. These are just a few ways that you can make a difference.

Please contact the ASAP office to request items.

# An Introduction to Nystagmus

Nystagmus is a term to describe fast, uncontrollable movements of the eyes that may be:

- Side to side (horizontal nystagmus)
- Up and down (vertical nystagmus)
- Rotary (rotary or torsional nystagmus)

Depending on the cause, these movements may be in both eyes or in just one eye. The term “dancing eyes” has been used to describe nystagmus.

## Considerations

The involuntary eye movements of nystagmus are caused by abnormal function in the areas of the brain that control eye movements. The part of the inner ear that senses movement and position (the labyrinth) helps control eye movements.

There are two forms of nystagmus:

- Congenital nystagmus is present at birth.
- Acquired nystagmus develops later in life because of a disease or injury.

## Causes

Congenital nystagmus (present at birth) is usually mild. It does not become more severe, and it is not related to any other disorder.

People with this condition are not aware of the eye movements, but other people may see them. If the movements are large, sharpness of vision (visual acuity) may be less than 20/20. Surgery may improve vision.

Nystagmus may be caused by congenital diseases of the eye. Although this is rare, an ophthalmologist should evaluate any child with nystagmus to check for eye disease.

The most common cause of acquired nystagmus is certain drugs or medication. Phenytoin (Dilantin) - an antiseizure medication, excessive alcohol, or any sedating medicine can impair the labyrinth's function.

Other causes include:

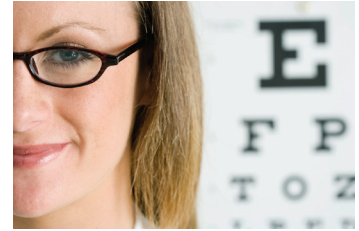
- Head injury from motor vehicle accidents
- Inner ear disorders
- Stroke
- Thiamine or vitamin B12 deficiency

Any disease of the brain (such as multiple sclerosis or brain tumors) can cause nystagmus if the areas controlling eye movements are damaged.

Call your health care provider if you have symptoms of nystagmus or think you might have this condition.

## What to Expect at Your Office Visit

Your health care provider will take a careful history and perform a thorough physical examination, focusing on the nervous system and inner ear. The doctor may ask you to wear a pair of goggles that magnify your eyes for part of the examination.



To check for nystagmus, the health care provider may use the following procedure:

- You spin around for about 30 seconds, stop, and try to stare at an object.
- Your eyes will first move slowly in one direction, and then will move quickly in the opposite direction.

If you have nystagmus due to a medical condition, these eye movements will depend on the cause.

Questions asked in a medical history may cover the following areas:

- When were the movements first noticed?
- How often does it occur?
- Has it ever happened before?
- Is it getting better, worse, or staying the same?
- Are there side-to-side eye movements?
- Are there up-and-down eye movements?
- What medications are being taken?
- What other symptoms are present?

There is no treatment for most cases of congenital nystagmus.

Treatment for acquired nystagmus depends on the cause. In some cases, nystagmus cannot be reversed. In cases due to medications or infection, the nystagmus usually goes away after the cause has gotten better.

## References

- Baloh R. Neuro-ophthalmology. In: Goldman L, Ausiello D, eds. Cecil Medicine. 23rd ed. Philadelphia, Pa: Saunders Elsevier; 2007:chap 450.
- Lavin PJM. Eye movement disorders: diplopia, nystagmus, and other ocular oscillations. In: Bradley WG, Daroff RB, Fenichel GM, Jankovic J, eds. Bradley: Neurology in Clinical Practice. 5th ed. Philadelphia, Pa: Butterworth Heinemann Elsevier; 2008:chap 16.

## Source

Medline Plus A service of the U.S. National Library of Medicine, National Institutes of Health

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Updated by: David C. Dugdale, III, MD, Professor of Medicine, Division of General Medicine, Department of Medicine, University of Washington School of Medicine. Also reviewed by Joseph V. Campellone, MD, Division of Neurology, Cooper University Hospital, Camden, NJ. Review provided by VeriMed Healthcare Network. Also reviewed by David Zieve, MD, MHA, Medical Director, A.D.A.M., Inc.

Monosodium glutamate and aspartame are common food additives that are culprits in many common medical complaints. MSG contains glutamic acid, and aspartame contains aspartic acid. These substances, both of which are neuroexcitatory amino acids, have been associated with headache, nausea, impaired ability to concentrate, attention deficit disorder, dizziness, flushing, muscle aches, digestive complaints and more.

Many “diet” products such as diet soda contain aspartame, a sugar substitute, and are labeled accordingly. But MSG is harder to identify, as labels may indicate only that a “flavor enhancer” has been added. MSG is commonly found in packaged gravies, readymade salad dressings, flavored chips, canned soups and many other highly processed foods. In addition, restaurants frequently put MSG in soups, gravies, sauces and salad dressings. Steer clear of both MSG and aspartame for a month, and note the results.

**3. Avoid trans fats.** Trans fats may be the worst thing you can eat but, if you live in Colorado and other states that don’t regulate these dangerous food additives, you probably aren’t even aware that you’re eating them.

Trans fats were engineered by food scientists who wanted to boost the shelf life of processed foods by reducing rancidity. This is achieved by adding hydrogen atoms to vegetable oils, rendering the fat more rigid and stable. When you ingest trans fats, your body tries to incorporate the rigid fats into its cell walls, causing damage in the process. The damage occurs because trans fats aren’t pliable like normal fats. Metabolizing them is like forcing the square peg into the round hole.

The health implications are serious. Trans fats increase the risk of cardiovascular disease by increasing LDL (bad) cholesterol, lowering HDL (good) cholesterol and raising triglycerides. Trans fats also increase inflammation, which accelerates many age-related disorders, including cancer, diabetes, Alzheimer’s and arthritis.

The federal government requires that trans fats be listed on nutrition labels, but this applies only to interstate commerce. As is the case with MSG, trans fats are hidden in many foods; for example, many deli and bakery items at the local supermarket. If there is a label on the packaging, it may say only that the product contains partially hydrogenated oils. What it won’t say is that partially hydrogenated oils are trans fats.

**4. Take appropriate supplements.** Americans spend more than \$17 billion a year on nutritional supplements, but few of us know what we are getting for our money.

Quality standards tend to be hit-or-miss among supplements manufacturers, and individual consumers don’t always know what kinds and amounts of supplements they need. The kinds and amounts of supplements you take should be based on your individual health status, which your physician or nutritionist can help you gauge, and on your budgetary requirements.



Too often, I encounter patients who are spending large sums on supplements that they simply don’t need or on supplements of low quality. Don’t hesitate to ask a health-care practitioner who has training in nutrition.

**5. Take Omega-3 fatty acids.** Some fats are essential to good health; for example, the Omega-3 fatty acids found in fish oil, cod-liver oil and flaxseed oil.

According to some experts, the most serious problem with the American diet today is the scarcity of Omega-3 fatty acids in our foods. Omega-3 deficiency has been associated with

anxiety, depression, attention deficit disorder, cardiovascular problems and arthritis.

**6. Take supplemental vitamin D.** Another common deficiency involves vitamin D; in fact, some medical experts are referring to this as an epidemic. Recent studies have linked vitamin D deficiency to a range of medical problems such as diabetes, chronic fatigue, osteoporosis, hypertension, multiple sclerosis, at least 16 types of cancer, and other diseases, including influenza.

Vitamin D is unlike other vitamins in that our bodies manufacture it when touched by sunlight. Yet many of us spend little time in the sunlight, especially in the winter and early spring. When warmer weather arrives, we apply sunscreen in order to prevent skin cancer. Without supplemental vitamin D, few of us are likely to get as much as we need.

The current recommended daily allowance for vitamin D, most experts say, is woefully inadequate. How much you should supplement is in debate.

**7. Get your blood tested.** If you suspect that you have vitamin D deficiency, ask your physician to perform a simple blood test and, based on the results, to help you determine how much vitamin D your body needs for optimal health.

You also might want to undergo a blood test to determine whether your hormones are balanced. This is crucial for patients who are taking statins (medications that reduce cholesterol) as both vitamin D and the sex hormones are synthesized from cholesterol.

One other test you might consider: Researchers are finding that gluten sensitivity is more common than previously thought. A blood test can determine whether you are glutensensitive. Symptoms may include auto-immune disorders and diabetes.

**8. Reduce inflammation.** Inflammation is a natural and vital part of the body’s response to injury, helping fight infections and ward off cancer, but it can go awry. Poor diet, lack of exercise and ineffective responses to stress contribute to the problem. Many age-related illnesses and obesity arise as a result of excessive, chronic cellular inflammation.

## Ten Steps to Better Health continued from page 4

Reducing chronic inflammation can help delay or, in some cases, reverse the aging process. Changing your diet, engaging in regular exercise and managing stress more effectively are critical parts of any plan to achieve these goals.

Some foods are pro-inflammatory and others are anti-inflammatory. Knowing the difference and choosing healthier foods will help you look and feel better. Generally, foods have four distinct properties that merit consideration:

- **Type and amount of fat.** Foods that contain saturated fats and trans fats are proinflammatory. Some fats are essential to good health—for example, Omega-3 fatty acids—and help reduce inflammation.
- **Glycemic index.** This measures how rapidly the body converts food to sugar. The faster it does so, the more pro-inflammatory the food. Avoid foods that contain sugar or that are rapidly converted to sugar in the body. Examples include white flour products, white potatoes, pasta and other low-fiber, starchy foods.
- **Phytonutrient content.** Phytonutrients are vitamins, trace elements and micronutrients found notably in plants, grains, nuts and fruits. They promote healthy cellular growth and reduce inflammation.
- **Anti-inflammatory compounds.** Some herbs, spices and other food items contain natural anti-inflammatory substances. Turmeric and ginger, for example, fight inflammation. Cinnamon also has beneficial properties and helps prevent rapid rises in your body's blood-sugar level.

**9.** Listen to your physician. Don't overlook the value of all the usual advice that physicians and other health-care professionals offer: stop smoking; work out regularly and appropriately; learn to manage stress more effectively; keep your weight within recommended limits; and get a good night's sleep.

**10.** Make the most of your office visit. One of the most important things you can do is to make the most of the time you spend with your doctor. A few suggestions:

If you're a new patient, check out your doctor's Website, which should include forms you will need to bring on your first visit. Fill them out at home and bring them with you. If your doctor doesn't have a Website and hasn't sent you any forms to fill out, visit our Website at [www.thecaregroupcc.com](http://www.thecaregroupcc.com) and review the forms we provide to new patients. Feel free to fill these out and take them to your doctor, who probably will ask for the same information. Some other suggestions:

- Before you call for the appointment, list and prioritize the issues you hope to address. When you make the call, mention all the reasons for the visit. This will help the staff allocate an appropriate amount of time for your visit.
- Make a list of your medical conditions and your medications (and doses). Also make a list of any vitamins and supplements you take.

- Keep a diary regarding your health, medications and life events. Often, the onset of medical problems coincides with other changes—a new prescription or supplement, a change in diet, new sources of stress.

- At check-in, let the medical assistant know whether you need refills for any prescriptions. Often, he or she can begin to take care of this while you are seeing the doctor.

- Bring your insurance card.

Finally, if you recently changed primary care physicians, consider seeing your old doctor, even if he or she isn't a part of the network with which your health plan contracts. Many plans cover out-of-network care; the patient simply pays a higher co-payment. It may be worth the extra expense to hang onto a relationship built over many years.

[A speaker at ASAP's Chiari & Syringomyelia Conference this past July, Gerard L Guillory, MD is board-certified in internal medicine and has been practicing in Aurora, Colorado since July 1985. As an assistant clinical professor of medicine at the University of Colorado Health Sciences Center, Dr. Guillory is actively involved in teaching medical students, resident physicians, and nurse practitioner students. He has lectured extensively on the role of nutrition and disease. Over the years, he has fostered an interest in patient education and has authored three books on digestive troubles. He also has served as medical director of a Colorado-based health plan and as a health consultant to employer groups.]



### ASAP Elects New Board Members

Kerry Chu and John Caemmerer joined the Board of Directors in July.

Kerry started ASAP's Long Island Support Group a couple of years ago which continues to meet monthly. Last year she raised funds for our organization by running in the New York Marathon. Kerry serves as Chair of our Chapter/Support Group Committee. Her enthusiasm and experience complement the Board.

John has been involved with ASAP for several years helping with fundraisers in the New Jersey, New York and Pennsylvania areas. In July he attended his first ASAP conference where he took on a host of duties, including Master of Ceremonies. The Board will work well with John's warm and efficient manner.

We thank Kerry and John for volunteering to serve.

Remember ASAP...

### When It's Time to Remember Loved Ones

Our appreciation to everyone who made a recent donation to ASAP on behalf of their friends / loved ones.

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Donor  
**Amelia Weed**  
Jena Weed  
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Kathie Hall



### We Want to Hear From You

ASAP was founded on the principle that every individual affected by Chiari and syringomyelia has access to information. For 23 years, we have been sending newsletters to those who have contacted our office. Originally we assumed everyone who communicated with us was interested in being involved with our cause. But we haven't heard from some of you in years.

It is possible numerous newsletters delivered by the United States Post Office are being sent to old addresses. Or maybe a few contacted us for information but later discovered it was a wrong diagnosis.

Over the next year we will be examining our database to make sure it is an efficient means of distributing information to those who need it. Annually we run a national change of address to ensure addresses are deliverable. But we need to confirm the thousands of homes that receive the newsletters are in fact interested in our cause.

Please return the form on page 7 with your contact information to confirm your continued interest in our cause. We understand that some cannot financially support the organization but please let us know you have an interest in staying informed.

## 2011 ASAP Volunteer Awards

### Helping Hand Award

Sara Balla  
Cindy Chrysler  
Jeannine Forbes  
Flora Guss  
Kristy Lee  
LeeAnn Leske  
Treika Morgret  
Fred and Mary Parker  
Preston Wells  
Laurie Yeh

### Visionary Award

Colleen Callahan  
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Julie Jarvis  
Jerry Lindner  
Candice Reinert  
Renee Tobias

### Shining Star Award

April Barillari  
Debbie Culver  
Susan Sparkevicius  
Lori Tutrow

### Key Volunteer Award

Kerry Chu  
Sara Patterson

### Barbara White Award

Ellie McCallum

### Outgoing Board Members

Theo Kotjarapoglus  
Ellie McCallum  
Sara Patterson

# "Yes, I want to make a difference!"

*I support the work of the American Syringomyelia and Chiari Alliance Project, Inc.*

Name \_\_\_\_\_  
Address \_\_\_\_\_  
City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_  
Email \_\_\_\_\_ Phone # \_\_\_\_\_

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**Return form to: ASAP, Inc., PO Box 1586, Longview TX 75606-1586**

10-2011

## Awareness and Fundraising



Greenfield, Indiana walk hosted by the Tutrow family, June 11



Summerville, South Carolina walk hosted by Laurie Yeh, June 18



Albemarle, North Carolina walk hosted by Tammy Helms, September 3



The Purple Hearts team,  
Scranton, Pennsylvania, July 23

The American Syringomyelia & Chiari Alliance Project (ASAP) is a tax-exempt 501(c)(3) organization. Our goals include providing a clearinghouse for information on syringomyelia (SM), Chiari malformation (CM), and related conditions. We offer a supportive network of programs and services and fund research to find better therapies and cures. ASAP is supported by tax deductible donations.

*ASAP Connections* is published bimonthly for ASAP members. Your articles, letters to the editor, etc. are encouraged. The deadlines for these submissions are the 1st of February, April, June, August, October and December. The editor reserves the right to edit any article in order to accommodate space. Please send newsletter suggestions to: Patricia\_Maxwell@ASAP.org or ASAP, PO Box 1586, Longview TX 75606

Patricia Maxwell Editor, **ASAP Connections**

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### ASAP's Mission

to improve the lives of persons affected by syringomyelia, Chiari malformation and related disorders while we find the cure